Duchenne UK

pathfinders neuromuscular alliance

DMD FAMILY FOLDER FOR ADOLESCENCE AND ADULTHOOD

SUPPORT AND GUIDANCE FOR PARENTS AND CARERS OF TEENAGERS WITH DMD

Important information for the transition from childhood to adulthood

Join us to end Duchenne

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Our writing team

Editor: Margaret Webster

Writers: Lisa Andrews, Lorraine Forrest-Turner, Jon Rey-Hastie and Margaret Webster

Researcher: Benjamin James

Thank you all for enabling young people growing up with DMD and their families to access a vital source of information and support.

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This guide was produced as a resource for parents and carers who are supporting children, teenagers and adults with DMD. The opinions expressed in this guide should not be taken as an endorsement, either expressed or implied, by Duchenne UK or its publisher.

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Parents and carers of people with DMD should always rely first and foremost on the advice of their neuromuscular consultant.

Chapter 1

Chapter 01 — Introduction

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This guide is for parents and carers whose son or daughter with DMD is aged between 10 and 21. It covers the transitions from childhood to adolescence to adulthood.

Language in this book

We have mostly used 'teenager' to refer to the person with DMD in this book. However, they may still be a child or already be an adult. We have used gender-neutral language so that girls, women, transgender and non-binary people with DMD are included.

DMD Family Folder: Support and Guidance for Newly-diagnosed Parents

If your child has recently been diagnosed with DMD or is under 10, please read the *DMD Family Folder: Support and Guidance for Newly-diagnosed Parents*. You can request a copy by emailing us at support@duchenneuk.org. Alternatively, you can download PDFs of all the chapters from our website (www.duchenneuk.org/support-at-diagnosis).

Dear parents and friends,

This folder is the second in our series designed to help families navigate the journey of care when you have one or more children living with Duchenne Muscular Dystrophy (DMD).

As parents and carers of children and teenagers with DMD, we have already been on a huge emotional journey and climbed a steep learning curve. It begins the day when we receive our child's diagnosis and continues every day as we try to come to terms with it. Well done for making it this far.

Each new stage of DMD brings unique challenges. As our children have grown, we have experienced this first-hand, and we wanted to be able to share what we have learned with other families.

As we've created this book, we've worked closely with people across the DMD community. We have leant heavily on the wisdom of Jon Rey-Hastie and Benjamin James of Pathfinders Neuromuscular Alliance. We have drawn on the experience and compassion of many parents of DMD families, especially Phillippa Farrant of the Duchenne Family Support Group and Janet Hoskin and Nick Catlin of Decipha. And we've been guided by the expertise of medical professionals who specialise in DMD.

In this folder, you will find practical advice and guidance on topics specific to teenagers and adults, such as work, education, health, friendships, relationships and sex, finances, holidays and fun, life skills and clinical trials.

Adolescence throws up challenges to all parents. If your child also has DMD, those challenges are bigger. We hope this folder will give you reasons for optimism, tools that will enable you to connect and talk to your teenager, and the confidence to dream big.

There are so many reasons to be hopeful. Better technology is giving our young people more and more opportunities to participate in education and employment. Many schemes exist to encourage disabled people to be part of society and the workforce.

Of course, there is still a long way to go.
But together, we can go far.

With love,

Emily and Alex

Emily Crossley and Alex Johnson
CEO and Co-founders of Duchenne UK

There are so many reasons to be hopeful.

In a nutshell

Life changes for every parent when their child enters adolescence. As parents of a teenager with DMD, we have more changes and adjustments to navigate than most.

We hope this folder will help you save time and energy by pointing you towards the people and resources that can help you. We hope it will help you to get the most out of life for your teenager, yourself and your whole family.

This is our advice in a nutshell:

1

Shape a good life

Teenagers and adults with DMD are living good lives with friends, partners, hobbies, education, jobs and holidays. Your teenager can have a good life too.

Every person has their own definition of a good life. For some, education might be the most important thing. For others, it might be volunteering or developing their hobbies.

So, encourage your teenager to talk openly with you, family members and teachers about their interests, goals and plans. Expand their horizons of what's possible so they don't limit themselves.

Ask others – especially family members and teachers – to focus on the person, not the condition. This way they will see your teenager's potential, rather than just the challenges of DMD.

Don't let other people limit your teenager because of their assumptions about what's possible – even if they have good intentions or are trying to be protective.

Your teenager's dreams and goals should drive the process of shaping a good life. If their wishes sound difficult or impractical, we encourage you to seek advice from adults with DMD or other DMD parents. You may be surprised by what people with DMD are able to do.

2

Accept that things will change

As much as we wish it weren't so, DMD has a bigger impact on our sons and daughters as they go through adolescence.

DMD progresses differently in each person. No one can predict exactly how it will impact on your teenager or how quickly.

3 Understand DMD's effects on your teenager's body and brain

DMD's effects on your teenager will increase during their adolescence. They will also be experiencing the effects of puberty on their body and brain.

Your teenager's neuromuscular consultant and their teachers should provide the support they need during these changes. You will find information about the social model of disability in this chapter. It will help you to spot and challenge unhelpful attitudes and the barriers in the environment that are preventing your teenager from fulfilling their potential.

4 Be part of the DMD community

We hope you are already part of our active DMD parent community.

If not, please join us. You don't have to do this alone. We support each other with advice, resources and practical help as much as we can.

As a community, we have a wealth of experience and resources. If your teenager needs something or wants to explore a particular hobby, education, career or life goal, you'll be able to find someone who can advise you.

You can find us on Facebook at www.facebook.com/duchenneuk. Or you can email at support@duchenneuk.org.

5 Enjoy the journey

Finally, we encourage you to take time to enjoy life with your teenager and your family as it happens.

DMD undoubtedly brings extra challenges and work with it. So, it's really important that we remember to make time for relaxing, having fun, celebrating milestones and taking pleasure in our family.

Guides to DMD on our website

Our Guide to Financial Support and Work for DMD Families is designed to help all DMD families to get the financial and practical support they need from the Government, their local authority and their employer.

We also have four guides that were produced to help newly-diagnosed parents talk to others about DMD.

You might find them useful too.

The guides are:

- *Guide to DMD for Grandparents, Family and Friends*
- *Guide to DMD for Employers*
- *Guide to DMD for Teachers*
- *Guide to DMD for Babysitters*

www.duchenneuk.org/support-at-diagnosis

Families with two or more children with DMD

We know that some families are caring for two or three children or teenagers with DMD. And we know this brings huge challenges.

Please use this folder and draw on the DMD community to get the help you need. We're here for you.

Where we are now

Adolescence is a time of significant change.

Many new opportunities open up. They'll start secondary school and, maybe later, college or university. They'll form new more grown-up friendships and relationships. They'll take on more responsibility for their lives and their care.

New challenges also emerge during adolescence. Their experience of puberty is likely to be different to their peers. Their muscles will become increasingly weak, so they'll need more care and support. And, of course, they'll also face the usual challenges that all teenagers face.

Shaping a good life for your teenager

Duchenne UK and its parent community are here to help you and your teenager on your journey.

We've created this guide to give you the resources, advice and encouragement you need to help your son or daughter get the most out of life as a teenager and adult.

In this guide, you'll find resources to help you:

- **Make the most of teenage life** – family life, health, education, friendships, home, financial support, and holidays and fun
- **Prepare for the future** – life skills, work, relationships and sex, and transition to adulthood
- **Respond to challenges and opportunities** – emergencies, research and clinical trials, and contacts

Challenge 'common sense' ideas about what a person with DMD can and can't do.

Our top tips for shaping a good life

These are our three top tips for helping your teenager to make the most of their adolescence and set themselves up for a good adult life:

Keep exploring!

1. Have high expectations

We encourage you to have high expectations for your teenager and your family. People with DMD are achieving more in education, work and living more independently every year.

So, challenge 'common sense' ideas about what a person with DMD can and can't do. Explore the different options for your teenager. Meet people in the DMD community and ask them what they do and how they do it.

2. Help your teenager figure out who they want to be

Your teenager will probably need your support to figure out what they want to do and how they want to live as an adult. That's the case for most teenagers.

You'll be able to help them most if you begin with short casual conversations when they're about 13 or 14. As they get older, you can talk to them for longer and in more detail. It's best not to leave it to 16 or 17 when they've already been at school for many years.

Ask them about their dreams and interests.

In the last 20 years, many things that people believed were ‘impossible’ have been achieved.

Ask them about their dreams and interests - what would they like to do? It’s okay if they don’t know straight away. Most teenagers don’t. So, keep exploring.

Have these conversations on many occasions so they can talk things through with you repeatedly. This will help them develop a vision of themselves and their life. (Don’t just talk about the future when you’re about to go to an Annual Review Meeting with school or the local authority.)

Then, you can figure out what educational qualifications, work experience and life skills they’ll need to achieve their dreams. This will help you plan better.

3. Seek out opportunities

Finally, we encourage you to actively seek the things your teenager wants. Then, you can create opportunities, rather than just reacting to whatever is currently available.

Talk to education and healthcare professionals about what they want to do. Make sure their goals and interests are reflected in their Education, Health and Care Plan (EHCP). Then, ask the professionals to help you work out how to do it.

This way, your teenager and you will be able to shape the life that they want to live. And their school will share their high expectations and support them.

In the last 20 years, many things that people believed were ‘impossible’ have been achieved. As a community, we hope to achieve even more in the next 20 years.

See Chapter 5: Education for more information about Education, Health and Care Plans.

Enjoy the journey

For us as parents and carers, we have to balance preparing for the future with living in the present.

The good news is that not everything needs to be done at once. Your teenager's needs will change slowly, so you can pace yourself.

Some things need to be started early

Some things can take a while, so it's best to give yourself as much time as possible.

For example, you need time to figure out what your teenager wants for their higher education, career and adult life. It's best to begin early while they're a young teenager. Then, you'll be able to explore different options and talk things over with education and healthcare professionals and other DMD parents.

Adapting your current home or moving to a new home can also take years. So, it's best to begin planning this a long time before your teenager's needs have changed substantially.

Some things need to be done at particular times

You do have to prepare for some things at particular points in your teenager's life.

For example, you'll need to plan their move to secondary school when they're 10 years old. Also, you'll need to begin planning their transition to adult health services when they're 16 years old.

There's still time to enjoy life

You'll still have time for fun and laughter along the way.

So, don't be scared of tomorrow. Embrace it. Celebrate life. Seek out opportunities. Try new things. Then, you can enjoy the journey from childhood to adulthood as it's happening.

DMD's effects on teenagers

As we support our teenagers so that they can make the most of life, we need to be mindful of the changes they'll experience during the coming decade.

Effects on teenagers' bodies

DMD has a significant impact on teenagers' bodies. Their muscles get progressively weaker as they go through adolescence.

In general, people experience a steady decline in muscle strength between the ages of 8 and 12. By their early teens, many people with DMD are full-time wheelchair users.

By their late teens, most have reduced ability to move their arms and experience more problems with their lungs, heart and other organs. They may need their doctors to monitor their heart and lungs, and may also need ventilation at night.

Life expectancy is increasing because medical advances are improving the way DMD is managed. Increasingly, people with DMD are living into their 20s, 30s, 40s and even 50s.

More young people with DMD are able to lead independent lives and go to university or college, get jobs and pursue their hobbies. Some get married and have children of their own.

See Chapter 3: Health for more information, including getting support from your neuromuscular consultant.

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Effects on teenagers’ brains

People with DMD are significantly more likely to have a learning disability or behavioural condition than the general population. Some teenagers are more affected than others.

This is because dystrophin plays an important role in cell-to-cell communication in the brain. However, learning disabilities and behavioural conditions are not inevitable. If they are present, they do not get worse over time.

These disabilities and conditions are usually specific, not global. Specific disabilities and conditions cause a difficulty or difference with particular aspects of learning or behaviour. Global disabilities and conditions cause difficulties with all aspects of learning or behaviour.

People with DMD may have one or more of the following conditions:

- **Language delays** – in understanding or expression or both
- **Attention, listening and memory challenges** – especially short-term memory
- **Executive functioning weaknesses** – planning, organisation, initiation, mental flexibility and self-analysis
- **Dyslexia** – reading disorder
- **Dyscalculia** – mathematics disorder
- **Dysgraphia** – written expression disorder
- **Depression and anxiety** – deep sadness or worry
- **Oppositional, explosive and aggressive behaviour** – arguing, not following directions, tantrums or refusing to do what they’re asked
- **Attention deficit hyperactivity disorder (ADHD)** – inattentiveness, hyperactivity or impulsiveness
- **Autism spectrum disorder (ASD)** – challenges with social skills, repetitive behaviours, speech and non-verbal communication
- **Sensory processing disorder** – finding particular textures, foods, lights and sounds overwhelming
- **Obsessive-compulsive disorder (OCD)** – obsessive thoughts or compulsive behaviour that can’t be controlled

Diagnosis and treatment of learning disabilities

Sometimes, these conditions are diagnosed late or not diagnosed at all because parents and doctors have focused on managing the physical aspects of DMD.

If the learning or behavioural disability is not disruptive in class, the risk of late diagnosis increases. Sometimes, a teenager's difficulties only become obvious during secondary school as their workload increases.

If you're worried that your teenager is struggling with their education in general or one aspect in particular, then we encourage you to get help. The Special Education Needs Co-ordinator (SENCO) at their school or their social worker at your local authority should be able to support you.

Early intervention by trained professionals can make a big difference to your teenager and their education. We encourage you to seek help as early as possible.

> If you're worried that your teenager is struggling with their education **then we encourage you to get help.**

Free education support from Decipha

You can get free support to help your teenager with their education and social development from Decipha. Duchenne UK is funding their services for DMD families.

Decipha is a non-profit organisation focused on special educational needs, including DMD, dyslexia and communication difficulties.

Find out more at

www.duchenneuk.org/support-with-education or **www.decipha.org**

See Chapter 5: Education for more information about getting free help from Decipha.

Puberty and the brain

Puberty also has a big impact on the brain. During their teenage years, your son or daughter's brain will be building new connections and pruning old ones.

The pre-frontal cortex is one of the last parts of the brain to develop adult wiring. This is the part of the brain that we use for complex thinking, decision making and moderating our social behaviour.

Teenagers tend to 'think with their feelings'.

So, teenagers tend to 'think with their feelings' rather than logically analyse a problem. Sometimes, they struggle to manage their emotions and they are more likely to be impulsive or take risks.

Remember your teenager will be experiencing the effects of puberty as well as DMD. If they take steroids, puberty may be delayed. If that's the case, you'll need to seek medical advice.

See Chapter 3: Health for more information about puberty and the effects of steroids on puberty.

See Chapter 5: Education for more information about how DMD affects the brain. You'll also find advice about how your teenager's teachers can support their education in this chapter.

See Chapter 2: Your Teenager and Family and Chapter 6: Friendships, Relationships and Sex for more information about helping your teenager to develop their communication skills.

Need more information about DMD?

If you would like to learn more about DMD, including its causes and why it affects boys more than girls, please go to the Duchenne UK website, **www.duchenneuk.org**

In particular, we recommend that you download Chapter 1: Introduction of the *DMD Family Folder: Support and Guidance for Newly-diagnosed Parents*
www.duchenneuk.org/support-at-diagnosis

The social model of disability

Two different ways of looking at disability

The way you think about disability can make a big difference to your teenager's journey through life.

There are different ways of looking at disability. The two main ways are the medical model and the social model. (Models are simply ways of thinking about something.)

Most disabled people prefer the social model because it focuses on what needs to change in society so they can live the best possible lives.

However, the medical model is used by most people in society, including some doctors and some parents of disabled children and teenagers.

The medical model of disability

The medical model of disability says that people are disabled by their impairments or health conditions. People using this model tend to focus on what is 'wrong' with the person with the impairment.

This model can seem 'common sense'. The problem is that it focuses on what needs to be changed about the disabled person and accepts society as it is.

> The social model of disability says that people are disabled by barriers in society.

The social model of disability

The social model of disability says that people are disabled by barriers in society, not their impairments or health conditions. These barriers exist because society has been designed by and for non-disabled people.

People using this model tend to focus on what needs to be changed in the physical environment or society's attitudes.

The social model was developed by disabled people. Now, most social workers and some healthcare professionals use it too. It's helped disabled people to live more fulfilled lives and led to the legal protection of disabled people, such as the Disability Act 2010.

Impairments and disability

Impairments and disability are not the same thing.

Impairments are the loss of physical or mental abilities because of injury, illness or genetic condition (for example, blindness is an impairment).

Impairment effects are the difficulties that someone with an impairment has carrying out the tasks and activities of daily life (for example, not being able to walk). DMD has many impairment effects that limit your teenager's function. But if society is accessible, they can still participate in work, leisure and travel on an equal basis.

Disability is the loss or reduction of opportunities to take part in society on an equal basis with others due to social and environmental barriers. Having access to an audiobook or a page-turning device means someone with a physical impairment can still read. It is only a disability if these adaptations are not available in society.

Equipment and support can prevent people with impairments from becoming disabled by their environment. Wheelchair ramps, speech-to-text software, personal assistants and supported housing are examples of the equipment and support used by people with impairments to prevent or minimise disability.

Disabled people or people with disabilities

'Disabled people' is the term supported by the social model. In the UK, all disability organisations which follow the social model use 'disabled people'.

'People with disabilities' was a term developed by non-disabled psychologists in the US. They were attempting to create 'person-first language' that was respectful and inclusive. However, it implies that disability is inside people rather than outside them in society.

Barriers in the environment or attitudes

One of the easiest ways to understand the social model of disability is by thinking about your own experience.

How long does it take you to make a cup of tea? About five minutes?

Now, suppose that you're in an unfamiliar kitchen. You don't know where the teabags are. The kettle has been hidden at the back of a cupboard. And when you turn on the tap, you find the water has been switched off.

Your abilities haven't changed. But the unsupportive environment has turned making tea into a really difficult task.

Choose your attitude

Your attitude is one thing that you can control and change.

If you believe your teenager can reach their potential and live a good life, this will have a huge impact on their attitude to life too. And it can empower you to challenge other people's assumptions about what's possible and the barriers in society which are holding your teenager back.

The social model can empower you to challenge other people's assumptions.

Challenge the barriers in society

The barriers our teenagers face are often there because the world is built around non-disabled people. By changing those barriers, we open up a world of opportunity for them.

Realistically, we can't make the world perfect, but we can make it better. Some things are more in our control than others. For example, we can re-organise our kitchen shelves by ourselves, but we can't ensure that every building has wheelchair access alone. That can only be achieved by many people working together over a long time.

Often, we can get the support and resources we need from education and healthcare professionals or the DMD community. For example, the local authority can help you to adapt your home, or other DMD parents can recommend their favourite equipment.

Sometimes you need to push hard to get society to change or provide the resources you need. For example, you may need to campaign to get a wheelchair ramp installed in your local high street. Or you may need to fight to get funding for educational support from your local authority if they're having budget problems.

You have the right to challenge things that don't work for your teenager. You don't have to accept things the way they are because that's how it's always been.

Look for role models

Disabled teenagers need to see themselves represented and have disabled role models to look up to.

Role models could be older teenagers or young adults whom your teenager meets socially.

Role models don't have to be famous names such as celebrities or paralympians. They could be older teenagers or young adults whom your teenager meets socially.

Your teenager will be able to see that their role models have overcome similar obstacles and achieved their goals. The world isn't built around disabled people. So, it's important for disabled people to see other disabled people making successful lives for themselves.

You can find out more about the social model of disability from Scope at **www.scope.org.uk/about-us/social-model-of-disability**

See Chapter 10: Life Skills and Chapter 11: Work for more information about role models.

Where you can find support

Support for young people with DMD

Pathfinders Neuromuscular Alliance helps teenagers and adults with DMD to live longer and happier lives. It is a user-led charity which promotes choice, control and quality of life for people with DMD and other neuromuscular conditions.

You can find them at www.pathfindersalliance.org.uk

* * *

Support from other Duchenne parents

Parental Support Network – you can find other DMD parents at the Duchenne Parent Zone on Facebook.

We can also put you in touch with other parents and families from our network. Please get in touch with us at support@duchenneuk.org

* * *

Duchenne Family Support Group

Duchenne Family Support Group www.dfsg.org.uk is a positive national support network of parents, their families and professionals.

They run a helpline and newsletter. They signpost families to the relevant organisation and other families in similar situations. And they provide days out and holidays which are tailored for people with DMD.

* * *

Emotional support

Your GP, paediatrician and neuromuscular consultant can provide referrals to counselling services for your family.

Information about DMD

You can get reliable information about DMD from your neuromuscular consultant and the Duchenne UK website, www.duchenneuk.org

While the internet has a lot of high-quality information, it can also be a source of misleading information and false hope. So, please rely on your neuromuscular doctor for expert and professional advice.

* * *

Decipha

Decipha is a not-for-profit organisation that provides educational advice for people with special educational needs. It was set up by DMD parents who are experts in this field.

* * *

Parent Information Days

Duchenne UK hosts free Parent Information Days for parents and caregivers. You can find out about current medical research, clinical trials and talk with DMD doctors.

Find out about events by signing up for our newsletter at www.duchenneuk.org or by following us on Facebook or Twitter.

* * *

Medical research and clinical trials for DMD

You can find out about research and trials on the DMD Hub website (which is run by Duchenne UK) at www.dmdhub.org

> **You are not alone.** There's a whole community of DMD families ready to welcome you with open arms.

Duchenne UK

As the leading Duchenne muscular dystrophy charity in the UK, we connect the best researchers with industry, the NHS and families to advance and accelerate every stage of drug development to make the incurable, curable.

We are already making great progress by focusing on three main activities:

1 Funding research and trials

We fund medical research and clinical trials which increase the scientific understanding of DMD, and develop and test treatments.

We focus on advancing the most promising medical research, and invest in projects that could benefit this generation of patients.

This includes groundbreaking research into how to treat the underlying causes of DMD, as well as its symptoms.

£13.9 million

committed to research, access and support.

2 Advancing treatments

We actively invest in every stage of drug development to improve and speed-up the drug development process.

We work with healthcare providers, the pharmaceutical industry and governments in the UK and globally to achieve this aim.

We also run the DMD Hub, www.dmdhub.org, which supports pharmaceutical companies and hospitals running clinical trials. The DMD Hub also provides patients and their families with information about trials so they can take part in them.

Great advances

have been made.

Our drive and ambition

comes from our deep understanding.

3

Community engagement and support

The children, teenagers and adults with DMD and their families are at the heart of everything we do.

Our drive and ambition comes from our deep understanding of the challenges that families face. So, we work closely with the Duchenne community and collaborate with other charities to improve the lives of people with DMD.

Why we have produced this folder

Duchenne UK is a parent-led charity. We know how daunting adolescence can feel when your son or daughter has DMD.

So, quite simply, we want to help all the parents in the DMD community to have the resources and support they need during their son's or daughter's adolescence. We want to help them get the most out of life for their teenager, their family and themselves.

We do hope this folder will be useful to you. And we hope that we will meet you in person one day if we've not done so already.

With warmest wishes
The parents of Duchenne UK

Chapter 2

Chapter 02 — Your Teenager and Family

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In a nutshell

1 Exciting changes are ahead

Your teenager is growing up. Thinking about their future. Developing new skills and abilities. You can help them in all sorts of ways, including choosing to see the opportunities in life, not just the obstacles.

2 Good communication helps build strong, healthy relationships

DMD doesn't have to dominate the conversation. You can talk about school, work, video games, music or anything else under the sun. Be open to questions and, if you can, face tough conversations head on. The more you talk, the easier it gets.

3 Hobbies can help your teenager express themself and build confidence

Be guided by their interests so that hobbies feel fun, not a chore. Be open to unfamiliar interests and support their enthusiasm. Help your teenager use their interests to shape a good life but stay flexible. If one goal doesn't work out, encourage them to look for the next one.

4 Set clear limits and expectations

Try to be consistent in your approach to family discipline. Make time as a family to create lasting memories. If your teenager has siblings, involve them in each other's worlds to help them build their relationship and develop their empathy skills.

5 You're doing your best

DMD is a marathon not a sprint. Taking care of yourself is the best way to take care of your family. Having a break restores energy levels and teaches your teenager the importance of respecting your own needs.

A time of change

Watching your child become a teenager is an exciting, bittersweet experience.

Their personalities blossom. They develop new skills and abilities, and their interest in the world grows. It's also a time of physical and emotional changes. They may become more self-conscious, worry about fitting in and test boundaries.

Teenagers with DMD are no exception. They are, after all, still teenagers. But, of course, DMD will bring particular challenges during these years too.

The next few years are an opportunity for your teenager to find out who they are – beyond the limits of their DMD.

They'll start to imagine what a good life looks like for them. They'll also start to think about their sexual identity and form new relationships.

See Chapter 11: Work and Chapter 6: Friendships, Relationships and Sex for more information on supporting your teenager as they grow up.

You can help them through this important period of change. Your love, support and encouragement will make a huge difference to them. That being said, try not to put too much pressure on yourself. There's no such thing as a perfect parent – we're all learning as we go.

Choosing your attitude

We can't control the future, but we can choose how we approach it. And we can help our children to do the same.

If we see the opportunities in life and not just the obstacles, then our children are more likely to grow up with the same positive outlook.

This isn't always easy. We all have low days and DMD will bring new challenges as your teenager grows up. But there are still ways that we can make things better for our teenager, our family and ourselves.

We may have to challenge some of our own assumptions. Disability isn't the same as inability. People with DMD are living good lives with friends and partners, hobbies and holidays. They're volunteering and working. They're living with their families or independently in their own homes or residential care. Your teenager can have these things too.

Happiness comes in many forms. Being flexible in our thinking, enjoying the positive days and accepting the difficult ones helps keep DMD in its place.

This way we can help our teenagers become more resilient as they grow into independent young adults.

People with DMD are living good lives with friends and partners, hobbies and holidays.

Adapting as your relationship with your teenager changes

As your son or daughter grows from a child to an adult, your relationship with them will inevitably change.

See Chapter 12: Transition to Adulthood for more information on what to expect as your teenager grows up.

Building good communication between you and your teenager

Humans are social beings, so good communication skills are an essential part of strong, healthy relationships.

The earlier we help our children express themselves, the easier their transition to adulthood will be.

Sometimes communication is hard, especially when we're talking about a difficult subject. Parents naturally want to protect their children from painful issues.

Many teenagers feel the same way as they get older. Some even start to protect their parents from difficult things, such as bullying (see Dealing with bullies on page 38).

The earlier we help our children express themselves, the easier their transition to adulthood will be.

Communication and the teenage brain

Talking can also be hard for teenagers because of the way the brain develops.

As a teenager grows, more connections are made between different parts of the brain. This process starts at the back and works forward. The area that helps us plan, make decisions and assess risks is the last to mature.

This is why teenagers often feel overwhelmed by their emotions – particularly negative ones. The wiring hasn't yet been fully connected. That sulky silence or bad behaviour can be a sign that they're struggling to tell you how they feel.

All of this is natural. A teenage brain is simply different from an adult's. But keep trying to talk, even when it feels awkward. Sometimes silence can create more anxiety and make it harder for a teenager to share their worries.

The DMD brain

People with DMD are more likely to have attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (Autism or ASD) or obsessive-compulsive disorder (OCD). Your teenager might also show some typical signs even if they aren't officially diagnosed.

For example, people with these conditions find it difficult to express their thoughts and feelings. They often have trouble finding the right word at the right time. This is deeply frustrating for them. So, they may either get angry or withdraw into silence.

They may also have more limited social skills and find it harder to understand other people's perspectives. They may take your words literally or become argumentative. They find it harder to 'read between the lines' of a conversation.

Sometimes, it might even feel like they say 'no' to everything, no matter how reasonable the request. They're more likely to be described as stubborn. They can find it hard to move on and may have difficulty calming themselves down.

This behaviour can be very frustrating but your teenager isn't doing it on purpose. People with conditions like ADHD are often quite impulsive and find it harder to develop problem-solving skills. So when they say no or get stuck on an idea, it's because they can't move on, rather than because they won't.

We encourage you to get support from the Special Educational Needs Co-ordinator (SENCO) at your teenager's school. If you've not already done so, ask their neuromuscular consultant, paediatrician or local Children and Young People's Mental Health Services (CYPMHS – the new name for Children and Adolescent Mental Health Services, CAMHS) for a referral to educational specialists. Intervention can make a big difference to your teenager and their education.

How to have constructive conversations

Communication doesn't always have to revolve around DMD.

You can talk about anything – school, work, politics, books, films, video games, music, sport or anything else that interests them.

Good communication also means listening. It helps us understand other people's perspectives and shows we value their thoughts and feelings. It also lets your teenager know that it's okay to talk, even if it feels uncomfortable.

We can also use 'active listening' skills to help teenagers find ways to work through a problem themselves. This is particularly helpful for teenagers with DMD and learning difficulties, since they find it harder to develop these skills. Active listening includes focusing on what your teenager is saying instead of thinking about what you'll say next.

If the whole family feels able to talk, listen and share things, talking about difficult subjects will be easier when they come up. It will also bring you closer and be more fun for everyone.

Here are some tips on having constructive conversations using active listening techniques:

- **Ask open questions** that can't be answered with a 'yes' or 'no' – often begin with 'what', 'why' or 'how'.
- **Keep them talking by:**
    - Nodding or using encouraging sounds ('uh huh', 'mmm')
    - Asking short follow-up questions: 'in what way?', 'why's that?' or 'because?'
    - Using short follow-up statements beginning with 'tell', 'explain' or 'describe'
- **Pick your moment:** You don't have to answer a difficult question straight away. If it comes up at a tricky time, such as the school run, thank them and suggest you talk at a set time.
- **Use a positive tone:** Children and teenagers understand more than you think, so be careful not to patronise.
- **Create space for family conversations** that aren't about DMD. Family meals are a wonderful time for chatting and getting closer to each other.
- **Encourage them to take an interest in others.** Expect them to ask questions of you, your partner, and other family members.

Constructive conversations – a summary

1. **Ask open questions**
2. **Keep them talking**
3. **Pick your moment**
4. **Use a positive tone**
5. **Encourage them to take an interest in others**

For lots more practical advice, we recommend reading *How to talk so teens will listen and listen so teens will talk,* by Adele Faber and Elaine Mazlish, Piccadilly Press.

The book is available to buy on Amazon and in bookshops.

Test your assumptions

How we talk to disabled people depends on how much we understand their condition and the social challenges they face. For example, some non-disabled people assume that disabled people can't work or have families.

See Chapter 1: Introduction for information about the social model of disability.

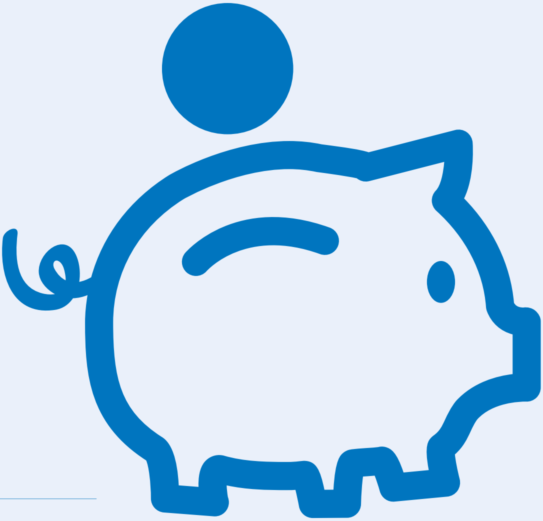
This model says that people are disabled by barriers in society, not their impairment or difference. These barriers exist because society has been designed by and for non-disabled people.

Understanding the model is useful for checking your own preconceptions and making sure you don't shut down important conversations.

Talking about health, careers and money

As your teenager grows up, they may want to have more control over areas of their life such as their health, money and career. For advice, see:

- **Chapter 3:** Health
- **Chapter 10:** Life Skills
- **Chapter 11:** Work



Talking about DMD's life-limiting nature

As your teenager gets older, they will probably have more questions about their condition. And they may ask about its life-limiting nature.

Even if they don't ask, there's a good chance that they will be aware. They might look it up on the internet or talk to someone else. While there are lots of useful resources on the internet, there's also lots of out-of-date or incorrect information. Encouraging your teenager to talk to you means you can help them understand what they've read or heard and assess whether it's correct.

So, be open to talking about it without letting it dominate your relationship. It's best to face the conversation head on if you can. Try not to have a fixed idea about the future. No one knows how long their lifespan will be.

People with DMD do have a shorter average lifespan than people without DMD – that's true. But many are living much longer, healthier and more fulfilling lives. And as medical research improves, it's possible people with DMD will continue to live even longer.

DMD's life-threatening risks do need to be managed. You might want to make some practical plans and talk to your teenager about the benefits of healthy eating, staying active and having regular check-ups.

Talk to your teenager about their future too. Ask them what a good life would look like for them. Encourage them to think about the sort of person they'd like to be and how to get there. This will help them to put DMD's life-limiting nature into perspective.

Talking about it is easier in times of wellness. The more you encourage your teenager and their siblings to talk to you, the easier these conversations will become.

Talking doesn't mean the worst is going to happen or that you've given up hope. It simply means your teenager will be more prepared for the ups and downs we all face in life.

Sometimes, though, it can feel easier for a young person to talk to someone outside the family, especially if they are trying to protect their family. If you think your teenager needs some extra help, talk to your GP or contact your local CYPMHS team for advice:

bit.ly/NHS-CYPMHS

Further support

The Together for Short Lives website has a helpful factsheet called *Talking with your child about their life-limiting condition* at

bit.ly/together-for-short-lives

See Chapter 3: Health and Chapter 4: Diet and Exercise for more information on helping your teenager stay healthy and active.

Developing hobbies and interests

Hobbies are a great way to discover new interests and develop new skills.

They help teenagers express themselves, build confidence and learn the value of goal setting. They're also a great way to make new friends with shared interests. And sometimes they even open up potential career choices.

Hobbies should feel like fun, though, not more homework. Let their interests guide their choices, rather than your own. Instead, be open to exploring new worlds with your teenager, such as computer games, Star Wars, sport or music.

Taking an interest in this way will encourage them to keep going. They may start to become an expert in their chosen area, creating a sense of pride and satisfaction.

Not every hobby will become a passion, but trying new things fosters a sense of curiosity. If your teenager moves on to something else, go with them. You never know where it might lead.

See Chapter 9: Holidays and Fun for ideas on the types of hobbies your teenager might enjoy.

Expand their horizons

Dreams and ambitions are powerful things. They help us create a happy, fulfilling life. They motivate us to keep learning and push us to take risks.

Teenagers and adults see risks differently because of the way our brains work. You may need to compromise.

See Chapter 12: Transition to Adulthood for more information on supporting your teenager as they grow up.

Here are some suggestions on how to help your teenager think about their options:

- **Explore their hopes and dreams by:**
  - Asking them what they'd like to do
  - Looking for opportunities that match their skills and interests
- **Look for role models to inspire your teenager:** Role models don't have to be famous. They could be someone your teenager meets socially. Encourage them to think about the ups and downs that the person might have experienced to achieve their goals. This will help them learn that becoming an expert requires practice and determination.

Dreams and ambitions are powerful things. They help us create a happy, fulfilling life.

- **Have a healthy attitude to failure:** Encourage your teenager to see mistakes and feedback as opportunities to improve, rather than a reason to give up (See 'Using a growth mindset to develop' on page 148)
- **Be ready to adapt:** Sometimes, things don't work out. Staying flexible and accepting that disappointment is a part of life will build your teenager's resilience. If something doesn't work out, encourage them to try again or set a new goal.
- **Keep an open mind:** Let your teenager set the goals. Look for what's possible rather than focusing on their limitations. If you're worried that a goal sounds too difficult, talk to other adults with DMD or DMD parents. Our community has lots of experience and resources that can help. And you may be surprised by what is possible.

Using a growth mindset to develop

Any new hobby or skill will be unfamiliar, even difficult, at first. There will be mistakes along the way. Learning from them and trying again is all part of how we become good at something. Some people find this hard to accept.

Fixed mindset

People who believe that you're either good at something or you're not have a 'fixed mindset'. They often give up after making mistakes or when something feels difficult. They say things like 'I can't do this, so why bother?'

Teenagers with DMD, their parents and teachers can develop a fixed mindset all too easily. It may even feel like the most realistic thing to do.

Growth mindset

People who believe that they can develop their abilities with time and practice have a 'growth mindset'. They love learning and understand the power of saying 'I can't do this… yet.' or 'I'm not good at this…yet.'

The reality is that teenagers and adults with DMD can learn to do new things. They need to practise in order to develop their new skills.

The good news is that it's possible to change your mindset!

Dr Carol Dweck is an expert on growth mindset. To learn more, visit www.ted.com and search for 'Carol Dweck'.

Dealing with bullies

DMD will affect your teenager's body as they grow.

Some changes will be hidden, such as heart problems. Some will be more obvious, such as scoliosis. It will probably affect their height, weight and strength too.

Sadly, this means bullying can be a problem, especially for teenagers who don't use a wheelchair. This is because other teenagers can see physical differences, but don't fully understand the changing needs.

No parent likes to think of their son or daughter being bullied. But it's our job to intervene. If your teenager asks for your help, or you suspect they're being bullied, here's what you can do:

No parent likes to think of their teenager being bullied. It's our job to intervene.

- **Talk to your teenager:** The earlier you encourage good family communication, the more likely your teenager will tell you when a problem occurs. When they do, create space to talk and use the 'handling emotional conversations' method on page 41.
- **Keep calm and reassure:** You and your teenager will get through this. Let your teenager know that they're not alone and that this isn't their fault.
- **Help them feel in control:** Ask them how they feel and what they need from you. They may worry about 'telling tales' so let them know you will work out the best plan together.
- **Keep a record:** Write down what happened, when, where, who with and for how long. Make a note of the impact it has had on your teenager.
- **Talk to the school:** Let your teenager know you intend to do this first. This will help them feel in control. When talking to the school, concentrate on the support your teenager needs and the steps needed to stop the bullying.
- **Talk to your GP:** Bullying can affect physical and mental health so you might want to talk through your options with your doctor.
- **Be aware of your own emotions:** If your teenager is bullied, you're likely to feel angry, tearful and upset. Make space for your own emotions by talking with your partner, a friend or a healthcare professional. When you're with your teenager, focus on their emotions so you can support them as much as possible.
- **Finally, keep trying:** Your teenager may not say anything because they want to protect you. But if you suspect something, keep trying and consider other lines of communication. For example, a family member or trusted friend may be able to help.

Cyberbullying

Cyberbullying is the misuse of digital technologies, such as a smartphone, computer or social media to bully someone. It often involves messages or actions that are threatening or intending to cause hurt or both.

Examples of cyberbullying include:

- Abusive comments, rumours or gossip using digital communications
- Sharing photos, videos or personal information without consent and with the intent to cause hurt
- Hacking email, phone or an online profile to share personal information without consent or sending hurtful content while posing as that person
- Pressuring someone to do something they don’t want to do, such as sending sexually explicit photos

What to do if you suspect cyberbullying

As well as the general tips on dealing with bullying, you can also:

- Help your teenager set high privacy levels and encourage them not to connect with anyone they don’t know offline
- Talk to them about the importance of not giving away personal information
- Make sure they understand the dangers of meeting someone in person after they’ve met with them online
- Check age recommendations on games
- Set rules on using social networking chat in games, especially if your teenager doesn’t know the other players
- Block and report social media and gaming bullies
- Check their headset to see if they have options to disable audio chat and screen text

Get more help:

For more advice on how to deal with all types of bullying visit:

www.nspcc.org.uk/what-is-child-abuse/types-of-abuse/bullying-and-cyberbullying

For information on specific apps, games and social media sites visit:

www.net-aware.org.uk [created by O2 and NSPCC]

Managing family discipline

Teenagers test boundaries. And if your teenager with DMD is one of several siblings, you can bet they're going to test each other!

It's our job as parents to set the limits and treat all our children fairly.

If your teenager has a learning disability, such as ADHD, be prepared for some negotiation. (See 'The DMD brain' on page 31). Meeting stubbornness with anger will only make the situation worse. Making future promises based on good behaviour can also set them up to fail because they tend to be impulsive and live in the moment.

Here are some other useful guidelines on managing family discipline:

Be consistent: Discipline is important whether a teenager has a disability or not. Structure and standards (for example, expecting them to say please and thank you) help them understand your expectations. It will also make discipline clearer when they don't meet those expectations.

Set chores: This helps teach all your children about responsibility and doing things for others. Set each child age-appropriate and ability-specific tasks.

See Chapter 10: Life Skills for ideas on the kind of chores you could give your teenager.

Avoid spoiling them: Granting every request for the latest gadget or trainers can't compensate for DMD. Also, letting them get away with bad behaviour without any consequences may mean they develop bad habits and poor ways of relating to other people. Neither help in the long run.

Take time to reflect: If stubbornness causes an argument, take a step back and a deep breath. When things are a little calmer, talk through what happened with your teenager. Work together to find a solution that matches your expectations with their abilities.

Keep talking: Sometimes anger and bad behaviour is a sign of a worry that your teenager is unable to express. Building rapport and strong communication skills in the good times will make it easier to address more emotional moments. (See 'Building good communications between you and your teenager' on page 30 for more information.)

> Discipline is important whether a teenager has a disability or not. Structure and standards help them understand your expectations.

Handling emotional situations

Humans react to emotions. If someone cries, we might feel like crying too. If they're angry, we might shout back.

Here is a simple method to help you handle an emotional conversation with your teenager:

1. Name the emotion and create a connection: 'I understand that you are frustrated…'
2. Show you understand their views: 'I too have felt that way when…'
3. Ask permission to explain: 'Would it help if…'
4. If they say no, ask what would help: this gives them control of the conversation.
5. Keep your body language neutral: avoid folding arms or pointing fingers.

Words to avoid in emotional situations:

- 'But' and 'however' – these words tell a teenager that you're about to override everything you've just said. For example: 'I see your point but...'
- 'You should' or 'you never' – these are very black and white with no room for discussion or negotiation. It can make someone dig their heels in.

Credit: Exec-Comm LLC

Rebelling against parents

Rebellion is one of the most notorious parts of adolescence. It can be worrying for parents and confusing for teenagers.

Teenagers rebel as a way to shape their own identity as a young person. They want to be different from their parents and maybe older siblings. And they want to be different to the child they used to be.

As parents, we still need to be concerned about our teenager's rebellion if it may cause them harm. We need to act if they're behaving in a self-defeating or self-destructive way, such as refusing to do schoolwork, taking dangerous risks or pushing away the people who care about them.

You can help your teenager to shape their own identity in a positive way by giving them challenges and supporting those challenges. Then, they won't need rebellion to transform themselves as much.

If your teenager's rebellion is harming them or causing family relationships to break down, we encourage you to seek advice from their SENCO, CYPMHS or their paediatrician.

Psychology Today has a good article about teenage rebellion - bit.ly/psychology-today-adolescence

> You can help your teenager to shape their own identity in a positive way by giving them challenges and supporting those challenges.

Smoking, drugs and alcohol

Most people experiment a little during their adolescence. Your teenager won't be the only one who might think about trying cigarettes, drugs or alcohol.

Talk to them about having the confidence to say no and making good decisions. For example, it might help them to think about the risks for them as someone who has DMD:

- Negative interactions with their medicines
- Reduced ability to balance and greater risk of falls
- Respiratory problems if they smoke cigarettes, marijuana or other drugs

Taking care of siblings

Sibling relationships are some of the most enriching and infuriating that we experience in life!

Moments of partnership and disagreement will occur. Living with DMD won't change that. Nor will it change the fact that your other children are experiencing their own physical and emotional changes. You may even have more than one child or teenager living with the condition. Supporting your whole family is important too.

Here are some suggestions from parents and siblings living with DMD on how to strike a good balance:

- Talk to all your children about their needs and their future, as well as their sibling's needs. They should feel that they're worthy in their own right, not just a support for you and their sibling.
- Non-disabled siblings can often feel guilty for not being ill or jealous of their brother or sister with DMD. You may need to help them process these complicated feelings. So, have open conversations with them. Encourage them to ask questions and share how they feel.
- Let them help. As your children get older, they will start to understand DMD's full impact. They may want to play their part and support the family.
- Be clear, though, that you don't expect them to put their social life or studies on hold. Time with friends will give them a break and the chance to talk to someone with a different perspective.
- Try new things together or plan family trips out to create lasting memories for you all.
- Make time for your children on their own. If one child has a particular interest, why not arrange a date together to help them explore?
- Involve siblings in each other's worlds to help them learn the importance of valuing other people's needs. For example, if one child plays football, attend the match as a family to show support.
- Try not to feel guilty about spending more time with your teenager with DMD. Over time, your other children will understand this is because of circumstance and not because you love their sibling more.

DMD Sibling Network

Your children might benefit from talking to other siblings living with DMD. Duchenne UK supports the DMD Sibling Network, which you can find at www.facebook.com/DMDsiblings.

Looking after yourself and your partner

Your children need you at your best.

Having a break can feel indulgent when we're living with DMD. But this is a marathon not a sprint. And our health is our children's most valuable resource. We need to protect it.

Taking time out to do something we love or to do nothing at all restores energy levels and reduces stress. It also improves focus. This will help you at times when you need to process lots of information about your teenager's condition.

You also deserve to enjoy your own life while creating good lives for your children. Making time for yourself teaches them the importance of respecting your own limits and needs.

If you're in a relationship, try to find time to be together on your own for the same reasons. It shows your children what a loving, balanced relationship looks like.

Breaks can be short or long. Half an hour with a book, a coffee with your partner or a walk in the park will do you and your family good. It also creates small moments of independence for your teenager, which will build their resilience and benefit them as an adult.

A family respite break through your local hospice might also help. The word 'hospice' can sound daunting, but they don't just look after people in the last stages of life. Many children's hospices offer a home from home, giving you and your teenager a chance to recharge your batteries. These breaks can also introduce your teenager to other people living with DMD. Many families find them very positive experiences.

Spotting the signs of stress

Stress can creep up on us even when we think we're coping. Here are some ways to spot if you're feeling under pressure:

- Constantly worrying or snapping at people more than usual
- Finding it hard to make simple decisions, for example, choosing food at the supermarket
- Eating too much or not enough
- Smoking or drinking more than usual
- Poor concentration or an inability to sit still
- Feeling tearful or crying

Half an hour with a book, a coffee with your partner or a walk in the park will do you and your family good.

Talking to a professional

We're living with something that we cannot control. Sometimes talking with a loved one about how that makes us feel can simply feel too difficult. They may be uncomfortable with our feelings or try to fix us.

In those situations, it can be useful to talk to a counsellor. Many DMD families have found counselling very helpful. These conversations are completely confidential and can offer another level of comfort
and support.

There are several ways you can get help:

- Find local services via the NHS's Improving Access to Psychological Therapies (IAPT) self-referral programme. This helps you find talking therapies in your local area. www.nhs.uk/service-search/find-a-psychological-therapies-service
- Your GP can refer you to a counsellor.
- The British Association for Counselling and Psychotherapy offers advice on how to find a therapist at www.bacp.co.uk

Duchenne Family Support Group

The Duchenne Family Support Group helps parents and siblings living with DMD.

The group runs a helpline for immediate support, organises days out around the UK and offers subsidised annual group holidays. It also runs a Facebook page and sends a quarterly newsletter to help you connect with other families.

Find out more at www.dfsg.org.uk.

Mindfulness techniques can help

Mindfulness helps us focus on the present moment. This technique can help you to spot signs of stress early and calm anxious thoughts. Many people in the community use meditation apps, such as Headspace.

For more information, visit www.nhs.uk and search 'mindfulness'.

Chapter 3

Chapter 03 – Health

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In a nutshell

1 Get to know the Duchenne Standards of Care

A new set of international Duchenne Standards of Care (SoC) was published in 2018. The SoC explain the health checks your teenager should have at different ages and how often to expect them. They also recommend certain types of medicine.

We recommend you get to know the SoC so you can discuss your teenager's needs with their healthcare team. Some information is better suited to US healthcare, so Duchenne UK is working to tailor it for the UK.

2 Understanding the pros and cons of steroids

Corticosteroids (commonly known as steroids) such as prednisone and deflazacort are the main treatment proven to slow down the progress of DMD. They have lots of benefits, such as improved muscle strength.

But they have significant side effects. For example, your teenager may start puberty later or not at all. They will need to have their development checked and may need testosterone treatment to bring on puberty. This can be tough for everyone, but your healthcare team will guide you through it.

3 Mental health is as important as physical health

DMD might affect your teenager's mental health. They may struggle with issues like self-esteem and grief.

These are tough, emotional subjects. Talking about them is never easy. But it is the most important way that you can help your teenager manage complicated feelings. Asking them simple, direct questions without judgement will help them open up.

4 Your teenager may develop breathing problems

As your teenager's muscles weaken, they may find breathing becomes more difficult. So, their lung volume should be tested at least once a year depending on the progression of their DMD.

You can also look for early warning signs, such as sleep problems, morning headaches or breathlessness. Eventually, your teenager might need to use a ventilator to help them breathe. But this is a gradual process.

5 In time, your teenager will move into adult health services

Deciding when to begin the conversation about your teenager's 'transition' to adult health services will depend on their needs.

Planning should be part of their Education, Health and Care Plan (EHCP). Depending on where you live in the UK, this plan may be called something different. It should focus on their needs and goals. All young people making this transition should have a named worker who coordinates their transition care and support. This could be a nurse or youth worker.

Preparing for changes in DMD health

You have lots to look forward to as your child becomes a teenager, but it's also a challenging time for their physical and mental health.

The physical impact of DMD will become more obvious and complicated. There will be more appointments, check-ups and planning. Teenagers often compare themselves with their friends, so these changes might have an impact on mental health too.

As families living with DMD, we know that this can feel a bit overwhelming. This chapter will guide you through the different things you'll need to think about.

You don't have to do this on your own. Our community is here to support you with advice and resources as much as we can. You can find us on Facebook at www.facebook.com/duchenneuk. Or you can email us at support@duchenneuk.org

You may find it helpful to know about the changes and priorities at different ages. The table below provides a guide, although exact times will depend on your teenager. You will find page numbers for more information on specific issues.

See Chapter 4: Diet and Exercise for lots more information on staying healthy, active and managing some of the digestive system issues that DMD can cause, such as constipation.

Age	Possible changes	Priorities
12-14	- Further deterioration in muscle strength, which affects walking and independence - Falls and fractures may become more frequent - Scoliosis may occur (page 79) - Steroids will most likely delay onset of puberty (page 56) - Mental health issues may occur (page 60)	- Extra medical checks on spine, heart and lungs - Regular stretching routine to maintain mobility - Annual spine x-rays to check for scoliosis and fractures - A wheelchair may be needed at this stage - Mental health support if needed
14-16	- Risk of heart, breathing and spine problems rises - Number of hospital appointments may increase - Night-time ventilator might be needed to help breathing (page 76)	- Regular medical checks on heart and breathing function needed - Support in wheelchair – if used – to help posture
16+	- Risk of chest infections rises - Reduced ability to move the arms - Respiratory, heart and orthopaedic checks remain essential - Cough augmentation machine might also be needed (page 77)	- Constant medical monitoring - Care support, including carers or personal assistants (page 299), need to be put in place

We recommend that you have a healthcare plan for your teenager. It will help you and your teenager's healthcare team keep up to date with the most important information. Your neuromuscular consultant can help you create this plan.

Their healthcare plan should include:

- Details of your teenager's DMD
- Their medicine
- Contact information for their healthcare team
- Information on how to look after their heart and lungs
- What to do if they need an anaesthetic

Duchenne Standards of Care

In 2018, the US Centers for Disease Control and Prevention published the new international SoC in *The Lancet Neurology*.

The SoC explain what care young people living with DMD need and should expect at different stages of their life. For example, they explain that a teenager with DMD should see their heart and lung specialists at least once a year. They should also have spine x-rays and scans every one to two years.

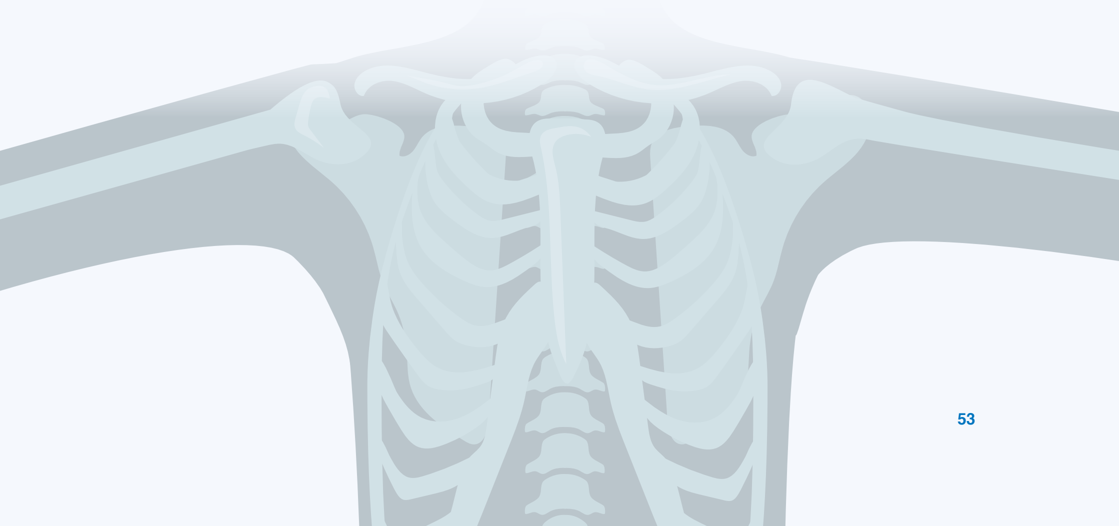
When the SoC were first published, TREAT-NMD – an international network of scientists, researchers and clinicians with expertise in neuromuscular disorders – worked with US patient organisations on the 2018 Duchenne Family Guide in English as well as translations into other languages. You can find it online at www.dmdcare.guide. It is also available to download at www.treat-nmd.org/care-overview/the-diagnosis-management-of-dmd/guide-for-families. However, some of the information is currently more suited to a US-style healthcare system.

Making the SoC relevant for the UK

At the time of writing, Duchenne UK is working to make the SoC more relevant for the UK and NHS system. We are also writing a UK checklist to help families living with DMD understand the level of care they should expect, especially when your teenager starts to transition to adult services.

The checklist will be based on research and agreement from an expert group of specialists and people living with DMD.

We will publish everything on the DMD Care UK website at www.dmdcareuk.org



Steroids

Steroids are the main treatment proven to slow down the progression of DMD. They are also part of the international SoC.

Your teenager might have taken steroids for a few years now. So, you've probably had lots of conversations with their healthcare team about them. Here's a quick reminder of their potential benefits:

- Improved muscle strength
- Reduced inflammation
- Reduced risk of developing severe scoliosis
- Delayed breathing and heart problems
- Helping your teenager walk for longer

Most healthcare professionals (HCPs) working with DMD accept that the likely benefits of steroids outweigh the risks. However, they can also have significant side effects that need to be managed:

- Reduced growth and changes in appearance, such as a round face (known as Cushing's syndrome)
- Reduced bone health
- Adrenal insufficiency
- Delayed puberty
- Changes in behaviour, such as increased naughtiness - not everyone will experience this though

Steroids and bone health

As we grow up, our bones get longer and stronger. However, steroids block this growth. This means that people with DMD who take steroids tend to be shorter than average.

They are also more likely to develop weak bones, which can lead to osteoporosis and fractures, including vertebral fractures in the spine. These vertebral fractures often go unnoticed, but can cause back pain if not treated early.

If your teenager is taking steroids, you can help protect their bones with a healthy diet and Vitamin D supplements.

Vitamin D helps the body absorb calcium, which we need to keep our bones strong. Your teenager's doctors should check their Vitamin D levels at least every year. This is because steroids can affect how well the body absorbs Vitamin D.

If your teenager is still walking, then weight-bearing activity that suits their ability can also help build bone strength.

If your teenager falls over and complains of any new pains, you should get them checked immediately for fractures. It can take people with DMD longer to recover from a fall. They might need extra physiotherapy.

Your teenager's medical team should carry out an x-ray of the back bones to identify fractures and a DEXA scan every year. DEXA scans measure bone density and give some information on how strong the bones are.

Steroids, adrenal insufficiency and adrenal crisis

The adrenal glands are small organs that sit on top of the kidneys. They make important hormones, such as cortisol. This is a steroid hormone that helps the body fight infection and stress.

The steroids prescribed in DMD are an artificial version of cortisol. They are given in much larger amounts than our bodies produce naturally. Once the body gets used to this amount, the adrenal glands go to 'sleep' and stop making their own cortisol.

This 'sleepiness' can be a big problem if a person gets sick and is unable to take their steroids. This is because their body will not produce extra cortisol (known as adrenal insufficiency).

Without extra steroid, the body cannot cope with the stress of the sickness. This can lead to a serious condition called an adrenal crisis. As well as symptoms from the illness or trauma itself, the person may feel lightheaded and very weak, and may have low blood pressure and low blood sugar levels.

In a person with DMD, this might happen because of severe vomiting or diarrhoea, or both. It can also be caused by any serious illness that prevents them from taking steroids by mouth or after an accident when the body would usually make extra steroid. An adrenal crisis can be life threatening but is easily treatable by giving extra steroids.

If your teenager is ill and cannot take their steroids, treat this as an emergency and take them straight to hospital. Make sure adrenal insufficiency/crisis is included in your teenager's emergency plan so that A&E staff will know what to do.

See Chapter 13: Emergencies for more information about emergency treatment for adrenal insufficiency.

If your teenager wants to stop their steroids, they must not do this suddenly because of the risk of adrenal insufficiency. Doses need to be reduced slowly – and only their doctor can properly manage this process. Special blood tests will be needed to monitor their cortisol levels.

Steroids and puberty

Puberty is a big part of growing up. It's the time when we make new hormones that help children develop into young adults. For example, in boys, these hormones tell the testes to grow bigger and make testosterone. This leads to changes in their bodies and genitals.

Steroids have a big impact on puberty in teenagers with DMD. They switch off these natural hormones. That means your teenager may start puberty late or not at all. This will happen at a time when young people often start to compare themselves with their friends. As well as a physical impact, this might affect their mental health, especially if they look much younger than others in school. Puberty hormones are also very important to help bones become stronger.

As DMD parents, we know how tough this is to read. And we know that many parents wrestle with the pros and cons of steroids. But having your teenager's puberty checked regularly and delayed puberty managed properly has many benefits. Your teenager's healthcare team can help you.

> Steroids do have an impact on puberty in teenagers with DMD. **But regular checks and management by a doctor will help.**

DMD Care UK for more advice

Duchenne UK has produced two new factsheets that have lots of useful information on:

- Adrenal insufficiency and crisis
- Puberty and testosterone

You can find both online at www.dmdcareuk.org/information-leaflets

Getting specialist help

When your teenager is about 12, your doctor should examine them for signs of puberty. They may refer you to a specialist hormone doctor called an endocrinologist. They will carry out an examination and tests to assess your teenager's development.

The examination can be very personal. For boys, the endocrinologist will check the physical development of their genitals and measure the size of their testes. They may also take a morning blood test to check hormone levels.

Talk to your teenager about what to expect before their appointment with their endocrinologist.

Endocrinologists do this all the time. They'll make sure that they talk you and your teenager through the process before the examination happens. Because this examination can be so personal, we recommend talking to your teenager about what to expect before they have the appointment.

What is an endocrinologist?

An endocrinologist is a specialist doctor who treats conditions and diseases connected to problems with hormones. Hormones are released through our glands, such as the adrenal glands, ovaries, testicles and thyroid. They have an effect on specific parts of the body. A paediatric endocrinologist commonly looks after children with issues relating to growth and puberty.

Testosterone treatment for boys

If your son is showing no signs of puberty by the age of 14, then their doctor will suggest testosterone treatment. Testosterone can be considered from the age of 12.

If your teenager has particularly weak bones, treatment may start earlier. This is because puberty hormones help build and strengthen bones.

Lots of parents are wary about testosterone treatment. They imagine their teenager might turn into one of those muscly bodybuilders!

They won’t. We promise. A teenager with DMD just needs extra help. This treatment is replacing a natural process in the body.

The treatment will happen gradually. Teenagers are usually given monthly injections or daily gels in slowly increasing doses over two to three years.

In time, your son’s body hair will grow and their penis size will increase. They will be more physically mature and their voice will deepen. Often, this will help them feel more confident and similar to their friends. It may increase their height a bit too.

Your son will be monitored about every six months. Their testes may grow during treatment, but don’t be surprised if they don’t. It’s more common for testes to start growing naturally after treatment has ended and boys start to produce their own testosterone.

Puberty for girls with DMD

DMD only affects a very small number of girls. Some girls develop DMD because both their X chromosomes have faults in their dystrophin genes. Others have one faulty gene and are known as ‘manifesting carriers’. This means they experience some symptoms of DMD, such as fatigue.

Because so few girls are affected by DMD, there is still very little information about puberty in manifesting carriers who are on steroids. However, we know from other conditions that long-term steroid treatment will also have a negative effect on puberty in girls. Your endocrinologist will carry out a physical examination to check breast and pubic hair development, as well as appropriate tests.

If your daughter is a DMD carrier, on steroids by the age of 13 and showing no signs of puberty, then her doctor will suggest oestrogen treatment. This can be given in several ways. You will be referred to an endocrinologist who will discuss the options with you and your teenager.

Supporting your teenager's mental health

A healthy mind is as important as a healthy body. But talking about our problems isn't easy, especially if they involve body image. For a teenager with DMD, this will probably be even harder.

As parents, we need to help teenagers find ways to explain their feelings. We all have days when we feel low. But if negative emotions last a long time or are severe, then this can be a sign of depression.

According to the World Health Organization, 20% of adolescents may experience a mental health problem in any given year.

Talking is one of the most helpful ways in which we can manage our mental health. And because good communication is so important, we've included information on it in several chapters. Here, though, we talk about some of the ways in which DMD's impact could affect your teenager's mental health.

Self-esteem

Your teenager's DMD will become more obvious as they get older. They may start to compare themselves with their friends or experience bullying. Some of their treatments may feel embarrassing.

See Chapter 2: Your Teenager and Family for more information about how to help or what to do if they are bullied. Also, see Chapter 6: Friendships Relationships and Sex for more information on helping your teenager develop positive relationships.

DMD progression and lifespan

As your teenager grows up and their DMD progresses, it may start to affect how they see themselves in the world. Be open to talking about it without letting it dominate your relationship. It's best to face the conversation head on if you can.

See Chapter 2: Your Teenager and Family for more information about how to talk about DMD's life-limiting nature.

Mortality and grief

Your teenager may start to worry about their own mortality or lose a friend with DMD at an early age. This is a very emotional subject. But it is possible to help them live life in the moment and feel more hopeful.

See Chapter 2: Your Teenager and Family for more information about handling emotional conversations.

What if a conversation isn't enough?

If you are worried about your teenager's mental health, talk to their healthcare team. They will help you get extra support.

Your healthcare team can help you get extra support if you are worried about your teenager's mental health.

Mental health services

The NHS provides the Children and Young People's Mental Health Services (CYPMHS) for free. However, the support you get will depend on where you live. Waiting times also vary. The CYPMHS in your area should have their own website with information on access and referrals.

Your GP can also refer you to a counsellor. Also, the British Association for Counselling and Psychotherapy offers advice on how to find a therapist at **www.bacp.co.uk**

Suicidal thoughts and how you can help

It's natural for our mood to go up and down at times; but for some people, those lows can last longer. Their thoughts may even sometimes turn to suicide.

Talking about suicide is never easy. It's complicated and upsetting for the person having suicidal thoughts and the people who love them.

But talking is the most important thing you can do.

Asking someone directly about suicide doesn't make it more likely to happen. Instead, you're letting them know it's okay to talk. You're showing them you care. And you can tell them that they are not a burden.

Research suggests that asking someone if they are experiencing suicidal thoughts can reduce the risk of them ending their life. Some people who have experienced suicidal thoughts say it's a relief when someone asks.

One in four young people say they have experienced suicidal thoughts at some point. We know that doesn't make this any less distressing if it's your teenager. Learning about the subject and how you can support them can be helpful.

For example, suicide isn't necessarily about wanting to die. Instead, someone might think about it as a way of taking control or escaping a painful experience. They think about it because they don't want to keep living the life they have.

This is a very big emotional subject. The information in this chapter is just a snapshot. The most important thing to remember is that you don't have to face this alone.

There are brilliant charities dedicated to helping people experiencing mental health issues or having suicidal thoughts, as well as their families. You will find their details at the end of this section.

How do I know if someone is suicidal?

There is no definitive checklist, but some signs may include:

- Changes in behaviour – such as losing interest in hobbies or the outside world
- Lack of interest in appearance
- Using certain words when talking about their feelings, such as 'hopeless', 'guilty' or 'worthless'
- Using certain phrases when talking about themselves or their loved ones, such as 'I can't take this anymore' or 'People would be better off without me'

> The most important thing to remember **is that you don't have to face this alone.**

What do I do if my teenager is feeling suicidal?

The most important thing you can do as a parent is ask your teenager if they are experiencing suicidal thoughts.

The best way to do that is to ask simple, direct questions. For example, you could ask how they feel about the future. Or you could ask if they are having thoughts about suicide.

They may be relieved that you've asked about feelings they didn't know it was okay to discuss. Letting them talk may also help them untangle their thoughts. Being open and direct can encourage them to be honest with you about their feelings.

Here are a few tips from support charities PAPYRUS and Samaritans on what to do if they say yes:

- Stay calm, take them seriously and listen.
- Avoid offering advice or opinions. Instead, ask open questions that cannot be answered with a simple 'yes' or 'no'.
- Try not to say things like 'Things will get better' or 'Why are you letting that bother you?' This will make your teenager feel that you don't care or aren't listening.
- Make space to talk. Telling you that they're having suicidal thoughts is very brave. But your teenager might need time before they talk it through with you. Let them know their feelings are important and arrange a time to talk.
- You don't have to know what to say. Tell your teenager you're glad they've told you, but be honest. Your honesty will help them open up.
- Write a 'safety plan' – this will help your teenager create some steps for coping in a crisis. It will also make sure they have the support they need (see "How to get extra help" on page 64).

Look after yourself

It's natural to worry if your teenager is experiencing suicidal thoughts. But they need you at your best.

Try to look after yourself physically and mentally. Eat well and exercise. Make sure you sleep. Try to relax.

We know this is easier said than done. If you're finding it hard to manage your own mental health, you may want to talk to your doctor about taking anti-anxiety medication or antidepressants to help. Many DMD parents will, at times, do this.

See Chapter 2: Your Teenager and Family for more information about talking to your teenager and taking care of yourself.

How to get extra help (including safety plans)

You can get help for your teenager if they are having suicidal thoughts. You don't have to cope on your own.

Friends and family might be able to offer support. Your teenager may also benefit from professional help, especially if they find it hard to share their feelings.

There are excellent charities that can help you if you are concerned about your teenager's mental health. Others provide information and support to help people who are having suicidal thoughts. For example, Samaritans and PAPYRUS have safety plan templates that you can download. Both run helplines that either you or your teenager can call.

If you’re concerned about your teenager’s mental health:

YoungMinds
www.youngminds.org.uk

If your teenager is having suicidal thoughts:

Samaritans
www.samaritans.org
Telephone: 116 123

PAPYRUS – for people under 35
www.papyrus-uk.org
HOPELINEUK:
0800 068 4141

Childline – for young people under 19
www.childline.org.uk
Telephone: 0800 1111

For advice and support from other families living with DMD:

Duchenne Family Support Group

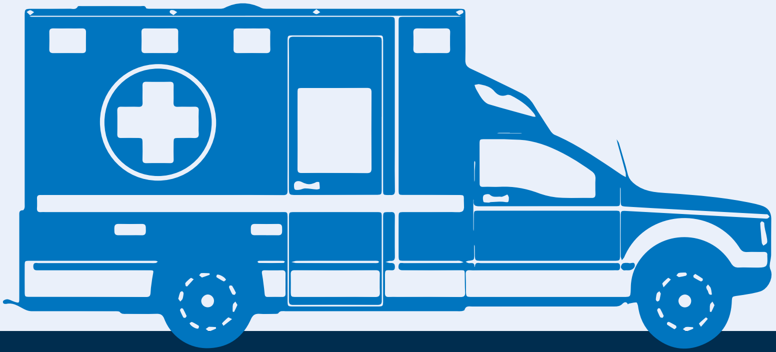
www.dfsg.org.uk

Helpline: 0800 121 4518

What to do in an emergency

If you are worried your teenager is going to immediately act on their suicidal thoughts, take them to A&E or call an ambulance.

The emergency services understand suicide, so they won’t see it as a waste of their time.



Working with healthcare professionals

Your teenager's needs will be getting more complicated. So, it's more important than ever to have a good healthcare team working together.

You're probably used to making decisions on your son or daughter's behalf. But as they get older, start to involve them in conversations with their HCPs. This might feel strange at first. However, encouraging them to ask their own questions will help them become more independent.

In time – and when appropriate – that might mean your teenager having conversations with their HCPs on their own.

Encouraging your teenager to ask their own questions will help them become more independent.

Teenagers with learning difficulties and HCPs

Some teenagers with DMD also have learning difficulties, which may make it harder for them to understand their healthcare conversations. Some may also find it difficult to talk to HCPs on their own. Even so, encourage them to participate in conversations as much as possible. You can also talk through any decisions together so they know their voice has been heard.

If your teenager has learning difficulties, they might need more time at appointments and encouragement expressing themselves. As they get older, you may want to use an advocacy service. An advocate can participate in your teenager's healthcare conversations. This may help you feel able to take a step back.

Either way, it can be tempting to speak for your teenager or for HCPs to only talk to you directly. However, taking the time to involve your teenager in the conversation as much as possible will help them as they grow older.

How to get the most from your team

Your teenager's care will fall under two separate authorities – your neuromuscular clinic at a hospital and community care via your GP or local authority.

Some families have access to all their services under one roof. If that isn't possible, your GP or care adviser can help you find local support.

Your neuromuscular clinic should be aware of the Duchenne SoC (see page 53). We recommend you get to know them too. That way, if your teenager is not receiving the correct care, you can discuss it with their HCPs.

Your GP

Your GP should be an important source of support for you and your teenager.

They can help you access services such as physiotherapy and occupational therapy. They should also keep a list of people who are carers. Anyone can register as a carer by filling out a form at their local surgery.

A good GP will always:

- **Listen** and not make you feel rushed during an appointment.
- **Ask questions** about what you want, not tell you what to do.
- **Remain open** to your concerns and offer support.

What if you're not getting enough help?

Sometimes it can be hard to get the help our teenagers need from a local authority, GP or NHS services. This is frustrating. Sometimes, as parents, we have to push hard.

You have the right to challenge things that don't work for your teenager. You don't have to accept a situation just because it's always been that way.

The 'social model of disability' may be useful to help you push for the things your teenager needs. This model was developed by disabled people. It says people are disabled by the barriers in society, not by their condition. These barriers exist because society has been designed by, and for, non-disabled people. By contrast, the medical model of disability says that a person is disabled by their condition.

It's likely that your GP and other HCPs are using the medical model. They might not have even heard of the social model of disability. But they should be aware of it. You might want to ask them to learn about it if they're not aware of it.

If they don't want to learn or if you're unhappy with the help your GP is offering, you have the right to change. Your preferred GP must provide care in your area.

If you are unhappy with any specialist advice, you also have the right to a second opinion from a different doctor. Often, this is called a further opinion. Although there is no legal right to a further opinion, the NHS rarely refuses requests.

See Chapter 1: Introduction for more information about the social model of disability.

Neuromuscular clinics

Neuromuscular clinics bring different doctors and specialists together to treat your teenager. They are multi-disciplinary clinics that provide regular monitoring, treatment and management strategies.

A neurologist will be in charge of your teenager's treatment. Neurologists diagnose, treat and manage disorders that affect the brain, spinal cord, nerves and muscles.

Your teenager's neurologist will monitor changes in the impact of DMD on them and their general physical wellbeing. They also manage their steroid therapy. They will work with your teenager's other specialist doctors and HCPs.

The North Star Network of neuromuscular clinics offers the best possible treatments to young people with DMD. It sets national standards and shares information between doctors. The network has led major breakthroughs in DMD care, such as the use of steroids.

Healthcare Travel Costs Scheme (HTCS)

If your teenager is 16 or older, they might be able to claim a refund of travel costs to a hospital, doctor, dentist or other primary HCP.

To qualify, they must meet three criteria, including specialist referral for further treatment or tests. Find out more online at bit.ly/NHS-healthcare-travel-costs

Keep your own records

We recommend that you request copies of your teenager's results or take a photograph of the results and notes yourself. That way, you can track and record their health over time.

Records can get lost. Or you may have to show these results to another doctor if you travel aboard. So, it's a good idea to have your own copies. You may also want to create digital copies as back-ups.

> A neurologist will be in charge of your teenager's treatment. **They will monitor changes in the impact of DMD on them.**

Other HCPs

Your teenager will continue to need support from a range of HCPs, including:

- **Physiotherapists:** Your teenager should see a physiotherapist at each six-monthly appointment at the neuromuscular clinic. They should also have a local physiotherapy team.
- **Occupational therapists:** Can help you arrange specialist equipment, such as a wheelchair, and advise on adaptations.
- **Orthotists:** Make special supports for legs and ankles, called splints or orthotics. Your teenager may need to wear their splints more frequently as they get older.
- **Speech and language therapists:** Help people with DMD with any delays in their speech or language development. They can also help with swallowing problems.
- **Dietitians:** Provide advice on diet, weight control, food types and alternative feeding methods if your teenager develops problems swallowing.

Apart from physiotherapists, your teenager will need to be referred to these specialists. Your GP or neuromuscular team should be able to help you arrange that.

Hospices - places of support

We know that the word ‘hospice’ can sound daunting. But hospices don’t just look after people in the last stages of life.

They offer lots of services for people with long-term conditions, such as hydrotherapy, counselling and respite breaks. They also offer a way for young people to meet friends with similar conditions. And they may be able to introduce you to other local families living with DMD.

When you are ready, talk to your GP about your local hospice and the services it offers.

Hospital admissions

Teenagers with DMD will have to go to hospital from time to time. Most trips will be planned, but some may be an emergency.

A planned hospital visit

Taking the time to plan a hospital visit can make it easier when appointment day arrives. Here are some ideas to help:

Ask questions: Ask about what to expect before, during and after a procedure, and what tests and procedures your teenager will have.

Make a list: Write down all the things you think might be difficult while your teenager is in hospital.

Visit the ward: Seeing the layout may answer your questions.

Ask to bring special equipment: You might have equipment at home that could help make your teenager's stay more comfortable.

Give the ward team instructions: Write down the specific help your teenager needs.

Ask if you can stay: Some hospitals will allow parents to stay overnight.

An emergency visit

Planning for an emergency is more difficult. But there are a few things you can do to be as prepared as possible:

- Use the Duchenne UK 'In Case of Emergency' app, which stores all your teenager's personal details. It's online at www.duchenneemergency.co.uk and available via the Apple and Android app stores.
- Have a small bag of essentials, such as toiletries and spare clothes, prepared and stored in a safe place.
- Keep a copy of your teenager's emergency plan in a safe place, such as in the essentials bag or the pocket of a wheelchair.
- Keep photos of your teenager's latest clinical results on your phone.
- If possible, get to know local specialists so that they know some of your teenager's needs in advance.
- Be ready to be the expert. A&E staff may not have any experience of DMD. You'll need to be able to tell them any dos or don'ts that could affect your teenager's health.
- Take your teenager's medication with you, in case there is a delay in finding it at the hospital.

If your teenager has carers or personal assistants (PAs) or both, you may need to let hospital staff know. You might need to explain why it is important their carer or PA is with them, especially if you are unable to accompany them.

See Chapter 13: Emergencies for more information about preparing for emergencies.

Be ready to be the expert. A&E staff may not have experience of DMD.

Care considerations

By law, your local authority must provide care to meet your teenager's eligible needs. They will assess your teenager's ability to wash and dress themselves and manage daily tasks.

Sadly, your teenager may not be offered the care you feel they need. So, you may have to push for the help your teenager needs.

Financial support is also assessed. It will be based on things like your savings, household expenses and disability benefits.

Your local authority must leave you with a minimum level of income. You can call your social services department at your local council to ask for a needs assessment or apply online at www.gov.uk/apply-needs-assessment-social-services

See Chapter 8: Financial Support and the *Guide to Financial Support and Work for DMD Families* for more information. You can download the guide from Duchenne UK's website at www.duchenneuk.org/supporting-your-teenager-with-duchenne

Challenging your social care needs assessment

It can be upsetting if your teenager doesn't get the support you'd hoped for. If you're unhappy with your assessment, you can ask your local authority about its appeals process.

You have the right to take someone with you when you appeal. This could be someone you trust, someone from a local charity or someone provided by your local authority. This person is called an advocate and can speak up for your needs and offer emotional support.

> If you're unhappy with your assessment, **you can ask your local authority about its appeals process.**

Breathing and respiratory care

While they are still walking, teenagers with DMD don't often have trouble with breathing, swallowing and coughing. But problems will arise as their muscles weaken.

What causes breathing problems

Certain muscles, like the diaphragm, work like bellows to help our lungs breathe in oxygen. As the muscles weaken, our lungs can't take in as much air. These muscles are also an essential part of coughing.

Scoliosis (see page 79) can also affect the amount of air that reaches the lungs.

Swallowing muscles will get weaker too. This makes it more likely that your teenager will experience food 'going down the wrong way' and into their lungs (see page 78). Poor coughing and swallowing problems can cause chest infections.

How to spot breathing problems

If your teenager is still walking, then their lung volume should be tested once a year. Lung volume is the amount of air that the lungs can hold.

If your teenager is using a wheelchair, then these tests will be more frequent. They should also be carried out before surgery and when your teenager is unwell.

Sleep problems are usually the earliest sign that your teenager needs extra help. This is because our muscles relax when we sleep. Each breath becomes shorter and oxygen levels fall. If muscles are already weak, then those levels are even lower.

Common signs of sleep problems include:

- Morning headache or sleepiness
- Poor appetite at breakfast
- Breathlessness
- Daytime sleepiness
- Nightmares
- Heavy snoring or sweating at night

Talk to your teenager's neuromuscular team as soon as you notice any of these symptoms. They may recommend a sleep study to assess their breathing while they are asleep.

> Sleep problems are usually the earliest sign **that your teenager needs extra help with their breathing.**

Breathing exercises

Like other parts of the body, we can stretch and exercise our breathing muscles. For example:

- Taking deep breaths can help inflate your teenager's lungs and encourage greater range of movement.
- Assisted coughing – sometimes called 'huffing' – can help clear mucus from deep inside the lungs. See page 77 or more information on cough augmentation devices and how they can help.
- Singing or playing a musical instrument, such as a recorder, helps exercise the breathing muscles. It can also teach your teenager how to breathe more deeply and slowly.

Your physiotherapist can recommend specific exercises and, if needed, types of treatment.

What you can do to help

You can help your teenager protect their breathing muscles on a day-to-day basis by:

- Following a healthy diet. Extra weight adds pressure on breathing muscles. Constipation can also reduce diaphragm movement.
- Encouraging good sitting posture to help your teenager's rib cage expand fully.
- Using steroids to help protect lung muscles.

Ventilators

Your teenager's neuromuscular team may recommend they start using a ventilator. These are machines that will help them breathe or breathe for them.

Deciding to use a ventilator can feel like a big step. But ventilation is very effective and can improve your teenager's quality of life. Using ventilators is a gradual process. While they're a teenager, they'll probably only need help at night.

Here are the answers to common questions about ventilators.

1 How does a ventilator work?

A ventilator is a machine that helps push air in and out of the lungs, increasing oxygen and lowering carbon dioxide.

Your teenager will wear a close-fitting face mask that is connected to the ventilator (often called non-invasive ventilation). It is important to choose the right mask that fits your teenager's face. A ventilator can be quite noisy and it may take your teenager some time to get used to it. They may also need their own room.

There is some evidence that ventilators can reduce the frequency of chest infections. They also support the heart. If swallowing becomes a problem, then tracheostomy ventilation might be needed. This is more invasive and rarer in teenagers.

2 How do I help my teenager get used to the mask?

Wearing a mask might feel a bit scary at first for your teenager. This is completely natural. Many people do get used to it and find that their sleep quality improves quickly.

You can help your teenager get used to the feeling of wearing the mask. For example, suggest they wear it while sitting with you watching TV. That way, they can get used to breathing with it in a relaxed environment. Over time, you can gradually increase how long they wear the mask.

3 How do I get the equipment my teenager needs?

Your teenager's neuromuscular team or GP can refer them to a respiratory or ventilation clinic. The clinic will assess your teenager and then provide equipment and training.

4 Can my teenager travel with a ventilator?

Yes. Many ventilators are portable and easy to operate. You should always keep a bag with some spare tubing and a ventilator battery with you. Some wheelchairs have a carry bag that can be fitted to the back of the chair. Others may need to be adjusted to carry the ventilator.

Longer journeys – such as on an aeroplane – are possible, but need careful planning.

The link between diet and ventilation

Sometimes, a person with DMD might lose weight because they are finding it hard to breathe. This can reduce appetite or make it harder to eat. Using a ventilator can, therefore, increase appetite because the person finds it easier to breathe again.

If you notice any changes in your teenager's appetite or that they are regularly unable to finish meals, talk to their healthcare team. More regular check-ups and weight checks might be needed.

Cough augmentation machines

Coughing relies on lots of muscles. As your teenager gets older, they might find it difficult to clear mucus from their lungs.

Cough augmentation machines (also known as cough assist machines) help by blowing air into the lungs and then pulling it out quickly, taking mucus with it. This can reduce the risk of chest infections and blocked airways.

Like ventilators, cough augmentation machines can be a bit loud and scary at first. It may take your teenager some time to get used to one. They will be given training, including how to cough in time with the machine.

You can also give them lots of positive encouragement to help them keep going. Very often, teenagers accept these machines as part of everyday life once they realise that they feel better.

Other health issues

DMD is a complex condition that affects lots of different muscles. This means your teenager's health might be affected in other ways.

Difficulty swallowing and eating

Difficulty swallowing is known as dysphagia. It is caused by weakness in the face, jaw, tongue and throat muscles. This can sometimes cause small pieces of food to stick in the throat or enter the lungs. This is called aspiration. People with DMD can also have difficulty chewing food. This can add to swallowing problems because the pieces of food are bigger.

Dysphagia can lead to weight loss, dehydration and chest infections. This can be difficult to spot in the early stages because it happens so gradually. Your teenager's swallowing function should be checked every 6-12 months.

Look out for the following signs and symptoms of dysphagia in your teenager:

- Feeling as if food is stuck in their throat
- Unexplained weight loss
- Taking longer to eat a meal (more than 30 minutes)
- Regularly failing to finish a meal – it's easy to confuse fullness with tired swallowing muscles
- Drooling
- Persistent coughing or choking
- Needing to use a cough augmentation machine during or after a meal
- An unexplained fever or chest infection (caused by food in the lungs)

If you notice symptoms, ask your GP to refer your teenager to a dietitian and speech and language therapist. They will be able to arrange further assessments, such as a swallowing x-ray.

Your dietitian and speech and language therapist can help you create a mealtime plan and suggest any changes to your teenager's diet. They will also decide how often your teenager's swallowing function should be checked.

See Chapter 4: Diet and Exercise for more information on helping your teenager manage dysphagia and aspiration when eating.

Weakened smooth muscles

Our bodies are made up of three different types of muscle, called skeletal, smooth and cardiac. Smooth muscles are found in ‘hollow’ organs like the intestines and stomach.

Smooth muscles work automatically without you knowing (a bit like breathing). DMD can affect these muscles too, although we don’t yet fully understand why.

Constipation is a particular problem for people with DMD because the stomach, intestines and bowel contain smooth muscle. It can also be made worse by a lack of movement, especially in people who use wheelchairs.

Although less common, some people with DMD also have difficulty emptying their bladder because it is made of smooth muscle.

These problems can be a bit embarrassing to talk about. But there are ways to help your teenager manage them. Talk to your GP or specialist team for more advice.

Scoliosis and lordosis

Scoliosis and lordosis are conditions that cause a curve in the spine. Scoliosis causes the spine to curve sideways (think of an ‘s’). Lordosis causes the spine to curve inwards (imagine a ‘c’). Over time, both can cause chronic pain.

Lordosis is harder to avoid, as young people with DMD will adapt their posture to stay stable and upright for longer.

Scoliosis can put pressure on other internal organs. This can cause other problems, such as constipation, heartburn and incontinence. In more serious cases, scoliosis can put pressure on the lungs. This might make it more difficult for your teenager to breathe, cough and clear chest infections.

The longer a teenager can stand and walk while still growing, the less likely they are to experience scoliosis. Steroids help young people with DMD stay on their feet for longer, so fewer teenagers now experience scoliosis at all.

There are some things you can do to help prevent scoliosis:

- Encourage good sitting posture and avoid slouching – for example, when watching TV.
- Add extra support to their wheelchair – for example, a back support can help prevent back, hip and neck pain.

The importance of standing

Standing is very important for a healthy spine. It can also improve blood pressure and circulation, help digestion and encourage muscle development.

Even if your teenager is no longer able to walk, helping them find ways to stand is important. Some teenagers will be able to do this independently or with help from you. Some may need special equipment, such as a standing frame or a sit-to-stand hoist.

In time, your healthcare team may also introduce ankle and/or foot supports (also called orthotics) to help your teenager continue to stand.

Your occupational health therapist and physiotherapist will be able to give you advice on ways to help your teenager reduce the risk of scoliosis developing. They will also be able to advise you on getting an assessment for appropriate seating at home and school.

If your teenager does develop scoliosis, they will need extra support over time – for example, more wheelchair adaptations, such as a head rest or lateral supports to prevent them from leaning to one side.

In very severe cases of scoliosis, surgery may be needed. This is a big operation that involves straightening the spine with metal rods, screws, hooks or wires. But thanks to steroids, this is extremely rare now.

Chest infections, coughs and colds

Chest infections, coughs and colds create mucus, which can affect your teenager's breathing.

Cough augmentation machines can help with coughs and colds. Chest infections must be treated seriously and early with antibiotics and physiotherapy.

Talk to your GP to make sure they understand your teenager's need for antibiotics. Ask about keeping some at home so that your teenager can start them at the first sign of a chest infection.

> Ask about keeping some antibiotics at home **so your teenager can start them at the first sign of a chest infection.**

Vaccinations

Your teenager will need regular flu and pneumonia vaccinations. From 2021 onwards, they'll need Covid-19 vaccinations as well.

Severe flu and pneumonia can place extra pressure on the heart and lungs. Steroids and other medicines can affect your teenager's immune system, increasing the risk of catching flu.

The pneumonia vaccine is given every five years. Flu jabs are updated every year. Both are very safe and can be given by your GP.

If your teenager is on steroids, they must not be given a live vaccine.

At the time of writing, the first Covid-19 vaccination programme was being rolled out. So, we'll have to wait for a year or so before we know how future vaccinations will be delivered.

If you have any questions or concerns about vaccinations, talk to your teenager's neuromuscular consultant.

Fat embolism

Fat embolism is a very rare complication after a bone is broken or a person has a bad fall.

It can be a potentially life-threatening condition if not diagnosed and managed in hospital. It happens when fat from the bone marrow gets into the bloodstream. (Bone marrow is the thick, spongy jelly-like area in the middle of bones.)

The fat can travel into the lungs, blood vessels in the brain and skin, and cause problems with breathing and circulation. Symptoms include confusion, rapid breathing, rapid heart rate, shortness of breath and small purple rashes.

If your teenager has a fracture, fall, knock or stumble and shows any of these symptoms within the next one to two days, take them to A&E immediately. Tell the emergency staff that fat embolism is a possibility.

> If your teenager has a fracture, fall, knock or stumble, **look out for health problems in the following two days.**

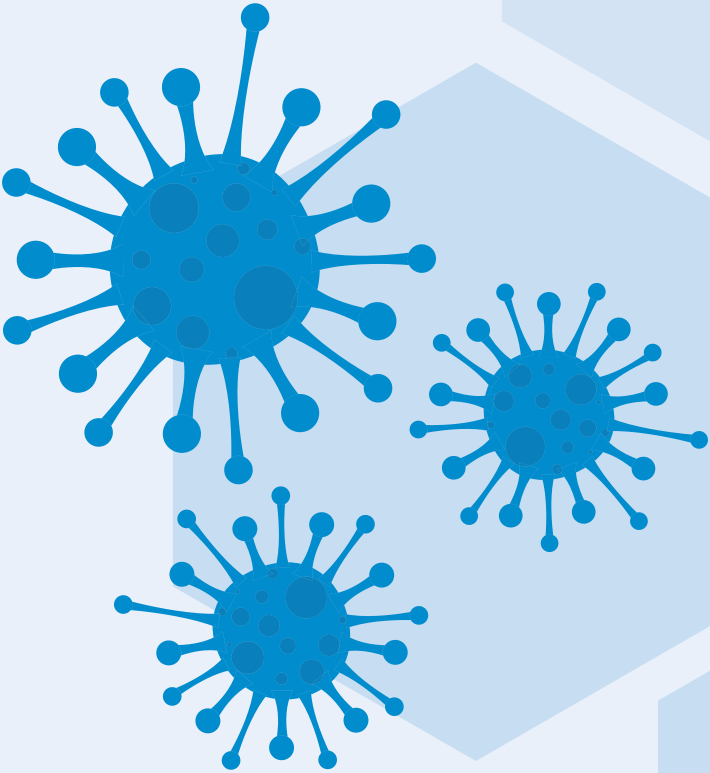
Pandemics

People with DMD are more likely to develop complications from respiratory illnesses, such as flu and Covid-19.

We know that the Covid-19 pandemic has caused a lot of extra worry. We also know that we are going to be living with the virus for a long time. Duchenne UK has the latest government and medical advice on our website.

We also recommend:

- Getting to know the DMD A&E website (see emergency plans on page 83)
- Getting to know the DMD SoC – www.dmdcare.guide
- Keeping medicines up to date and having an adequate supply of them
- Making sure all your teenager’s equipment is in good working order



Emergency plans

We can't plan for everything in life. But having an emergency plan can help you be prepared. That way, you can get on with enjoying your life as a family.

An emergency plan also gives A&E staff important information. They may never have met someone with DMD before, which means you might be the expert.

If you have a plan, responding to an emergency will be easier for everyone. Your plan should include all your teenager's information, such as medicines, ventilator use and contact numbers for specialists.

Learn what is an emergency

Some healthcare problems can become emergencies for people with DMD – even if they are not emergencies for the general population.

Breaking a bone, needing an anaesthetic or missing a steroid dose can all be emergencies.

The Duchenne A&E Pack has a list of all the different emergencies. We recommend you read the information and make sure A&E staff use this resource as well. You can find it online at www.duchenneemergency.co.uk

Be prepared

You should ask your GP to make sure your teenager has all the following essentials:

- **Emergency Alert Card** – bit.ly/alertcard: This tells A&E doctors and other medical staff about the special emergency procedures for people with DMD. You should also list your teenager's allergies.
- **Medical alert bracelet:** This tells first responders in emergencies (e.g. ambulance staff) what to do. It is very important if your teenager takes steroids.
- **Duchenne UK's In Case of Emergency app:** The app is available on the Apple and Android app stores. You can also download it on our website at www.duchenneuk.org/dmd-emergency-support
- **Emergency information for medical practitioners:** available at www.duchenneemergency.co.uk

See Chapter 13: Emergencies for more information about preparing for and responding to emergencies.

Beware of advice on the internet and social media

Your GP, neurologist and the other HCPs caring for your teenager are the best people to give you information and advice about DMD.

We also run a website called DMD Hub, which has lots of information about taking part in a clinical trial and how to get involved – **www.dmdhub.org**

Be cautious of what you find on the internet and social media. There's a lot of misinformation and false hope out there. There's also a lot of out-of-date information, so choose your sources carefully.

See Chapter 14: Research and Clinical Trials for more information about clinical trials for DMD.

Research and clinical trials

Clinical trials are research studies that explore whether a medical treatment, drug, procedure or device is safe and effective for humans.

They are an important part of making new treatments available to patients and giving new data to healthcare decision-makers. They are required by the Medicines and Healthcare Products Regulatory Agency (MHRA), which licenses new medical products in the UK.

Many families living with DMD want to keep up to date with new research. Some teenagers and children take part in the trials.

A trial should never be a substitute for your teenager's regular treatment and healthcare. However, there are some benefits to taking part, including:

- Access to an experimental treatment that is only available as part of a trial
- Regular follow-up meetings
- Understanding DMD better
- Helping develop future treatments for the DMD community

There are also some risks associated with clinical trials. You and your teenager should discuss these with the doctors running the trial before deciding whether or not to take part.

Duchenne UK funds dozens of research projects and clinical trials. We also work with pharmaceutical companies to speed up the approval process for new treatments by government regulators.

We help fund an international network of scientists, researchers and clinicians called TREAT-NMD. The network makes sure the most promising new treatments reach patients as fast as possible.

Transition to adult services

As your teenager grows up, you will need to start planning their move into adult health services. This is often known as ‘transition’.

Deciding when to start this conversation will depend on your teenager’s needs. About 12 to 14 years old is a common age to begin.

Transition planning should be included in your teenager’s Education, Health and Care Plan (EHCP). It should be centred on their needs and goals. By law, every child and teenager with special needs must have an EHCP. Your teenager should have one by the time they reach secondary school.

EHCPs have different names in different parts of the UK. See Chapter 11: Work for a full list.

According to the National Institute for Health and Care Excellence’s (NICE) guidelines, all young people making this transition should have a named worker who will coordinate their transition care and support. This could be a nurse, youth worker, GP or other professional in healthcare, social care or education.

Your teenager’s named worker can help organise a comprehensive team of community providers, including educators, social workers, HCPs and family.

However, the process of transition is often unclear and can be inconsistent. It will vary depending on where you live and the services you can access.

Adult services are funded in a different way from children’s services and often feel less joined up. Some services may change and some may reduce. You will probably have to work with more individual specialists. Your GP may become the only person who has a complete picture of your teenager’s care.

The amount of support your teenager gets usually depends on a transition assessment by your local authority. Sometimes the transition they suggest isn’t the best one for your teenager. You have the power to change that transition. So, if you or your teenager are unhappy, you have the right to challenge an assessment and ask for different HCPs.

If transition planning is not offered to your teenager, you have the right to push for it. Duchenne UK is working with specialist healthcare professions and patients to improve the transition model. You also have the right to push for specific treatment as outlined in the updated SoC (see page 53) for more information on the standards).

Transition is a gradual process over several years. This is an outline of how transition should work.

More information

There are lots of new things to think about as your teenager gets older, many of which are covered in other chapters:

- For more on what to expect as your teenager grows up, including paying for care and working with personal assistants, see Chapter 12: Transition to Adulthood.
- For more on EHCPs and what should go in them, see Chapter 5: Education.
- For more on accessing financial support, see Chapter 8: Financial Support.

Late childhood onwards

Begin including your son or daughter in conversations about their health, education and care.

12-14 years (as appropriate)

Healthcare transition from child to adult services should be planned with a multi-disciplinary support team. Discuss this at least once a year. Start including your teenager in conversations about transition planning.

Teenagers want increasing independence from parents and authority figures. They may test boundaries. Try to support them in making their own decisions.

15-18 years

Transition should be well underway. A named worker should be appointed. A comprehensive plan based on your teenager's wishes should be developed.

They should be supported in proactively planning their future and involved in assessments. Encourage your teenager to start meeting care teams on their own, at least for the first part of the consultation. Teenagers with learning difficulties may find this harder. However, you can still encourage them to participate in conversations.

18-24 years

Your teenager (now an adult) will be defining their life by their career, relationships and hobbies. They'll have increasing financial and psychological independence.

They should be supported by multi-agency teams in adult services. They should have a key worker who helps coordinate their care and support between agencies. They'll still need to keep planning so that support can be properly organised.

When your teenager starts wanting to speak and make decisions for themselves, it's time to start moving from family-centred interactions to person-centred interactions. Work with health and social care professionals to make that change.

Helping your teenager take control of healthcare conversations

When our children are very young, we make all the decisions for them. But as they get older, that balance starts to change.

Your teenager might want to be more involved in decisions about their treatment, instead of being told what to do.

Every teenager is different, of course, and that balance will change gradually. It may even feel a bit strange at first. But the more you encourage them to express themselves, the more you can help your teenager become a confident young adult. It will also make their transition to adult services easier.

You can help by using these tips:

- **It starts with you:** Encourage your teenager to speak up and listen when they talk. This will help them know you value their opinion.
- **Back them up:** Insist that professionals talk to and listen to your teenager as well as you.
- **Be prepared:** Encourage your teenager to think about questions they have before a meeting with their GP or HCPs.
- **Stepping back:** As they get older, let your teenager take more control of the conversation.
- **Give them complete control:** In time – and if appropriate – support them to have conversations with their HCPs without you in the room.

Chapter 4

Chapter 04 – Diet and Exercise

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In a nutshell

1 A good diet can help your teenager's health

We all need a balanced diet to stay fit and healthy. Teenagers with DMD are no different. But their condition makes them more prone to weight problems – either gaining or losing too much weight.

Good food choices can help them maintain a healthy weight and avoid stress on the body's organs. A balanced diet will also provide the essential vitamins and minerals your teenager needs for good general health. This is an important time to help your teenager establish good eating habits for adulthood.

2 Chewing and swallowing may become more challenging

As your teenager gets older and their DMD progresses, they might have problems eating. This occurs because DMD affects chewing and swallowing muscles in the face, jaw, tongue and throat. It can cause weight loss and put extra stress on their body's internal organs and immune system.

We encourage you to work closely with their speech and language therapist and dietitian to develop the best solutions.

3 Your healthcare team can help you

Your teenager's healthcare team can help you create a diet that suits their needs. They can suggest changes to help manage weight and constipation. They can also advise on important nutrients, such as calcium and Vitamin D, which help protect different parts of the body. And they will monitor other aspects of your teenager's diet-related health, such as sugar levels.

4 Exercise for a good life

Exercise is good for our physical and mental health. It helps keep us active for longer, improves stamina and sleep, and can even reduce pain.

DMD shouldn't stop your teenager exercising. Encouraging them to choose sports and exercises based on their ability and interests will help them stay motivated. Stretching can also help them maintain range of movement in their hands, arms, legs and feet and stay active for longer.

5 Wheelchairs are just another tool

Your teenager may need a wheelchair as they get older. Many non-disabled people tend to see wheelchairs in a negative light. But for many disabled people, they are liberating. They give them the independence to do more and go to more places.

Your teenager will be guided by you and your attitude. When the time comes, it might be helpful to see a wheelchair as another tool to help them live a good life.

General advice

Helping your teenager stay fit and healthy

A good diet and physical activity are important aspects of a healthy life for everyone. They are especially important for teenagers with DMD.

This is because some children and teenagers with DMD can put on weight more easily if they are using steroids, such as prednisone or deflazacort. (The medical name for steroids is corticosteroids.)

Steroids can increase their appetite and, as their muscles get weaker, they may start to move less. Your teenager may also start using a wheelchair, which means they need less energy.

Extra weight puts more pressure on already weakened muscles – for example, the breathing muscles. Teenagers who carry extra weight – whether taking steroids or not – are more likely to have problems processing sugar in their blood. This is called insulin resistance. They may also have high blood pressure and problems sleeping at night. Day-to-day tasks – for example, moving from a wheelchair to a shower seat (known as transferring) – may also become more difficult.

Other teenagers with DMD may struggle with weight loss, which creates different problems. For example, being underweight can make it harder for the body to fight infections or prevent certain medicines working properly.

DMD can also cause constipation because of weak stomach muscles and lack of movement.

See Chapter 3: Health for lots more information on many of the health factors covered in this chapter, such as steroids, constipation and difficulties chewing and swallowing.

Diet

The risks of being overweight and underweight

While some teenagers with DMD put on weight easily, others might experience unexplained weight loss. Some teenagers may experience both excess weight gain and weight loss during their teenage years. Both can put your teenager's body under extra pressure.

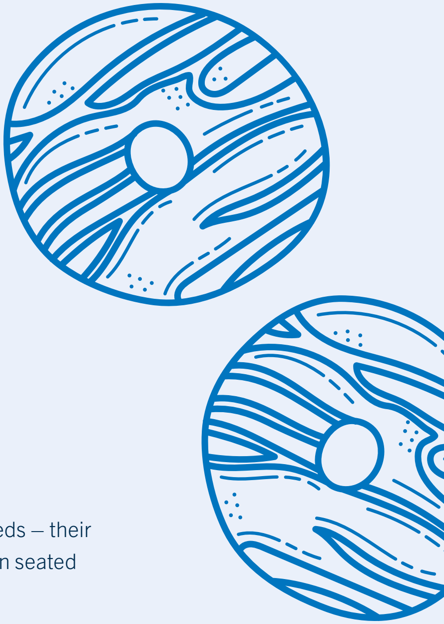
Energy balance is also very important. The number of calories your teenager needs depends on the energy they use. Someone using a wheelchair will probably exercise less and need fewer calories. But someone who has difficulty breathing without support will use more energy and need more calories.

Obesity puts more pressure on already weak muscles. A lack of nutrition can affect the breathing muscles, the immune system, strength and the body's ability to recover from illness and heal wounds. Both can affect a teenager's self-esteem.

Common causes of weight gain

Your teenager may put on weight because they:

- Have an increased appetite due to steroids
- Are burning fewer calories because of lack of movement and reduced muscle mass



A balanced diet can help your teenager avoid putting on extra weight. If your teenager does gain weight, you could try:

- Introducing more low-calorie foods, such as fresh fruit and vegetables
- Reducing high-calorie foods with lots of fat or sugar, such as chips and chocolate
- Being more active, depending on your teenager's needs – their physiotherapist can help them move more, even when seated
- Considering portion size at mealtimes

Common causes of weight loss

Your teenager may lose weight because they have:

- Physical problems with feeding
- Difficulty swallowing and chewing
- Tiredness during mealtimes
- Reduced appetite at breakfast because of poor sleep
- Burned more calories because of breathing problems
- Loss of appetite
- Colds, flu and chest infections
- Gastroesophageal reflux (GORD)
- Major surgery – for example to fix fractures

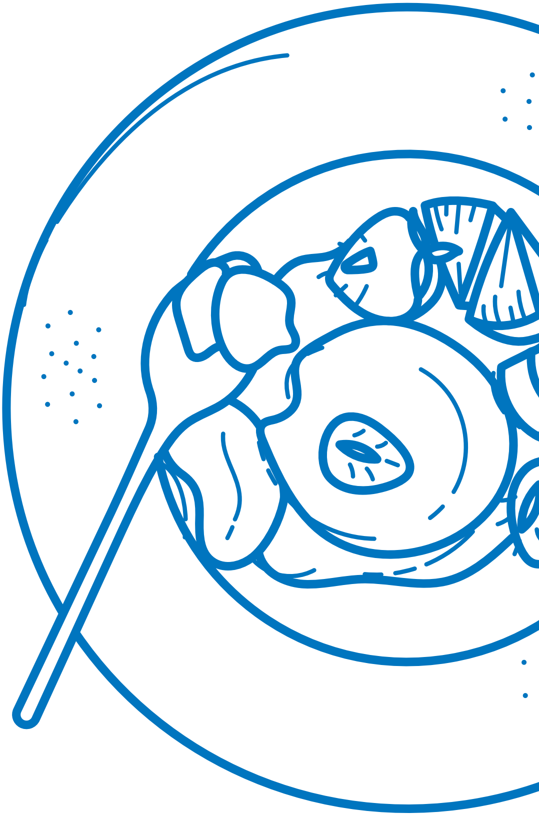
A lack of calories can cause blood sugar levels to drop. This can leave your teenager feeling weak or dizzy, or give them mood swings and hot and cold flushes.

To help your teenager gain weight, try:

- Increasing the 'nutrient density' of the food they eat rather than the amount – for example, by adding more fats (butter, cream) and protein (eggs, chicken, tofu)
- Choosing nutrient-dense snacks, such as full-fat yoghurt or peanut butter on bread
- Encouraging them to eat and drink milky drinks or condensed soups

If your teenager is experiencing unexplained weight loss, talk to their GP and dietitian. They can help you work out the problem and how to address it. Their dietitian can prescribe high-calorie drinks and liquid supplements, if necessary.

Any big changes in diet should always be discussed with them first.



What a good diet looks like

There is no special type of diet to manage DMD. However, a well-balanced diet, with different foods from different groups, is especially important for your teenager. It can help them manage some of the effects of DMD.

Doctors and dietitians

recommend a diet with enough protein, lots of fibre and plenty of water.

For example, some teenagers with the condition can put on weight very easily because of reduced mobility. They may also struggle to get the nutrients they need to maintain good health. This can be caused by problems with chewing, swallowing, reduced appetite, tiredness and difficulty bringing food to their mouth because of weak arm muscles.

Gaining or losing weight can be hard for some teenagers, so a good diet is the best way to help your teenager manage their weight before problems occur. It also makes sure they get all the essential vitamins and minerals they need. And now is a great opportunity to help your teenager develop healthy long-term eating habits.

Doctors and dietitians recommend a diet with enough protein, lots of fibre and plenty of water.

Your teenager should eat foods such as:

- Fish, lean red meats, chicken, eggs, beans and pulses – all of which are important sources of protein
- Vegetable protein, such as beans and soya
- Lots of fresh fruits and vegetables for fibre, vitamins and minerals
- Wholewheat or wholegrain breads, pasta, rice, cereals and potatoes – wholegrains help keep blood sugar levels stable
- Dairy foods or calcium-fortified dairy alternatives, such as almond or soy milk – important calcium sources for healthy bones and teeth, and good sources of protein
- Oils and spreads, such as olive oil – these should be eaten in small amounts, although they are useful if your teenager is finding it hard to put on weight
- Plenty of water, to help them stay hydrated, feel fuller and manage constipation

You should also reduce or exclude:

- Fatty and processed meats, such as salami, bacon and sausages
- Refined grains and cereals, such as white bread and sweetened breakfast cereals
- Packet snacks with lots of fat and salt, such as crisps
- Refined sugars, such as cakes, ice lollies, chocolates and other sweets
- Juices, soft drinks, sports drinks and any other sugar-sweetened drinks (also important for healthy teeth)

These foods contain very little nutritional value.

A note on protein

Protein is essential for growth, development and tissue repair.

While there is little medical evidence about how much protein individuals with DMD need, your teenager should eat at least the recommended amount.

So, try to include protein-rich foods in all meals and snacks. Our bodies use some proteins – such as lean meat, chicken, eggs and dairy foods – more efficiently.

If your family or teenager is vegetarian or vegan, use plant-based proteins, such as tofu, chickpeas or lentils. Protein-rich foods can also help manage appetite by increasing feelings of fullness.

Try to include protein-rich foods in all meals and snacks.

A note on fibre

Fibre is important for gut health and managing constipation. It increases the amount of good bacteria in our bodies, which can help our immune system.

Fibre comes from plant-based carbohydrates that are not digested in the small intestine. They are digested in the large intestine or colon. Wholegrains, fruit, vegetables, nuts and seeds, beans and pulses are all rich sources of fibre.

If you have any questions about your teenager's diet, talk to their GP or dietitian.

Get help from healthcare professionals

Your teenager's dietitian can assess their diet to make sure they're getting all the nutrients they need – including calcium.

Our bodies need calcium to build and maintain strong bones and help our heart, muscles and nerves work efficiently. Your teenager may need a calcium supplement if they're not getting enough from their diet.

Your teenager's dietitian can also suggest changes to their diet to help manage weight or constipation. If your teenager does not already have a dietitian, ask their neuromuscular consultant for a referral or advice.

Your teenager's height and weight should be measured at least every six months by their neuromuscular clinic, GP or dietitian. This will help you keep track of changes over time and spot potential problems early. And it will help your teenager prevent significant weight gain or loss.

Talk to your teenager's GP or neuromuscular clinic if you think they need extra help or medication for constipation.

Your team can also monitor your teenager's sugar levels, via a blood test, as well as Vitamin D levels. Vitamin D helps control the amount of calcium and other nutrients in the body to protect bone health. Your teenager may need a Vitamin D supplement to help raise the levels in their blood.

Supplements

If you want to try any new supplement, we recommend talking to your doctor first. They can work out the correct dose and check its safety.

> Our bodies need calcium to build and maintain strong bones and **help our heart, muscles and nerves work efficiently.**

Steroids and diet

Steroids are the main treatment proven to slow the progression of DMD. While they have many benefits, they can increase appetite and also put a strain on the body. Dietary supplements can help counteract the side effects caused by steroids.

All teenagers and adults taking steroids should take Vitamin D supplements and make sure they get sufficient calcium through their diet. Your teenager can also get Vitamin D from oily fish and fortified foods, such as milk, which have nutrients added to them.

Vitamin D is also in sunshine, so encourage your teenager to spend time outside. On sunny days, take care to avoid sunburn or sunstroke. If your teenager is unable to get enough calcium through their diet, their clinician may recommend a calcium supplement.

Bisphosphonate infusions can protect your teenager from a condition called osteoporosis, which weakens the bones. Currently, bisphosphonate is only prescribed after a fracture occurs, including vertebral fractures.

Some teenagers may experience gastroesophageal reflux (GORD), more commonly known as heartburn, that happens repeatedly. GORD can be triggered by steroids. It can also be caused by things like the way we sit, eating too much or eating lots of fatty foods.

Your teenager may find it helpful to have a low-fat, high-fibre diet with lots of wholegrains, fruits and vegetables.

Children and teenagers using steroids and those with heart problems may also need a low-salt diet.

Managing chewing and swallowing issues

As your teenager gets older, they might start to have problems chewing, swallowing and feeding themselves.

Difficulty swallowing is known as dysphagia. It is caused by weakness in the face, jaw, tongue and throat muscles. It can cause small pieces of food or drink to enter the lungs. This is called aspiration.

Dysphagia can lead to weight loss, dehydration and chest infections. Jaw weakness or tightness can sometimes make it difficult for someone to open their mouth wide. This can make eating and brushing teeth more difficult. It may also affect your teenager's visits to the dentist and even their ability to have a general anaesthetic.

Chewing and swallowing techniques

Your teenager can make chewing and swallowing as easy as possible by:

- Taking time to chew food well before swallowing
- Avoiding 'difficult to chew' foods
- Cutting food into small pieces, mashing, adding extra sauce or gravy, or mincing meats
- Sitting upright during and after a meal
- Avoiding talking while eating
- Drinking water after meals to help them clear their mouth and throat

Eating and drinking can be even more difficult when your teenager has a cold or chest infection. You may need to help them be extra careful during mealtimes.

Extra support and equipment

Over time, your teenager will lose upper body strength. This means they will need more help with eating and drinking. At first, this might just involve cutting up their food for them. Later, they may need your help with getting food into their mouth. Some teenagers might find equipment, such as dynamic or mobile arm supports, helpful.

Your teenager's occupational therapist can suggest different types of feeding equipment to make meals easier. Their dietitian and speech and language therapist can also help you find ways to make chewing and swallowing easier. If necessary, they may also recommend incorporating meal replacement drinks into your teenager's diet.

Your teenager's dietitian and speech and language therapist can help your teenager find ways to make chewing and swallowing easier.

See Chapter 3: Health for more information about:

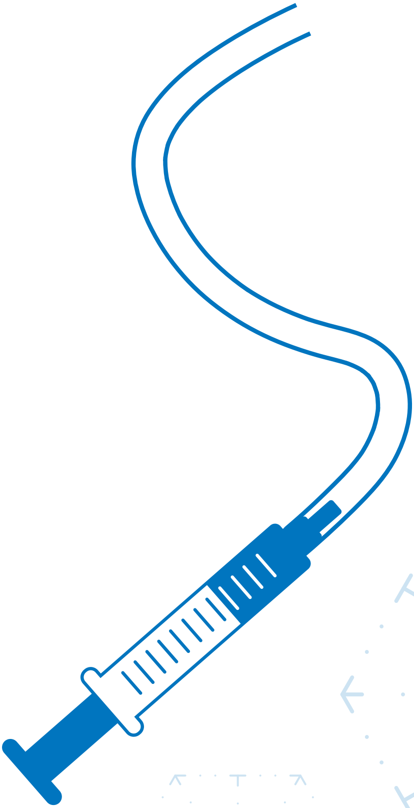
* the signs and symptoms of dysphagia and aspiration

* how your healthcare team can help your teenager manage them

Feeding tubes

When they get older, some people with DMD might have to use a feeding tube, known as a gastrostomy. This involves a small procedure to insert the tube into the stomach. This is common if someone has frequent chest infections because of aspiration, or if they cannot eat and drink enough to maintain a healthy weight.

We know this might sound a bit scary. Not everyone needs a feeding tube, but delaying the decision could affect your teenager's health. Many adults with DMD use feeding tubes very successfully. Tubes can take the pressure off eating and make mealtimes enjoyable again. Many adults with DMD say they wouldn't go back now.



Exercise

The benefits of physical activity

Like diet, exercise and physical activity are an essential part of a healthy life. It's not always easy to persuade a teenager to do things that are good for them though!

So, try helping them understand the benefits first. For example, exercise can help them to:

- Stay active for longer
- Reduce the risk of other diseases, such as type 2 diabetes
- Protect their heart and lungs, and improve stamina
- Keep other unaffected muscles working well
- Manage their weight
- Sleep well
- Reduce pain and tiredness
- Improve bone density
- Maintain or improve the range of movement in their joints
- Improve their mood and manage stress

Research has not yet identified the best amount and type of exercise for people living with muscle-wasting conditions. However, it is widely agreed that being inactive is harmful for health. UK guidelines for children up to 18 years advise 60 minutes of exercise each day.

Choosing the right sort of exercise

Living with DMD should not stop your teenager from exercising. However, the activity should match their needs, ability and interests.

A moderate amount of physical exercise can improve your teenager's general fitness. Physical or aerobic exercise should raise the heart rate and leave your teenager comfortably out of breath. A good way to judge this is that your teenager can still talk through their heavier breathing.

Exercise doesn't have to mean going to the gym or doing a formal class. Finding simple ways to keep moving throughout the day can be just as useful.

Talk to your teenager's neuromuscular consultant and physiotherapist for advice on the types of exercise that best suit them. They can also explain what a healthy heart rate looks like for your teenager. DMD can increase the heart rate and some medication can bring it down to normal levels.

Your team can also help you learn how to spot signs of heat exhaustion, such as heavy sweating, clammy skin, cramps and dizziness. In very rare circumstances, a person with DMD may have very dark urine (think the colour of cola) after exercise. If that happens, take your teenager to A&E straight away, as this could be a condition called myoglobinuria.

Caution: choose your exercise carefully

Not all types of exercise are good for people with DMD. Certain exercises and sports may increase the risk of them getting injured.

Always talk to your teenager's physiotherapist before trying any new exercise or physical activity.

Exercises that help people with DMD

Here are some examples of exercises that are helpful for people with DMD:

- **Hydrotherapy and swimming** – Spending time in the water helps tone muscles and improves lung function. It also protects muscles from strain and injury.
- **Cycling** – Some teenagers may be able to continue using a low-geared bike or trike. Tomcat Trikes (www.tomcatuk.org) has a good range for all ages.
- **Powerchair football** – This is a fun, fast-paced sport that gives disabled people access to the game of football. It is open to anyone who uses a powered wheelchair or who has limited movement in a manual wheelchair. For more information, visit www.thewfa.org.uk

Exercises to avoid

Teenagers with DMD should avoid exercises that put undue strain on their muscles or only exercise one side of their body. This can damage their muscles.

The following exercises are harmful for people with DMD:

- **Trampolines and bouncy castles** – Jumping and hopping involves eccentric exercise, which means muscles must work twice as hard. This can lead to severe fatigue, pain and muscle damage.
- **Weight training** – Your teenager should not lift heavy loads. This causes muscles to contract and increases the risk of injury.
- **Contact sports** – High-impact sports, such as rugby, should be avoided because of the risk of injury.
- **Two-wheeled scooters** – Although popular, teenagers with DMD should avoid these scooters because they place stress on one side of the body.

Sport

Teenagers are much more likely to keep up an exercise routine if it involves something they like. Like general exercise, the sport they choose should match their ability and needs. There are lots of options available to people using wheelchairs.

The British Paralympic Association has an online tool that matches your postcode to local accessible clubs and gyms. The tool is available at www.parasport.org.uk

WheelPower is a national charity dedicated to wheelchair sport. Their website is full of ideas on helping wheelchair users get active – www.wheelpower.org.uk

See Chapter 9: Holidays and Fun for more information on different sports and exercises.

Stretching

Daily stretching and position changes are very helpful for teenagers with DMD and should be part of their exercise plan. Stretching helps keep muscles and tendons supple, improves flexibility and preserves range of movement.

Stretches that help maintain range of movement in the hands and wrists are as important as ones that help them walk. Lots of teenagers with DMD play computer games to relax and make friends. Stretching their hands and wrists will help them maintain this interest for a long time.

It's best to stretch when your body is already warm, so after exercise or a bath is a good time.

It's likely your teenager has been working with a physiotherapist at their neuromuscular clinic for some time now. Talk to them about how to adapt your teenager's routine to match their needs. They can help you make sure your teenager doesn't overstretch any muscles.

Wheelchairs

Many people with DMD are walking for longer thanks to steroids. Helping your teenager stay on their feet can help them maintain strength and address other problems, such as scoliosis.

However, while walking is good for the spine, it still places pressure on the body. Over time, DMD muscles will weaken, even with steroids. This means the risk of falling and breaking a bone will rise as your teenager gets older. Their physiotherapist can help you plan how to lower the risk of falls. A wheelchair can help your teenager stay mobile when walking becomes difficult or if they are falling over a lot.

Your family's attitude to wheelchairs

We know that wheelchairs are a big change for families. Getting one can also be an emotional decision.

Lots of people, especially non-disabled parents, have strong negative feelings about wheelchairs. They can see it as a loss.

But many disabled people see wheelchairs as liberators and enablers. They can do more and go to more places with a wheelchair than they can without one.

Your teenager will be guided by your attitude. So, you might find it helpful to think about a wheelchair as just another tool to help them live a good life. Many teenagers have lots more energy and independence once they start using a wheelchair. Your teenager probably will too.

Many disabled people see wheelchairs as liberators and enablers.

Transitioning to a wheelchair

Often, people switch from walking to wheelchair gradually. For example, your teenager might start to use one for travelling longer distances.

The earlier you start this gradual transition, the easier it will be when they need to use a wheelchair all the time.

Organising a wheelchair takes time and the NHS should be your first port of call. NHS wheelchair services in your area will offer you an assessment. You'll need to complete the assessment before you can get an NHS wheelchair. They will decide if your teenager needs a wheelchair and talk to you about your options and budget. NHS services will only usually fund one wheelchair per person.

The range of wheelchairs available via the NHS is very good these days. However, some parents do choose to buy one privately, particularly if an NHS chair isn't suitable for any reason. Some families use charitable funding to raise the money they need to do this. Charities like Whizz-Kidz can help (www.whizz-kidz.org.uk).

Fundraising can take a long time, though. And you will need to do your research. For example, a charity might not cover any ongoing wheelchair maintenance costs or upgrades, such as seating adjustments.

Whichever route you choose, your teenager's needs and wishes should drive the conversation about wheelchairs. That way, they'll get a chair that suits them best.

Choosing a wheelchair

There are lots of wheelchair types to choose from. Each has its pros and cons. Posture support is important to help your teenager stay independent for as long as possible.

As you look at different wheelchairs, think about:

- **Lifestyle and environment** – What does your teenager need from their chair? Will they use it inside, outside or both?
- **Sport** – Will they use it to play sport? If so, which ones? Some sports, like powerchair football, require a separate chair.
- **Your home** – Will there be enough space to move around your home?
- **Features** – Do they need raised seats or back support, or other extra features?
- **Practicalities** – Is the chair easy to get in and out of your car?
- **Adaptability** – Will it adapt to your teenager's needs as they change?

We do recommend getting an elevated seat riser for your teenager's wheelchair. This will help them access classroom benches. It will also lift them to the same height as their peers and may support their mental wellbeing. Some NHS services may only provide a seat riser with a letter of support from your local muscle team.

For more advice on how to choose the right wheelchair, talk to your local wheelchair service and your teenager's physiotherapist, or occupational therapist, or both.

Accessing a personal wheelchair budget

Some NHS wheelchair services provide a voucher scheme to give you a better choice of wheelchair. The voucher is to the value of the chair you would have been offered after your assessment. You can use this towards the cost of the chair you wish to buy.

If you live in England, your teenager has the legal right to a personal wheelchair budget. Since April 2017, all clinical commissioning groups have had to develop plans to offer these budgets. Although many groups have delayed their introduction, you have the right to ask for one.

As part of this budget, your teenager should receive a personalised assessment and care plan based on their health and wellbeing goals. You should also be given information about the amount of money in their budget and options to use it. This budget may help you buy extras, such as an elevated seat riser or even Bluetooth.

The NHS has more information about wheelchair budgets at bit.ly/nhs-wheelchair-budgets

Chapter 5

Chapter 05 — Education

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In a nutshell

1 Help your teenager get the best education possible

Many adults with DMD are now living into their 30s and 40s or longer. Many are making good lives for themselves, holding down jobs, enjoying loving relationships and living as independently as they can.

When you help your teenager get the best education possible, you'll be giving them the best start for a more independent adult life.

You can get free advice and support from Decipha, a not-for-profit organisation focused on special educational needs. It is run by teachers who are DMD parents.

2 See the possibilities

Be excited. See opportunities. Ask your teenager about their hopes and dreams. Encourage them to think of the endless possibilities the future could hold.

There are so many education and job opportunities these days. Go beyond being hopeful. Help them shape a good life.

3 Make the most of schools and colleges

Educational establishments can provide so much more than just education. They can also provide access to sport, drama, special interests, mentors, careers advice and work experience.

They might also be the place where your teenager receives physiotherapy or other treatments. Choose the best place possible and help them make the most of their teenage and early adult years.

4 Look at all the career choices

Encourage your teenager to think beyond school. Ask them how they see their future. Do they want to go on to further or higher education? Do they want to follow a career path?

These days, there's an amazing array of options. People work or study both at home and away – full time, part time or shared time. Help them choose the path they want and the subjects they'll need for life beyond their school years.

5 Keep developing Education Health and Care Plans

The Education Health and Care Plan (EHCP) in England brings together all your teenager's education and care needs in one statutory document. In other parts of the UK, similar support is available. Check with your local authority for details.

By reviewing the plan regularly, you can make sure it still meets your teenager's changing needs and interests. You don't have to face this alone. You can get help from your teenager's Special Educational Needs Co-ordinator (SENCO), healthcare professionals and charities such as Decipha.

Finding the right educational support for your teenager

When it comes to academic diversity, teenagers with DMD are no different from teenagers without DMD.

Some are highly intelligent and need to be challenged academically. Some are averagely intelligent. Some have learning or behavioural difficulties and need extra support. The important thing is to find the right type of education and educational support for your teenager. There is a wide range of options available.

You might find your local mainstream school is ideal. Or you might find a special educational needs (SEN) school better meets the needs of your teenager. They might want to go on to higher academic education. Or they might prefer further education or vocational studies.

We know everyone is different and not everything in this chapter will apply to every family. Please use it to see what's possible and then choose what's right for you.

If you live in Scotland, Wales or Northern Ireland, you'll have a different system for accessing educational support. Speak to your teenager's social worker, teacher or other healthcare professional for details on how to get support outside of England.

Education Health and Care Plans in England

The EHCP brings together all your teenager's education, health and care needs in one document.

The Children and Families Act 2014 introduced changes to the way that Special Educational Needs and Disability works in England. Children and young adults with DMD are now entitled to an EHCP up to the age of 25 if they're still in education.

You can read more about the EHCP in Chapter 4 of *The DMD Family Folder – Support and Guidance for Newly-Diagnosed Parents.* You can find the book on the Duchenne UK website at www.duchenneuk.org/support-at-diagnosis

Keeping your EHCP up to date

Your teenager should already have an EHCP or equivalent in place.

If they don't, you'll need to contact your local authority. You can do this yourself or through your teenager's SENCO, GP or another health or social care professional.

If your teenager does have an EHCP in place, it will need to be reviewed regularly. Plans need to be updated as your teenager gets older and their education and care needs change.

You have the legal right to have your EHCP formally reviewed every 12 months. But you can ask for an informal review at any time. You don't have to wait until the annual review if you have concerns about your teenager's progress or how the plan is being carried out. Your teenager's SENCO is usually the best person to speak to about an informal review.

See the Independent Provider for Special Education Advice (IPSEA) website for more information at bit.ly/IPSEA-EHCP

Informal reviews

Informal reviews are an important way of keeping on top of your teenager's progress. Some schools set up reviews each term. Others wait for you to request one.

You can ask your teenager's SENCO to invite teachers, other members of staff or healthcare professionals working with your son or daughter to the informal review.

Informal reviews won't change what's in your teenager's EHCP. That only happens at formal annual reviews.

Formal reviews

You can request an earlier formal review if you are unhappy or concerned about your teenager's EHCP.

For example, you or the school might ask for an early formal review because:

1. Your teenager's special educational needs have changed significantly and their EHCP no longer meets their needs
2. Your teenager has been excluded or is at risk of exclusion from school
3. The school is having problems and is no longer meeting your teenager's educational needs
4. The school is no longer able to provide special educational services such as speech or physiotherapy

The annual review

The annual EHCP review is your opportunity to see how your teenager is progressing against their agreed outcomes.

Your local authority must do all of the following:

1. Carry out a review of your teenager's EHCP every 12 months
2. Consult with you or your teenager, or both of you, and their school or educational institution at least two weeks ahead of the review
3. Gather information from you, your teenager and all their health and education professionals
4. Take account of all parties' views, wishes and feelings
5. Circulate the information to all parties at least two weeks before the meeting
6. Prepare and send a report of what happened at the meeting to everyone who attended or submitted information
7. Review the EHCP and notify you or your teenager of their decision within four weeks of the meeting

As shown in points 3 and 5 above, your local authority or SENCO must invite information from anyone involved in your teenager's care and share it with everyone else.

This is especially important when you have several authorities and people responsible for different areas of your teenager's health and education needs.

The list of people involved could include:

- You and your teenager
- The health or social care agencies involved in their care
- Teachers and teaching assistants (TAs)
- Therapists
- Child and Adolescent Mental Health Service (CAMHS) professionals
- Any other health and education professional working with you

If you haven't received the report within two weeks of the review meeting, ask the school for a copy.

How to prepare for an EHCP review

With so many professionals at the meeting, it’s easy to feel intimidated. But remember, this is your teenager they’re talking about. No one knows them better than you.

So, what you as a parent says is as important as the educational psychologist’s report.

Fortunately, you can get help to make the process easier for you – and deliver a better result for your teenager.

Start early

Start preparing for the review meeting as early as you can. Talk to your teenager. Ask them what they like about their life now and what they’d like to see happen in the future.

You could begin with these questions:

- Where do they see themselves in five years’ time?
- What do they want to do in the future?
- What’s happening now to help make that possible?
- What more needs to happen?

Write down three things you’d like to get from the meeting. These could be three things you want to say, ask or make happen.

By writing them down and taking them with you, you’re more likely to remember them – and more likely to have the confidence to speak out among a group of professionals.

You might also want to talk to your teenager’s SENCO and Decipha.

> What you as a parent says is as important as **the educational psychologist’s report.**

Decipha's free advice and support for EHCPs

Decipha is a not-for-profit organisation made up of special educational needs teachers who support young disabled people. It is run by Nick Catlin and Dr Janet Hoskin, who are the parents of a young man with DMD.

Decipha offers free educational support and advice to families of young people living with DMD. This is funded through Duchenne UK's investment of £120,000.

Its 'Roadmap for Life' programme can help you identify key outcomes for your teenager's EHCP. The programme covers a range of services that can help your teenager with their education and social development.

These include:

- Education and care assessments
- Help with reading and writing
- Information and advice
- Support for parents and siblings
- Help with making friends at school

Find out more about the Roadmap for Life at www.decipha.org/roadmapforlife and at www.duchenneuk.org/support-with-education

Changes to your teenager's EHCP

Following the review meeting, your teenager's EHCP could be amended. This could mean changes to:

- The support your teenager receives
- Expected outcomes
- School or education
- Social care
- Health and educational support needs

If the suggested changes are big, such as moving school, the local authority will send you a draft EHCP and an 'amendment notice' telling you about the planned changes.

If you don't agree, you'll have 15 days to object in writing. You must explain why you disagree, and you can ask for a meeting with a local authority officer. You can also talk to your SENCO about the changes and ask them to write to your local authority too.

See the IPSEA website for more information on the annual review process at www.ipsea.org.uk/the-annual-review-process

You can find a comprehensive EHCP review checklist on the IPSEA website at bit.ly/ipsea-EHCP

Transition to secondary school

When professionals talk about ‘transition’, they usually mean ‘transition to adult services’, which is mainly about health.

This starts when your teenager is between 16 and 18 years old. However, the transition from primary to secondary school starts much earlier – usually in Year 5, when your child is about 10.

At the end of Year 5 or the start of Year 6, your local authority should provide you with information on secondary schools in your area. This should include details of admission criteria and important dates such as open evenings and deadlines for applications.

Finding the right school

Finding the right secondary school for your teenager will largely depend on their wants and needs. You’ll also need to consider the practicalities of getting them there – and how they will get around while they’re at school.

Visit as many schools as you can with your teenager. Keep your options open. And give yourself plenty of time to consider your choices.

Depending on what’s available in your area, your choice might be:

- Mainstream schools
- Mainstream schools with SEN units
- SEN day schools
- SEN residential schools (for example, Treloar’s) www.treloar.org.uk
- Home schooling

Your local mainstream secondary school (either with or without a SEN unit) is ideal. Your teenager will be local, which will help them make friends and feel part of the community. And it’s usually the best choice if your teenager is academic and wants to study for qualifications that could lead to further or higher education.

However, not everyone wants to be a ‘high-flyer’ academically. Feeling valued and able to achieve in other areas is equally important. Sometimes SEN schools are more appropriate, especially if your teenager needs a lot of care.

Some SEN schools don’t offer GCSEs. But they might offer lots of vocational qualifications not available in a mainstream school. And teenagers at SEN residential schools can stay until they’re 19.

(See the later section on post-16 education and different qualifications.)

The important thing is to find what’s right for your teenager. The aim is to make their education an enjoyable and rewarding experience.

School visits

You should try, if possible, to visit schools outside of their standard open days. This will give you a chance to spend more time with the teaching team and see what they're like on a day-to-day basis.

Find out as much as you can about the school's attitude and experience with disabled youngsters. And, of course, ask about the practicalities of how your teenager will get around the school in a wheelchair, wombat chair or other mobility aid.

Caring for your teenager is important. But you also want them to have as many educational opportunities as their peers.

Don't be afraid to ask lots of questions. Here are just some you might want to ask:

- What is the staff to pupil ratio?
- How will your teenager's care and learning needs be assessed and monitored?
- How will you be involved in planning the provision to meet their needs?
- Will the school respect your views and take them into consideration?
- How will the school assess the level of support staff for your teenager?
- What academic needs will the educational support assistants address?
- How will the school make the full curriculum accessible for your teenager?
- Will your teenager have full access to ICT, design technology and science labs?
- What, if any, facilities are available for disabled pupils?
- Are all areas of the building accessible?
- What seating do they provide if your teenager is not a full-time wheelchair user?
- Do they have height-adjustable furniture available?
- Do they have a transporting chair to move between classrooms?
- How much time do they allow for getting from one lesson to the next?
- Are the toilets adapted to meet your teenager's needs?

Talk to other parents and students. Ask to look at the latest Ofsted report. Your teenager's DMD doesn't mean you have fewer choices.

You can find a parents' checklist in 'Deciding on a School for Your Child' on pages 39 to 42 of the Muscular Dystrophy Education Guidelines document at bit.ly/MDUK-education-guidelines

Making the most of secondary school

The move from a small, familiar primary school to a large, unfamiliar secondary school is a daunting experience for everyone.

Your teenager might or might not share their worries with you. But it's likely they'll have them.

Talk to them about your own experience. Get older siblings, cousins, neighbours or friends involved. Reassure them that it's fine to feel a little anxious at first. Tell them that once they see the range of activities they can take part in, and start doing experiments in the science lab, they'll feel very differently.

Becoming more independent

The move to secondary school often coincides with becoming more independent.

You could consider getting a key cut (or sorting out an automatic opening device for the front door), so your teenager can travel to and from a local school independently. If their school is further away, you might need to look at accessible transport.

If your teenager isn't a full-time wheelchair user, an electric scooter could be an option. They could use it to travel to school and drive to different classrooms.

You'll find more advice about moving to secondary school at www.scope.org.uk/advice-and-support/education

> If your teenager isn't a full-time wheelchair user, an electric scooter could be an option. **They could use it to travel to school and drive to different classrooms.**

Friends for life

Secondary school isn't just about education. It's where many of us make lifelong friends. Our experience at school has a big effect on our mental wellbeing.

School can be difficult for those who look or act differently. Usually, people are awkward or insensitive because they don't understand disabled people. You or your teenager may be able to talk to those people and resolve these problems.

However, if your teenager is becoming distressed and you feel they're being bullied, you should step in. Scope's advice on education has a useful section on bullying.

Being comfortable with DMD

If others see that your teenager is comfortable with their speech, mobility, height or wheelchair, they'll be more inclined to feel comfortable themselves.

See Chapter 6: Friendships, Relationships and Sex for advice about talking about DMD.

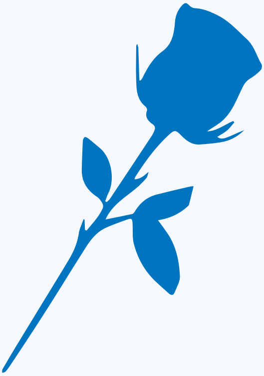
Romantic relationships

With young hormones at their peak in the early teens, secondary school is often the place where we have our first romantic encounters.

However, teenagers with DMD can have low confidence issues, which can create a problem when it comes to mixing with or talking to people they feel attracted to.

If your teenager seems smitten by someone, take their feelings seriously. It might come to nothing. They might even get their heart broken for the first time. But you can make a big difference to how they deal with it by giving your support.

See Chapter 6: Friendships, Relationships and Sex and Chapter 10: Life Skills for more information about developing good social and communication skills.



Hobbies, interests and fun

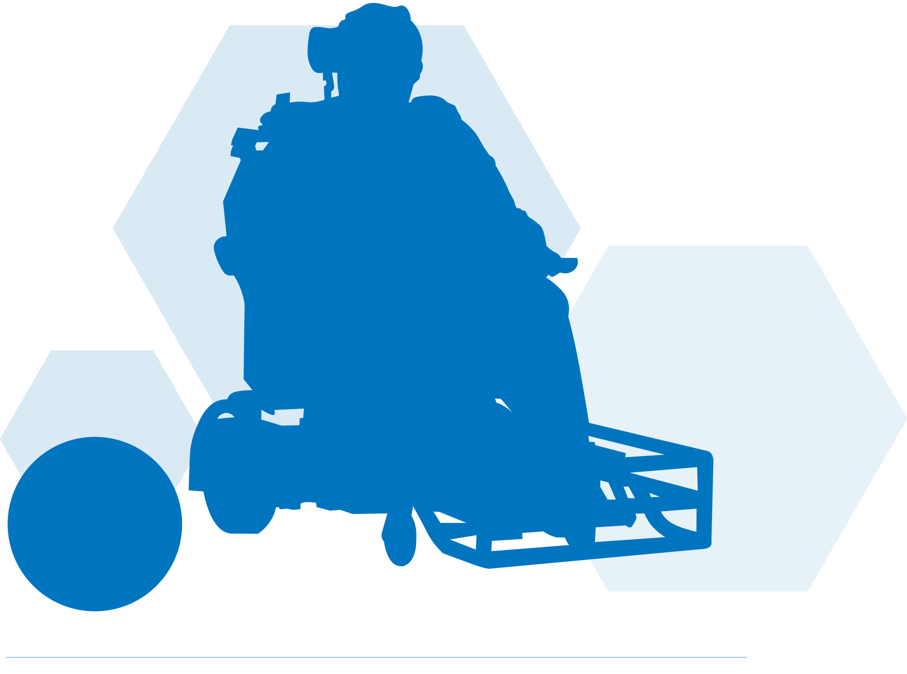
School is the place to explore new hobbies and interests, as well as learn about academic subjects.

Nowadays, schools offer a huge range of extracurricular activities. These activities are a great source of fun. They're good for mental and physical health, they help build communication skills and they can be an excellent foundation for further education or work.

When you visit schools, ask about their clubs and what they offer to disabled teenagers. Your teenager might not be in the school football team, but they could get involved in promoting it. Or they could join an out-of-school wheelchair football team and become the top scorer!

Encourage your teenager to consider all clubs, not just the 'common-sense' ones for disabled teenagers. There might be simple ways a club could be adapted to include them.

See Chapter 9: Holidays and Fun for more information about hobbies, and Chapter 11: Work for more information about developing skills that will help prepare your teenager for work.



Muscular Dystrophy UK have a very useful guide about inclusive education on their website at bit.ly/MDUK-education-guide

See Chapter 7: Education and School Policies.

The secondary school educational experience

Moving from the simple primary school environment to a complex secondary school can put added pressure on your teenager.

They might find it hard to adjust to the bigger school. In primary school, they would have had one or two teachers and classrooms. In secondary school, they'll have many teachers, locations, subjects and timetables.

They might need longer than their classmates to get from one location to another. They might find planning their week around a secondary school timetable is confusing. And they might find studying different subjects feels overwhelming to begin with. But they won't be alone. Many teenagers have similar experiences.

Working with teachers and teaching assistants

Teenagers with DMD need their teachers to see them in the same way they see other teenagers. This is especially true if they also have learning difficulties.

Arrange a visit outside of the usual parents evening to talk to your teenager's teachers and TAs. This extra meeting is sometimes part of the EHCP annual review.

Ask them to look for strengths in your teenager and develop those. Encourage them to have high expectations for your teenager and make sure they are accessing all the support available to them.

Many teachers rely on TAs to get more involved with disabled teenagers. This can be very helpful. You might want to talk to the TAs about encouraging your teenager to do as much schoolwork as possible for themselves. You could also ask for their help with daily physiotherapy and stretches.

However, TAs can sometimes get in the way of your teenager getting the support they need directly from their teacher. So, you might want to discuss the best place for your teenager to sit in the class. Ideally, this will be somewhere your teenager feels comfortable and the teacher can see when they need extra support or a short break.

Guide to DMD for teachers

We have produced a useful guide you can use when you talk to your teenager's teachers. This is especially helpful if the teachers haven't heard of or don't know a great deal about DMD. You might also want to suggest that teachers get in touch with Duchenne UK for a general overview of living with DMD or get involved in meetings and campaigns.

Our guide was originally written for teachers of young children in primary school, but most of the information is also relevant to secondary school teachers.

The Guide to DMD for Teachers will help you talk to them about:

- The effects of DMD on the body and brain – so they understand its impact on education and social development
- Physical education (PE) lessons, sports and games – so they can help them develop physical skills and strengthen their muscles, and avoid harmful activities
- Breaks – so they can encourage them to enjoy being with other teenagers
- Falls and minor injuries – so they know how to respond properly
- Emergency procedures – so they can tell the emergency services what they need

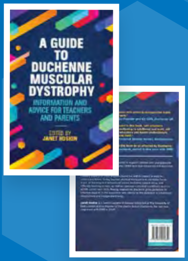
You can download the guide from www.duchenneuk.org/support-at-diagnosis

A Guide to Duchenne Muscular Dystrophy:
Information And Advice For Teachers And Parents

Edited by Janet Hoskin

This book is packed full of valuable advice for parents and teachers. It was written by education professionals who support children with DMD, parents of children with DMD and adults with DMD.

You can get the book for free from Duchenne UK by emailing us at support@duchenneuk.org. You can also buy additional copies from Amazon if you want to give them to your teenager's teachers.



Help managing the school week

The school week at secondary school is considerably different from the primary school week. It needs a lot more organisation.

As with all teenagers, it's important that your teenager is as organised as possible. That could mean doing homework on time and packing their schoolbag each night ready for the morning.

Some young people like to use a 'visual' timetable that they carry with them to remind them of the different lessons they have each day. This could be a handwritten or typed-up table on cardboard, or a planner on their mobile phone.

If possible, have a quick chat with them in the morning or the night before about what to expect in the day. This can help ease stress and anxiety, especially if anything out of the ordinary is happening, such as a school trip, visitors to the school or a class photograph being taken.

Choosing study subjects

During Key Stage 3 (Years 7-9 and ages 11-13), your teenager will study a wide range of compulsory subjects. These include English, maths, science and modern languages.

Toward the end of Year 9, they will drop some of the Year 7-9 compulsory subjects and choose between five and twelve subjects to study at GCSE level.

Scotland has its own education and examination system, independent of England, Wales and Northern Ireland. You can find out more about the Scottish system at www.gov.scot/policies/schools/school-curriculum

You can see the full list of national curriculum subjects at **www.gov.uk/national-curriculum/key-stage-3-and-4**

GCSEs and equivalent qualifications

Teenagers with DMD have a legal right to study for any GCSE subject. Sometimes reasonable adjustments have to be made, but your SENCO should be able to help with these. (See the later section on help with exams.)

Talk to your teenager in Years 8 and 9 about which subjects they'd like to study. Discuss which subjects they might need if they want to go on to further or higher education – or pursue a career. Teachers and careers advisers will also help them decide.

Teenagers with DMD shouldn't necessarily take fewer GCSEs, but they do need to make sure they have enough time to allow for extra commitments. For example, they may have hospital appointments, physiotherapy or hydrotherapy.

The compulsory national curriculum subjects are divided into 'core' and 'foundation' subjects:

- Core subjects are English, maths and science
- Foundation subjects are computing, PE and citizenship
- Schools must also offer at least one subject from arts, design and technology, humanities and modern languages
- They must also provide religious education and sex education

You can find out more about choosing GCSE subjects at **bit.ly/choosing-GCSEs**

Your teenager should think about what they enjoy studying and where they want to be in five or ten years' time. These are the most important things when they are choosing subjects.

Post-16 qualifications and options

Your teenager can legally leave school at the end of the school year in which they turn 16, normally the end of Year 11. However, all young people must be in a form of education or training until age 18. This can be combined with paid or voluntary work.

There's a range of study options for 16- to 18-year-olds. They can move into the sixth form of their mainstream or SEN school. Or they can move to another school if their school doesn't offer the options they're looking for. (See the later section on further and higher education.)

There's also a range of qualifications they can work towards. These include entry-level qualifications, GCSEs, BTECs and A Levels, or Highers in Scotland.

Mainstream further education colleges offer a wide range of courses to suit all levels of learning. These include:

- Academic courses (A Levels and GCSEs)
- Vocational courses (such as BTECs)
- 'Stepping-stone' courses in maths and English
- Courses which combine study with on-the-job training or work experience
- 'Life skills' courses to help young people prepare for adult life, work and living in the community

Whatever option they choose, your teenager will continue to receive extra help for their SEN if they need it.

Other education and training options

Of course, education doesn't have to be all classroom based. Your teenager might be more suited to workplace study.

Alternatives include:

- **Apprenticeships** – Apprenticeships combine study towards qualifications with paid-on-the-job training. You can find out more at www.gov.uk/education/apprenticeships-traineeships-and-internships

- **Traineeships** – Traineeships help young people gain skills to get a job or apprenticeship. You can find out more at www.gov.uk/education/apprenticeships-traineeships-and-internships

- **Supported internships** – These programmes combine workplace training and study. You usually need to apply for a supported internship through a further education college. The college will have links with suitable employers that can offer placements

- **Individually tailored education** – Flexible options for young people with EHCPs can include a mix of:
  - College-based learning
  - Work experience and volunteering
  - Independent training in life skills
  - Home-based tuition

A Levels and Highers

In Scotland, teenagers study Highers rather than A Levels, but they're very similar. If your teenager is considering further or higher education, it's a good idea to check what A Levels, Highers or BTECs they might need.

Teenagers usually study for A Levels after their GCSEs in their sixth form and upper sixth, when they're 16 to 18. A Levels are more intense qualifications, so most teenagers do between three and five in the first year of study and cut back to three in the second.

Not all schools offer A Levels, so that might be one of the things you need to consider when choosing secondary schools. But if a secondary school ticks all the other boxes, your teenager could still go there until they've finished their GCSEs. Then, they could study for A Levels at a local sixth form college.

Taking exams at secondary school

Special ‘access arrangements’ allow teenagers with SEN and disabilities to take exams in school with ‘reasonable adjustments’.

For example, your teenager might be given more time to complete the exam or access to a reader or a scribe (someone who will write their answers for them).

They might also be given ‘special consideration’ with their marks or grades to reflect their physical or mental condition at the time of the exam.

You can find out more about access arrangements at **bit.ly/JCQ-access-arrangements**

The physical management of DMD in schools and colleges

The physical management of your teenager’s DMD is one of the big things to think about when you’re choosing a school or college for them.

The physiotherapy and speech therapy in their EHCP usually takes place at school or college. As such, you’ll want to know who’ll be delivering it, what facilities and equipment are available, when it takes place and which lessons will be missed.

At some schools, TAs are trained by healthcare professionals to assist with physical exercises. Others call on specialist therapists or speech and language teachers.

You can find useful information in Chapter 3, pages 77 to 81, of *A Guide to Duchenne Muscular Dystrophy: Information and Advice for Teachers and Parents.*

This book was edited by Dr Janet Hoskin from Decipha and is free to parents and carers from Duchenne UK.

PE and sport at secondary school

PE can be challenging for teenagers with DMD. However, schools should support them by making reasonable adjustments.

Try to work creatively with your teenager’s school to come up with things that they can do. You might want to consider table tennis, dancing, stretching or yoga. Standing frames or standing wheelchairs may make it easier for them to play sports such as table tennis.

Typical school sports, such as football, rugby and cricket, are not suitable for teenagers with DMD.

Careers advice

These days, teenagers have an amazing array of career options. Schools provide independent careers advice between Years 8 and 13.

The advice can take many forms, including face-to-face meetings with careers advisers, visits to career fairs, mentoring and visits to and from employers and colleges.

Accessing good careers advice for your teenager

Good careers advice can make a big difference to your teenager's hopes and aspirations for the future.

Your teenager should consider their career goals when choosing qualifications and education options. Careers advisers can help teenagers identify their interests and choose appropriate subjects.

Good careers advice is empowering and solutions focused. It helps people identify their interests and how to pursue them.

Good advice starts with the young person and their hopes and strengths. So, ask your teenager's school how to access the best careers advice possible.

Getting over limitations

Bad careers advice is limiting and disempowering.

Bad advice includes shutting down potential career paths as 'impossible', or only giving a few options for possible careers. Bad advice starts by looking at a particular job and thinking about what is required for that job.

If you sense that your teenager is being given bad careers advice that's limiting their options, contact your SENCO and/or local authority to find out what careers advice is available for disabled young people.

Of course, some careers advisers might not have had many opportunities to work with disabled youngsters. And they probably won't understand DMD because it's a rare disease. So, they might have limited awareness of the opportunities available to your teenager.

That's fine if they're willing to explore opportunities with your teenager and take their dreams seriously. But it's not ok if they shut down options before your teenager has even looked at them properly.

Spotlight

Jack Ebanks

Jack, 21, lives in Birmingham with his parents and his older brother, Aaron, who also has DMD.

After mainstream school, the brothers found a springboard into work with The Hive College in Erdington. The specialist college welcomes disabled students aged 19-25. The pair are now working as technical engineers for the global infrastructure company, Aecom.

Jack says: “At The Hive the difference was amazing – six to ten students per class, lots of one-to-one teaching, spreadsheets for our targets, and everything was coursework. We all felt like we were in it together.

“The college is very active getting out to companies and explaining the benefits of giving its graduates work.

“I started as an intern with Aecom two years ago, Aaron started three years ago. After six months, we were taken on as part-time engineers.

“I now work in the roads department and Aaron works on bridge inspections. My main role is technical drawing. It’s really challenging, but you want that, don’t you?

“I’m also a keen powerchair footballer. My team, West Bromwich Albion, has just won the FA Disability Cup Powerchair final. I play for WBA Dudley, but I’m aiming to get into the premier league team.

“It’s important to do what interests you. Get the help you need – if you don’t ask, you don’t get.”

Other sources of careers advice

We encourage you to speak to adults with neuromuscular conditions at Pathfinders Neuromuscular Alliance (www.pathfindersalliance.org.uk). They can tell you how they manage in work.

You'll also find useful information on pages 175 to 180 of *A Guide to Duchenne Muscular Dystrophy: Information and Advice for Teachers and Parents*, edited by Janet Hoskin.

See Chapter 11: Work for more guidance on how your teenager can prepare for work while they're still in education.

Support for teenagers with learning or behavioural difficulties

If your teenager also has a learning disability or behavioural condition, they will probably need extra educational support.

See Chapter 2: Your Teenager and Family for more information about the effects of DMD on the brain.

Common learning difficulties associated with DMD include:

- Difficulty concentrating and holding information due to problems with short-term verbal memory (also called working memory)
- Language delays in understanding or expressing words, or both
- Weaknesses in planning, organisation, initiation, mental flexibility and self-analysis
- Reading disorders, such as dyslexia
- Mathematics disorders, such as dyscalculia
- Writing and expressing disorders, such as dysgraphia

Common behavioural and emotional difficulties associated with DMD include:

- Depression
- Anxiety
- Oppositional, explosive and aggressive behaviour, such as arguing, not following directions, having tantrums or refusing to do what's asked
- Inattentiveness, hyperactivity or impulsiveness due to attention-deficit hyperactivity disorder (ADHD)
- Challenges with social skills, repetitive behaviours, speech and non-verbal communication due to autism spectrum disorder (ASD)
- Finding particular textures, foods, lights or sounds overwhelming due to sensory processing disorder
- Uncontrollable obsessive thoughts or compulsive behaviour due to obsessive-compulsive disorder (OCD)

If your teenager is experiencing any of the above, talk to their SENCO about what support is available. Your teenager may be able to get help from:

- Educational psychologists
- Speech and language therapists
- Specialist teachers
- Occupational therapists
- Psychologists or psychiatrists to support mental health and wellbeing

Helping schools deal with your teenager's learning challenges

Some schools worry about challenging teenagers with DMD – especially if they also have learning difficulties. They don't want to put additional pressure on the student. Or they might find it difficult to deal with their behaviour.

You can help teachers understand that your teenager is not being deliberately difficult. Their behaviour is part of their DMD and there are many ways to manage their conditions.

Encourage the school to identify the behaviours that your teenager should reduce or increase. For example, they might need to reduce angry outbursts in class or spend more time on homework.

Ask teachers to note what triggers problems and praise your teenager when they cope well.

The three-step 'collaborative problem-solving approach' can work well:

1 Empathy and reassurance

Understand the teenager's concerns and tell them they're important. Avoid 'why' questions, such as "Why are you angry?" Instead, show you're listening and help them to feel they're being heard.

2 Defining the problem

Adults explain they have concerns too. For example, "I can see how frustrating that is for you. I'd be frustrated too." Then present your point of view using words your teenager will understand. "I feel sad that I can't help you. I feel uncomfortable when you shout at me."

3 Invitation

Adult and teenager work together to find a solution. Ask the teenager to come up with at least one compromise. Agree one way and try that first. Adjust next time if need be.

Practicalities in school

There's no single right way or checklist for working with students who have learning or behavioural difficulties. Everything depends on the needs and aspirations of the young person and the limitations of the classroom.

Under the Equality Act 2010, schools have a duty to make reasonable adjustments for disabled students. So, try to work with your teenager's school to see what they can do to support your teenager.

As much as possible, a calm and supportive atmosphere can help manage behavioural challenges.

Ask teachers to keep routines as predictable as possible and allow your teenager to have a 'space break' if they feel overwhelmed or frustrated.

Sitting near the teacher will make it easier for your teenager to concentrate. The teacher will also be better able to see if they're struggling.

Your teenager will also benefit from being able to move around. Ask teachers to allow for this where possible.

To make writing and language tasks easier for your teenager, teachers could provide copies of slides, notes and lecture outlines ahead of the lesson. Tests could be in the form of 'true or false' questions rather than essay writing.

For maths lessons and tests, your teenager could be allowed to use a table or calculator. Tests could have fewer questions or more time to complete them.

Most importantly, keep stressing to education professionals that you want your teenager to have access to the same opportunities as others.

You can read more about learning and behaviour with DMD in this useful guide from Parent Project Muscular Dystrophy at bit.ly/PPMD-education-guide

> A calm and supportive atmosphere **can help manage behavioural challenges.**

Further education

Further education includes university, vocational studies, apprenticeships and internships.

Your teenager could do an academic degree. They could do vocational studies, such as textiles or graphic design. They could study through an apprenticeship or internship. Or they could leave education altogether and go into work.

Every teenager is different. If your son or daughter wants to go on to further education, there are a lot of opportunities and support available.

Some adults with DMD have gone to university and attained bachelor's and master's degrees. At least three have earned a PhD.

In *A Guide to Duchenne Muscular Dystrophy: Information and Advice for Teachers and Parents*, two adult men have written chapters on their experience of growing up with DMD and going on to study at university. (See 'Going to university' on pages 184 to 185.)

The right to further education

Further education is any study after secondary education other than undergraduate and postgraduate degrees.

The Equality Act 2010 makes it illegal for education providers to treat disabled students less favourably because of their disability. Providers have a duty to make reasonable adjustments for disabled students.

Your teenager can do a further education course at schools and academies with sixth forms, colleges or specialist colleges.

> Every teenager is different. If your son or daughter wants to go on to further education, **there are a lot of opportunities and support available.**

College funding for disabled students

In England, education is free until age 19. (See the later section on funding education up to age 25 through an EHCP.)

Your teenager might also be able to get bursaries and funds that cover study costs, such as books, transport and even accommodation and meals.

After 19, they might have to pay for their course. But there are loans, bursaries and grants that can help them with costs.

Fees might be waived if:

- The course is their first Level 2 or Level 3 course
- The course is an entry-level course in English or maths (Levels 1 to 3)
- Your teenager is receiving benefits (the college might be able to offer free or reduced-price courses)

Further education through an EHCP

If your teenager has an EHCP, they can get funding for further education up to age 25.

After the age of 19, funding will depend on things like:

- The needs and outcomes described in your EHCP
- Your teenager’s progress
- How the course builds on previous learning
- Whether the chosen college or course suits their needs and is an ‘efficient use of resources’
- Course materials, books and travel

> Your teenager might be able to get bursaries and funds that cover study costs, **such as books, transport and even accommodation and meals.**

Disabled students' allowances

Disabled students' allowances (DSAs) are paid on top of other student finance and don't have to be repaid.

These allowances cover extra disability-related costs or expenses your teenager has while studying – costs over and above those provided as reasonable adjustments by the college or university.

For example, they could cover the cost of:

- Specialist equipment
- Non-medical helpers/support workers
- General expenditure
- Travel

DSAs aren't paid in set amounts because they depend on what's needed. The amount of money your teenager gets relates to their individual needs, not your family's household income.

Choosing a course and place of study

Encourage your teenager to choose a college or university based on what they think is the best course for them.

Specialist further education colleges

As well as mainstream further education colleges, there are also specialist further education colleges for teenagers with EHCPs.

Some have residential facilities and provide what's called a 'waking day' or '24-hour' curriculum. Some specialist colleges help students attend courses in mainstream colleges.

Speak to your local authority to see whether there are such colleges in your area and to find out how you can apply.

Residential post-16 opportunities

It might be possible for your teenager to attend a SEN college on a residential basis.

One teenager with DMD was a student at Victoria Education Centre in Poole from the age of 16 until 19. His local authority couldn't provide anything to suit his needs, so they agreed to fund his stay at the centre. The family chose for him to board during term time because they lived over two hours' drive away.

The young man thoroughly enjoyed his first experience of independent living. He had all the medical, care and educational support he needed. He particularly liked music and drama, and studied for several vocational qualifications. He left with a clutch of certificates at the end of his three-year stay.

You can find out more about the Victoria Education Centre at www.victoria.poole.sch.uk

Spotlight

Benjamin James

Benjamin, 24, graduated from Nottingham University with a BSc in Neuroscience.

He then went on to receive a Masters in Science Communication from Sheffield University.

Recently, Benjamin started an internship at a healthcare PR agency. He provides content by ‘translating’ scientific papers into layman’s terms, although the role is his to develop.

Ben says: “My desire for academia started at my primary school, Penwortham. Their care and direction was exceptional. So, when I went to secondary school and the one-to-one help wasn’t as strong, I already had the skills and drive to push on.

“I wanted to have an experience away from home, so I looked for a university that could support someone with DMD. Nottingham was my first choice. I had domestic support once or twice a week and access to academic support if I needed it.

“The year I was in Sheffield, I had support 24/7. I used AskJules, a service which assists disabled young adults with recruiting and paying their PAs. They helped me recruit two PAs and deal with the employment admin for them.

“Both universities gave good academic support and made sure my disability never got in the way of my education.

“It was very much academia that inspired me, rather than a clear career goal. But while studying, I became really interested in science communication. And that’s where I am now.”

Universities and colleges

Going to college or university is a big deal for any young adult. There's a lot of research to be done – not just into where to go, but also into what to study.

The usual starting point is the Universities and Colleges Admission Service (UCAS) website at www.ucas.com. Here, your teenager will see all the courses available at all UK colleges and universities.

Where they choose to study is as important as what to study. Start research early (up to two years ahead) and explore as many options as possible.

From the UCAS website, choose the universities and colleges that offer the courses your teenager is looking for. Then, visit their websites to narrow down the search.

Some universities are on one campus, with accommodation, lecture theatres and leisure facilities all in the same place. Others have buildings scattered around a town or city. You might need to eliminate those that would make getting around too difficult.

Visit those that seem to offer the right course in the right location. Talk to the tutors running the course about the possibilities for your teenager. Find out what support might be available. And try to contact other students.

Most college websites have online chat facilities or links to 'alumni ambassadors'.

For more information on further and higher education, see:

www.preparingforadulthood.org.uk/downloads/education-health-and-care-planning

www.disabilityrightsuk.org/fundinghighereducation

Suitable student accommodation

Every year, over 60,000 students with physical or mental health conditions or learning difficulties apply through UCAS to study at a university or college in the UK.

Many of them choose to move into student accommodation. These can be in halls of residence or shared houses or flats.

Many universities and colleges offer some suitable accommodation for disabled students. However, some DMD parents have said that finding appropriate, accessible accommodation can be difficult.

If the university has accessible accommodation, you need to check whether this is for the entire period of study. If students have to move out of halls, it's much harder to find an accessible student house.

So, start the search as early as possible. And be prepared to keep at it if you don't get the response you want immediately. Providing accessible accommodation is still a fairly new service and you might be dealing with someone who isn't fully experienced.

Most colleges and universities provide advice on their websites showing what types of accommodation are available and how to apply for them. Search for 'accommodation for disabled students' and you should be taken to the appropriate page.

Getting support from recruitment and employment agencies

Some organisations, such as AskJules (www.askjules.co.uk), help young disabled adults manage their health, personal care, budgets and student life.

They can help you recruit and employ personal assistants (PAs) for young disabled people at home, university and work, and provide payroll assistance. They match people by their interests, academic background and age.

Several young men with DMD used AskJules PAs when studying at university and highly recommend their services. AskJules can also arrange for their PAs to be university support workers.

See Chapter 12: Transitions to Adulthood for more information about recruiting PAs, including using specialist agencies.

> Many universities and colleges offer some suitable accommodation **for disabled students. But you should start your search early.**

University support workers

University support workers are specialist academic facilitators who are paid for by the university.

There are several types of support workers who can help your teenager in a variety of ways. These include:

- Taking notes and producing accurate records from lectures, seminars and discussions
- Helping students to search library catalogues, source and collect materials, photocopy and scan resources
- Providing practical and mobility support, such as carrying books and equipment and helping manipulate a wheelchair
- Providing specialist support roles, such as one-to-one study skills tuition or specialist mental health mentoring

The importance of reading

Of all the subjects and activities your teenager takes part in during their educational years, one stands out as the number one priority – reading.

Being able to read is the single most useful skill we can acquire at school. It enables us to learn, research, write, complete forms, understand instructions, entertain ourselves, communicate with others and live a worthwhile life.

Starting secondary school with good reading skills

You can help your teenager transition to secondary school by ensuring they leave primary school with good reading skills.

This might mean not relying completely on teachers – especially if your teenager has dyslexia, a common condition with DMD.

Encourage your teenager to read at home every day. Match your level of support to their level of reading. You want to encourage, not exhaust. The important thing is to make it an enjoyable habit.

Making daily reading practice enjoyable

It's not unusual for teenagers to see books and reading as boring or something they must do for school. So, help them find ways to make reading something they enjoy.

Look online at books and book reviews. Try to buy books your teenager likes the look of and would be able to read independently. Or visit the library together.

Reading is a relaxing way of ending the day and can become part of a nightly routine. Sometimes it helps to read the first chapter or so together. That way, your teenager becomes immersed in the story and wants to read on. Left on their own, they might not get started.

If books don't seem to interest them, encourage them to listen to audio books (there's a massive selection available via Audible), so they can still enjoy stories and develop their vocabulary.

Any 'non-book' tools can be used to encourage daily reading practice:

- Computer games, for example, usually require players to read instructions
- Films and TV programmes your teenager enjoys often have online reviews or cast lists or set locations
- Many young people use lots of messaging apps to stay in touch
- If your TV has a subtitles facility, you could turn this on. The campaign group 'Turn on the Subtitles' says that having subtitles on when a person watches TV can double their chances of becoming a good reader. See www.turnonthesubtitles.org for more information.

Once your teenager can see for themselves the benefits of reading, they're more likely to want to do it – and become better at it as a result.

Coping with reading difficulties

If your teenager has reading difficulties, talk to their teachers. Explain your concerns and ask what you can do to help.

Some teachers are reluctant to 'push' teenagers with DMD. They worry about overloading them and sometimes give them an easier time than their classmates.

Emphasise the importance you place on reading and ask them not to let your teenager off too lightly.

For help with reading if your teenager has dyslexia, see www.bdadyslexia.org.uk/advice/children/how-can-i-support-my-child/reading

Foreign language lessons

Teenagers with dyslexia can struggle to learn a new language at secondary school. Some drop the foreign language and devote that time to their other learning.

Speak to your teenager's school about what's the best option for them.

Pushing the boundaries

Like everything else covered in this chapter, encouraging your teenager to improve their reading will help them see more possibilities and fewer barriers.

We never know what's possible until we try. Finding small ways to tackle challenges can give your teenager the confidence they need to push further. Many DMD parents tell us they're constantly amazed by what their sons and daughters achieve on a daily basis.

Chapter 6

Chapter 06 — Friendships, Relationships and Sex

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In a nutshell

1 Developing friendships is an important part of adolescence

Teenagers living with DMD often have strong friendship groups. Friends will be a source of joy for your teenager and having DMD doesn't need to be a barrier to making friends. So, helping them to form those friendships is vital.

Making friends and building strong relationships are challenging for any teenager. For disabled teenagers, they can be even more so. You can help by building your teenager's confidence and giving them opportunities to interact with their peers.

2 Expect your teenager to be interested in love and sex

Your teenager is likely to show an interest in romance, love and sex. They may masturbate, have sex and fall in love. As with any other teenager, you will need to help prepare them for adult relationships.

Some people are asexual and not interested in romance, and that's okay too. It's possible that your teenager might identify in this way. Talking to them about sex and relationships is still important in case they develop an interest at a later age.

Historically, disabled people have often been treated as asexual. As a result, they have been excluded from relationships and sex education, and their opportunities to form relationships have been restricted. So, it's important not to assume that your teenager is asexual or uninterested in romance just because they have DMD.

3 Teenagers and adults with DMD can have successful relationships

Adults with DMD can and do have successful relationships.

Adults with DMD are in relationships with both non-disabled and disabled partners. They have relationships with opposite-sex and same-sex partners. Some have had children and now have their own families.

4 Your teenager may need extra support navigating social situations

Difficulties with managing emotions, social interactions, friendships and challenging behaviour can sometimes be linked to DMD. So, your teenager may need extra support from you when navigating relationships with friends and partners.

5 Dating as a disabled person

Finding romantic relationships can be more challenging with DMD.

Your teenager will need resilience and good self-esteem to deal with rejection and setbacks. Sometimes, they may need to find happiness in being single before they find a relationship.

How to use this chapter

This chapter looks at how you can prepare your teenager for adult relationships. This starts with developing social skills which are needed by people of all ages. Then, it moves on to look at romance and sex.

We recommend you consider using the sections as you need them:

- **From age 10 onwards**

Read **Working on self-esteem and confidence, Developing social skills** and **Building good friendships**.

These focus on how you can support your teenager in interacting with people, making friends, and thinking and caring about others. These are important skills for children and young people which will make adult relationships easier and happier.

- **Before your teenager is expected to start puberty**

Read **Puberty and DMD** which talks about the changes you can expect and how to prepare for the new challenges and experiences your teenager may go through.

- **When your teenager enters puberty**

Read **Dating and Relationships**, **Your Teenager and Sex** and **Starting a Family**.

These will help you to think about how you can enable your teenager to develop healthy adult relationships. Not all information will be immediately relevant, but it's best to be prepared.

You may not be aware if and when your teenager becomes sexually active. So, it's better to have conversations about sex and relationships well before that happens.

Working on self-esteem and confidence

If your teenager feels good about themselves, it will help them to establish friendships and romantic relationships.

They will be more willing to try new things and better able to recover from setbacks. They'll be more confident when they are with other people.

Self-esteem comes from feeling happy about who you are and believing in yourself.

Helping your teenager to believe in their own potential

Help your teenager to understand confidence. Confidence doesn't come from knowledge, ability and talent, but from believing in yourself and knowing your own worth. Teenagers with DMD can be confident too.

Lots of people struggle with confidence, but it is something that can be nurtured and developed over time. Your teenager may like to know that many people feel shy and nervous, but have learned to act confidently.

Using a growth mindset

See Chapter 2: Your Teenager and Family for more information about a growth mindset.

A growth mindset is the view that time and practice allow people to develop their abilities.

If you help your teenager develop a growth mindset, they'll learn they can improve through working hard and sticking with their goals over time. This will help your teenager to believe in their own potential.

You can nurture your teenager's growth mindset by focusing on their effort, perseverance and progress when they try something new. Look for every opportunity to praise them when they try a new approach, correct a mistake or stick with something difficult for weeks, months or years.

It's okay to acknowledge failure. You don't have to point out their mistakes. Instead, encourage your teenager to reflect on how they feel they are doing with a task, hobby or social situation.

If your teenager feels they have failed or could improve, acknowledge it. Encourage them to embrace mistakes as a learning opportunity. Without mistakes, we can't improve. Talk to them about what they think went wrong and what they have learned.

Setting achievable goals

It’s important that your teenager feels they are making progress in whatever they are doing. No one wants to keep failing at something, however valuable the experience.

Work with your teenager to set achievable daily or weekly goals that feel good when they achieve them.

If they are starting something new, help your teenager to think about how to start at the appropriate difficulty level. Help them to think about the extra challenges they already face with DMD. If they have extra support and time, this can level the playing field with their non-disabled peers.

Try to ensure you are modelling a growth mindset yourself. Show that you too can learn from failure. If you are doing something new, try, fail and try again. Show your teenager that you can improve if you stick with it – even when you don’t succeed straight away.

Finding opportunities for your teenager to build skills

Think about how you can nurture and develop your teenager’s skills.

Get them involved in picking events or activities for the family to do. This can give them a confidence boost when things go well. Importantly, it encourages them to think about what others will enjoy.

Picking up a new hobby, helping with cooking or gardening, starting a challenging computer game, fixing equipment and even doing chores can be opportunities for your teenager.

Encourage your teenager to take opportunities to spend time away from you. You may have to work hard to make sure that these opportunities are accessible and your teenager has the right care.

You may need to help your teenager prepare for trips away and social situations. But time away from parents is one of the best ways to show teenagers that they can manage by themselves.

See Chapter 10: Life Skills for more information about developing skills.

Empowering your teenager to have a positive self-image

Teaching your teenager to feel good about themselves can help them to become more confident about expressing themselves positively. This can help them to make connections with people with similar interests or outlooks, and improve their chances of making lasting friendships.

Take the opportunity to praise your teenager for what they do and how they act. For example, comment when they are kind, thoughtful or generous towards others; or thank them if they complete a task or project.

Talk to your teenager regularly about what they are good at, such as video games, art or finding information on the internet. Show you mean this by asking them to help you with these things (for example, fixing an IT problem, finding a YouTube video or tasting food).

Your teenager should not expect to be perfect. Help them to understand that everyone has strengths and weaknesses. Nobody is great at everything. So, your teenager can always improve on things they are doing.

Try to provide opportunities for your teenager to help others. This could be giving them chores to do around the house, asking them to help out a sibling or supporting them in volunteering. Helping others will help your teenager to feel they have something to offer.

Tackling low self-esteem

Where teenagers have low self-esteem, you will need to help them work on how they think about themselves. They may experience negative thoughts or self-talk, even if you are trying to help them focus on the positives.

So, make sure you ask your teenager themselves what they think their strengths are. If they can't think of any, ask them about the things you have noticed. These might be specific skills or being thoughtful, generous or kind to others.

It may help your teenager to write down or tell you their thoughts about themselves. They may not want to share these with you all at once, so take your time. Take the opportunity to ask how they feel about themselves when it feels right.

When your teenager shares how they think about themselves, it's important to listen to what they say without just dismissing it. That doesn't mean you have to agree if it's something negative. But you must acknowledge that this is how they feel.

Ask them whether what they have written or said about themselves is kind. Would they say these things about a friend? Ask them how they might say these things in a kinder way.

Ask your teenager what they would say to a friend who is feeling unsure of themselves. Write it down. Then, ask them to say this to themselves – maybe even say it aloud.

Family, friends and peers can have a big impact on your teenager's self-esteem. Help your teenager to identify who makes them feel good about themselves. Encourage them to spend more time with these people.

Thinking of differences as positive

Talk to your teenager about other people they know, role models or celebrities who are also different. Ask them what positive words might describe them.

Teach your teenager to see difference as valuable. Without people being different, we wouldn't have scientific progress, art, movies and music.

Celebrate the similarities too. Ask your teenager what interests they share with people who don't have DMD. Show them that they have common ground with many different people.

Dealing with being different

Having DMD will mean your teenager often feels very different from their peers. This can sometimes make them feel less confident.

If your teenager has had to deal with teasing or bullying in the past, this can further damage their confidence.

Your teenager will experience difficulties with activities that non-disabled peers are doing, such as going out by themselves or playing sports and games. Your teenager may sometimes feel frustrated or upset because of all the things they cannot do.

Although DMD is uniquely different, it may be helpful to your teenager to understand that other teenagers often feel different too. They can feel different because of their race, religion, politics, sexuality, health problems, weight, interests, career ambitions, family income level or family problems. Films, TV shows, blogs and videos on social media deal with this theme regularly.

Talk to your teenager about the differences they see in others as well as themselves. DMD won't be the only thing that is different. Help them to realise that everyone is an individual and has their own challenges.

Seeing DMD a bit differently

We won’t tell you that DMD isn’t awful. It is. But for your teenager, it’s important to think about the positives that come from their experience.

They shouldn’t think of themselves or their bodies as a problem.

Ask them what skills they have because of DMD. What subjects do they know about that their non-disabled peers don’t? What can they do that other people can’t? This might be steering a wheelchair or using a piece of technology.

Your teenager may be different, but DMD can make them more resilient. People with DMD must overcome difficult challenges and learn how to solve problems. They can become experts on disability and health. And many have achievements that are not related to DMD at all.

Teenagers with DMD can understand what it’s like to be different. So, they can go on to help other people who may be struggling with their own problems.

Disabled peers and role models can be important for teenagers to feel positive about themselves. Seeing others like themselves can help them feel less alone. So, look out for TV shows with disabled characters or disabled influencers on social media.

See Chapter 1: Introduction for more information about the social model of disability.

Interacting with other disabled teenagers

Playing sports, gaming or other activities with other disabled teenagers can help your teenager to feel more positive about what they can do.

They can take part in activities without an unfair disadvantage. And being part of a team and playing sports will help them to develop their social skills.

Your teenager may be reluctant to meet other disabled teenagers if they’ve not done this before. They may not want to see themselves as different at all.

So, they may not want to be seen together with other disabled people. They may even have negative assumptions about what other disabled people are like.

Teenagers should be encouraged to meet and speak to other disabled people from an early age. Help them to understand that no two disabled people are the same.

If they are reluctant, try talking to them about disabled people you know and the many different things they are doing. Disability is just one of many things that make people different.

Talk to your teenager about the social model of disability. Help them to understand that many of the difficulties they experience is because society is not designed to suit them. It is not their fault. This can be empowering and stop them blaming themselves for not being able to do things.

Developing social skills

All teenagers have to develop their social skills and relationships skills. No one is born knowing these things. But teenagers with DMD may need more support to develop these skills.

The impact of DMD on the brain can make it harder for children and teenagers to develop social skills. This might include difficulties in reading social cues and having conversations.

For some teenagers, this may be severe enough to lead to a diagnosis of an autism spectrum disorder. Others may experience milder issues with social interactions.

Learning about social skills

Teenagers with DMD may struggle, but they can still develop strong friendships with the right support at home and at school.

Dealing with social situations is easier when you have the right tools. Preparation is key. Your teenager will be more confident if they know what to expect, what to say and what to do if things go wrong.

Preparing for conversations

Help your teenager prepare for conversations with different people and groups by getting them to think about the conversations in advance.

Have practice conversations so they can try out their ideas; or get your teenager to create visual or written cues for topics they might talk about.

Conversations are two-way, so help your teenager to think about what other people might want to ask them. Some teenagers may struggle to see things from other people's points of view. You may need to help them to identify what strangers, friends or professionals might ask them and why.

Help your teenager prepare for conversations with different people and groups by getting them to think about the conversations in advance.

Ideas for conversation starters for your teenager

Get your teenager to practise introducing themselves. They could just say their name or add extra details such as where they are from, what they enjoy doing and why they decided to go to an event or join a group.

Remind them to ask other people to introduce themselves as well.

To keep the conversation going, your teenager could try asking the following questions:

- What type of music do you like?
- Which TV shows do you watch?
- Do you have any pets?
- Do you have any plans for the weekend?
- Do you like video games/movies/reading? What do you think of [name a video game/movie/book]?
- Do you have any brothers and sisters?
- What part of [your city] or [your country] are you from?

Talk to your teenager about how they could respond to each question themselves too. It's best if they choose topics that also interest them.

Developing listening skills

Listening skills are just as important as speaking skills. Everybody wants to be heard and understood.

Your teenager might be so focused on thinking about what to say next that they forget to listen. So, get your teenager to practise listening and responding in a conversation.

Encourage them to use phrases to validate what they have heard, such as “That’s interesting”, “I agree” or “I understand”. Get them to practise asking questions about what they have heard.

Body language and facial expressions

Some teenagers with DMD may have difficulty interpreting body language and facial expressions. This can impact negatively on their relationships with other people.

You may be able to find teaching materials from your school or online to help your teenager learn how to recognise these non-verbal cues.

Talk to your teenager about how they use their facial expressions and body language. The muscle weaknesses caused by DMD can affect how they use body language to express themselves. But you can encourage them to use eye contact, say please and thank you, smile and speak up so they can be heard.

Valuing your teenager’s contributions

Teenagers will be more likely to talk if they feel their contributions are valued. So, try to engage with them completely when they talk to you.

This might be difficult if they talk about the same topic repeatedly – but try to respect and value what interests them.

Make your teenager aware when what they say has an impact on the conversation. For example, when they talk to a health professional, what they say is more powerful than what you say.

If parents do all the talking, teenagers with DMD will usually let them. So, try to deliberately step back and expect your teenager to talk to other people. With preparation and support, they should be able to speak up for themselves.

> Step back and expect your
> **teenager to talk to other people.**

Using humour to build friendships

Sharing a joke or a laugh is a great way to make and develop friendships. So, encourage your teenager to develop playful humour at home and learn how to have fun with others.

You should enjoy a laugh with your teenager and praise a good joke. Try to avoid punishing or chastising harmless silliness.

Making yourself look silly or laughing at yourself is an important part of creating a fun atmosphere. Encourage everyone in the home, including you and your teenager, to laugh good-naturedly at themselves.

Making sure humour is appropriate

Part of developing a good sense of humour is understanding when to use humour and what to joke about. Emphasise that the best humour creates shared joy for everyone.

Challenge jokes that may be hurtful to others or are inappropriate. Take the time to explain why and how they cross the line. Discuss the difference between laughing WITH someone and laughing AT someone.

Explain that laughter can be hurtful and damage self-esteem. Discourage your teenager from laughing at pain, physical characteristics or how people express themselves.

Developing a sense of humour can be harder for teenagers with autism. You may need to spend more time explaining how jokes work and how to avoid hurtful humour. But with patience and practice, teenagers with autism can develop a sense of humour.

Empathising with people without DMD

Parents and professional carers often have to prioritise the needs of teenagers with DMD. This can sometimes make it difficult for the teenager to see other people's needs as equally important. And it can make it harder for your teenager to see themselves as someone who can help meet other people's needs.

Your teenager may need encouragement to ask how someone is, take an interest in their day or listen to their troubles.

Talk to your teenager about the problems other people might be facing which your family doesn't have. Ask your teenager how it might feel to be in that situation.

Try to help your teenager understand that everyone has different perspectives and challenges. When they're dealing with DMD, it's easy to think that people without DMD don't have any difficulties. But everyone has their own problems which matter to them. So, it's important to hear their perspectives.

So, encourage your teenager to listen to others and acknowledge their feelings. This will help them to form good friendships and relationships. But don't worry too much if they take years to develop these skills. Most teenagers focus on themselves and take years to develop empathy and consideration for others.

Talking about DMD with other people

When talking to non-disabled people, your teenager is likely to encounter curiosity and questions about their DMD. You may need to help prepare them to deal with this in public.

It can be helpful to explain to your teenager why people ask about DMD.

Most people are naturally curious. They may want to understand how or why your teenager is different. They may believe that if they identify the condition, they can connect your teenager to something they know about.

They may genuinely be trying to be friendly and helpful. Unfortunately, they might make assumptions about DMD or confuse DMD with another condition.

Members of the public usually use the medical model of disability. That means they focus on what is 'wrong' with the person and what they can or cannot do. They are more likely to ask why someone is disabled.

See Chapter 1: Introduction for more information about the social model and medical model of disability.

Helping your teenager to decide what to share

Your teenager's diagnosis and impairments are private. So, they have the right to decide who knows about their DMD diagnosis.

They don't have to share it with members of the public or even friends if they don't want to.

Some people with DMD are happy to talk about their condition with anyone. Sometimes, this can help raise awareness so more people know about DMD. It can help if they are taking part in fundraising for Duchenne UK and may encourage people to make places more accessible.

If your teenager is happy to share that they have DMD, talking about the condition can be a good conversation starter. They may wish to ask questions about the other person to make the conversation more equal.

On the other hand, sharing information about their diagnosis with people they don't know well may cause problems for your teenager. People might make assumptions about what your teenager can do. Or they might continue to ask increasingly personal questions.

Sometimes, your teenager just won't feel like talking about DMD. They may wish to keep it private. Or perhaps they may just be tired of answering questions.

Talking to friends and family about DMD

There is a big difference between speaking to someone you don't know well and to a friend or close family member. Sharing information about their DMD with a friend can be an important way for your teenager to deepen their friendship.

When your teenager's friends and peers understand the challenges they face, they may be more supportive. This may help your teenager to develop stronger friendships.

Sharing information about the condition with classmates and teachers may be useful. However, make sure your teenager agrees to this. They may be embarrassed or feel singled out if everyone knows about their DMD before they are ready.

> Your teenager has the right to decide **who knows about their DMD diagnosis.**

Choosing not to talk about DMD

Talk to your teenager about how to give a polite but firm response if they don't want to talk about their disability. They could say, "I'm sorry, I'd rather not share that information with you"; or they may wish to explain why the question is inappropriate.

It may be tempting for your teenager to be rude or to tease people with fake answers. It can feel empowering to do this, but it isn't usually productive. The other person may feel hurt and won't understand why your teenager is being mean.

Most of the people who your teenager talks to about DMD for the first time won't have heard of it. So, they may say the wrong thing or ask ignorant questions. Encourage your teenager to be as polite as possible when correcting people.

Occasionally, people may be hostile or say deliberately hurtful things about disability. This may be in person or online. This is prejudice, not ignorance. You can report actions like this to the police, as they may be hate crimes.

Hopefully, your teenager will not encounter hate crime. But it's important they know that it's wrong and they can get help from the police if it happens.

See Chapter 10: Life Skills for more information about hate crime and discrimination.

Building good friendships

Helping your teenager to make friends in a new place

Changing school or getting involved in new activities will mean your teenager may have to make friends in a new setting.

Putting your teenager in a room with other teenagers with common interests doesn’t guarantee they will become friends. Your teenager may feel shy and anxious in this situation, and not know what to say.

You will need to help your teenager prepare when they are joining a new group or meeting new people.

Meeting new people can be positive

Start by asking your teenager to think about the positives of meeting new people. What is good about having new friends? What could they learn from talking to other people?

Gently nudge them towards the answer if they struggle. New friends mean more people to support each other and have fun with. New friends provide an opportunity to learn about things they might enjoy, such as getting a good recommendation for a game, book or TV show. They might be able to learn about a different culture.

Preparing to meet new people

Work with your teenager to practise how they introduce themselves. Brainstorm topics of conversation they could use and questions they could ask.

Your teenager may be nervous about accessibility when they are visiting a new place. Ask them to help you research the venue. Consider visiting before the event so your teenager can become familiar with the surroundings.

If they know just one person at the event, your teenager may feel more at ease. Think about whether you could introduce them to someone else who will also be going to the event or group. Prepare for this one-to-one meeting in the same way you would for the main event.

Your teenager may feel better if you tell them that the other people at the new place or group will also be nervous about meeting new people. They may be surprised to know that non-disabled people also suffer from nerves. So, encourage them by telling them about a time when you were nervous and how you dealt with it. Other family members may be able to share their experiences too.

> You will need to help your teenager prepare when they are **joining a new group or meeting new people.**

Managing expectations when meeting new people

Try to manage your teenager's expectations when making new friends. Most friendships aren't formed in a day. It will take time.

Encourage your teenager to focus on making connections and learning things about the people they meet. Then, work with them to plan relevant follow-up conversations with the people they enjoyed talking to when they see them again.

Your teenager may find it easier to approach other teenagers on their own rather than trying to talk to an entire group. Let them know that this may help other people who are also struggling. Make sure they know to ask if they can join them in case the other person wants to be alone.

Learning how to be a good friend

Everyone has to learn friendship skills. This comes more easily to some than others. If your teenager struggles with maintaining friendships, you may need to support them to learn how to be a good friend.

Becoming good friends means learning about each other. As a teenager, this means learning about what is important to our friends and what affects their day-to-day life. Being a good friend means being able to listen and to be non-judgemental.

So, encourage your teenager to ask their friends questions to find out what they care about. Talk to your teenager about the importance of learning new things from their friends.

Encourage your teenager to be kind and help their friends where they can. Talk to them about how to be kind and generous, and how to share.

You may also need to help your teenager identify when they are being taken advantage of. Signs of this might include frequently lending their possessions, paying for things for their friends or not deciding what they do together.

Try to encourage your teenager to make friends that value them equally. If their friends treat them badly, support them to find new friends.

If teenagers only have a few friends, it's natural that they will want to do everything with them. It's important they know when to give their friends some space. If your teenager expects their friends to spend all their time with them, this could place a strain on their friendships.

You will need to observe how friendships are developing at first. If your teenager develops habits that alienate friends, you may need to help them develop better social skills. If necessary, offer guidance when the friends are not around.

Making sure your teenager isn’t left out

Non-disabled friends may sometimes be involved in activities that are harder for your teenager to join because of their DMD. You will need to prepare your teenager for how to handle this.

If trips are organised by schools, clubs or other bodies, they should be made accessible to your teenager. If they aren’t, they may be breaching the Equality Act. Ask your teenager if they are happy for you to speak to the organiser to ensure trips are accessible.

Your teenager’s friends may sometimes organise events at inaccessible locations. If this happens, speak to your teenager about what they might be able to do to make the activity more accessible.

If your teenager knows the organiser well, encourage them to speak with them about whether they can change plans. The organiser may simply be unaware that the location is inaccessible to your teenager.

Persuading people to change their plans is easiest when you have an accessible alternative. So, talk to your teenager about possible alternatives. Do some research together if you need to.

Remember to practise with your teenager what they might say in this situation – for example: “I just wanted to let you know I’m not able to attend the event because the location is inaccessible… I found a few accessible alternatives and I wondered if we could do this instead?”

Remember to be sensitive to other people’s needs and interests. People who are organising birthday parties or private social events may not always be able to change their arrangements.

If possible, encourage your teenager to help organise events or activities with their friends. You may need to help your teenager come up with accessible suggestions and make the arrangements. This is an opportunity for your teenager to develop organisation skills, so encourage them to do as much as they can themselves.

Dealing with being left out

Most activities can be made accessible in some way. However, sometimes this may be expensive, time-consuming or out of your control – for example, a party organised at an inaccessible location by someone you or your teenager doesn't know well.

Being excluded is awful. Your teenager may feel upset and angry about their DMD or their friends. Acknowledge the pain they feel.

The social model of disability can help make sense of these situations. Make sure your teenager knows the situation is not their fault. The problem is the lack of accessibility at the location, not their DMD or their friends (who probably just want to do something fun).

Because of the risk of being excluded, you may wish to make a bigger effort to ensure your teenager can attend events when they are accessible. This might mean changing your plans or transporting your teenager to an event yourself.

Cultivating a range of friendship groups

Encourage your teenager to develop a range of friendship groups, with both disabled and non-disabled peers. Then, they will have other options if one group does something without them.

There may be activities which specifically cater for your teenager's needs, such as disability sports, which their non-disabled friends aren't involved in. Try to show them that it's OK for them and their friends to have separate events and interests.

See Chapter 3: Health for more information about how DMD affects puberty.

Puberty and DMD

How puberty can affect your teenager with DMD

The changes all teenagers can expect from puberty will have extra impact on teenagers with DMD.

Changes such as increased body hair, body odour, sweating and acne mean your teenager will need to do more to stay clean. They will need to treat spots, apply deodorant and wash underarms and genitals more thoroughly.

You can find good-quality resources for understanding puberty from the NHS and other reputable sources. You might want to start here – bit.ly/nhs-puberty

Helping with intimate care

Getting help with intimate personal care can be embarrassing for your teenager. Even if they were never embarrassed as a child, they may become so when their body starts changing.

If your teenager feels self-conscious, they may not ask for help. You can support them by talking about what they can expect with puberty, offering your help and listening to what they say they want.

> Some teenagers will appreciate help with intimate care. **Others will want to do this themselves for as long as they can.**

Ask them what they are comfortable with. Everyone is different. Some teenagers will appreciate help with intimate care. Others will want to do this themselves for as long as they can. Try to be led by them.

When helping with intimate care, think about how you can minimise embarrassment. For example, when washing or dressing, strategic placement of towels can help preserve their modesty.

Talking about intimate care is important because of your teenager's decreasing arm strength. This may make it more and more difficult for your teenager to do these things for themselves.

Talking about changes you have noticed

Try not to draw too much attention to changes that they may be self-conscious about. You don't need to point out if they have an erection or a wet dream. Just put sheets and underwear in the laundry without any comment.

Because of their DMD, your teenager may not always be aware of problems. So, you may need to offer advice if you notice they have body odour, acne or unclear skin or other issues with their personal hygiene.

When pointing out problems, try to be as gentle as possible. It's awkward, but it's better if it comes from their parent rather than their friends, siblings or peers.

Dealing with delayed puberty

All teenagers go through puberty at different rates. In DMD, puberty can sometimes be delayed by steroids.

If necessary, your teenager can receive treatment for delayed puberty. Your teenager should have an endocrinologist on their healthcare team. Endocrinologists are doctors who specialise in hormones.

Developing at a slower rate than their friends and schoolmates may be distressing for your teenager. You can try to reassure them by explaining that everyone is different. But this is an issue many teenagers with DMD have to deal with. There's no easy solution.

If your teenager is embarrassed about their body or their stage of development, try to respect their feelings. Support them by giving them privacy. In particular, don't expect them to get undressed in front of others.

Cultivating body confidence

Puberty can have a big impact on body image and self-esteem. So, try to cultivate body confidence in your teenager.

Make sure your teenager knows that there is no such thing as a perfect body. Different people are attracted to different body types. Attraction is about more than just physical appearance.

Even if they don't have the body type they want, your teenager can learn to feel happy with their body. Wearing clothes they like, having a nice haircut and growing facial hair can allow your teenager to find and be proud of their style.

Treating what you can change

Help your teenager to understand the difference between what they can and cannot change. And encourage them to treat things they don't like that can be addressed.

For example, they can treat breakouts, spots or dry skin. They can get braces and guards to straighten their teeth. Taking control of what they can change can be empowering for your teenager.

Most importantly, watch out for changes which can worsen your teenager's health. Help them to maintain a healthy weight with regular checks and a good diet.

Ask for a dietitian to review your teenager's weight if you or they have concerns. Obesity, which is common for teenagers on steroids, can further restrict their mobility and affect their breathing. And being underweight can indicate other problems. A dietitian can help with both of these problems.

Make sure your teenager has good posture and positioning. As they grow, they will need wheelchairs and supports that grow with them. If they use a wheelchair full time, they may require lateral trunk supports to keep their spine straight. If they are still ambulant, walking and standing can help avoid the need for spinal surgery.

As a parent, you can model body positivity. Be proud of your body and use body-positive language around the home and when discussing people or celebrities. Try to take care of the things you can change and accept what you can't.

See Chapter 4: Diet and Exercise for more information about maintaining a healthy weight and good posture.

Dealing with emotions

Puberty can be an emotional rollercoaster for your teenager. Many young people find this a difficult time of life. Medication or other diagnoses may make puberty even more difficult for them.

If your teenager is angry or upset, try to give them time and space to calm down. Teenagers often feel overwhelmed by their feelings and don't know how to express themselves constructively.

Later, when they feel better, talk to them about why they were angry. Try to help them to learn how to process their feelings and communicate them to others calmly.

Understanding your teenager as a sexual person

Most teenagers will show an interest in romance, love and sex at some point during their adolescence. Teenagers with DMD are no different.

It's highly likely your teenager will have romantic interests in their life, who they may date. They will probably masturbate and think about sex.

Your teenager will want to keep many of these things private. But having DMD can mean it's harder to keep these things to themselves. So, try to give them privacy when you can.

While they are young, it's reasonable to want to protect your teenager. You should use parental controls on the internet and TV, and be able to enter their room to keep an eye on what is happening.

Make sure your teenager knows what is legal. For example, they shouldn't access websites for over-18s if they are underage. You should make sure they know about how to stay safe online.

Agree with your teenager how they can have privacy. Knocking and waiting before you enter their room and not reading their messages or social media profiles can be a good place to start.

Developing their identity

You may have already spoken about sexuality and gender with your teenager when they were a child. If not, you should start by acknowledging and respecting the diversity of sexual and gender identities that exist. Explain that part of adolescence is figuring out one's identity.

Your teenager may be straight, gay or bisexual. They may be transgender or non-binary. Or they may define their identity or sexuality in another way.

Make sure your teenager knows you will support them however they identify themselves. Show your teenager that they can discuss identity, sexuality, relationships and sex with you whenever they want.

If you create a safe, non-judgemental space, your teenager will probably talk to you when they feel ready. Don't push conversations about their gender or sexuality onto your teenager. If they aren't ready, they may not be honest with you.

The way you talk about gender, sexuality and sex will impact on your teenager. Think about the positive messages you want to send to your teenager and emphasise them.

Practise acceptance of diversity at home. Try to watch TV shows and movies or read books featuring disabled characters, those who are LGBTQIA+ or both. Don't tolerate insults or jokes based on gender, sexuality or other aspects of identity.

Try not to make any assumptions about your teenager. Even if they have previously shown interest in boys or girls, this can change. Many people take years to fully understand their own identity.

> Make sure your teenager knows you **will support them however they identify themselves.**

Knowing what to expect

Typically, DMD shouldn't cause any problems with erections, libido or sexual organs.

So, if you or your teenager are worried about an issue with any of these things, you should talk to a health professional.

Speaking to professionals

Too often, disabled people are treated as asexual, particularly by people and organisations providing care and support.

They focus on health and care needs, and not on enabling people to access sex and relationships.

Most professionals treating young adults are willing to discuss sexuality, sex and relationships. But your teenager may need to raise the issue with them first.

You could help your teenager to prepare for these conversations by explaining which professionals can advise them. Then, get your teenager to make a note of any questions they want to ask at their next appointment.

Dating and relationships

Your teenager's love life

Teenagers with DMD will often be interested in pursuing romantic relationships. They may have romantic partners.

Like all teenagers, they will probably want to keep their love life private from you.

If your teenager asks you for advice, make sure you listen and don't make a fuss. Don't judge their behaviour. Just answer their questions as best you can.

You can prepare them by teaching them about love and romance and giving them specific advice on their situation if they ask for it.

Understanding attraction

Talk to your teenager about what attributes people find attractive in others. Try to steer them away from thinking attraction is just about someone's body.

You don't have to talk about their feelings. Instead, you can talk about what's in the media or share some of your own experiences.

Many people are attracted to others because of their sense of humour, self-esteem, confidence, positivity, honesty, emotional resilience or enthusiasm about common interests.

Try to focus on the value of the qualities your teenager has. Take care not to emphasise the qualities that your teenager doesn't have. For example, telling them confidence is attractive if they are shy might make them feel worse.

Explain that different people are attracted to different qualities. It's not something that can be turned on and off. The challenge for your teenager is to find someone they like who is also attracted to the qualities your teenager has. (Everyone who is looking for a partner faces the same challenges.)

So, your teenager should understand that they can't force someone to like them. If someone isn't attracted to them, it's not personal. They just aren't a match. Someone else will be attracted to the qualities they have.

Similarly, your teenager may find that people who they are not interested in are attracted to them. Talk to them about how they can communicate about their feelings in a way that respects the other person.

Spotlight

Jon and Tomas Rey-Hastie

Jon Rey-Hastie is 40 and lives in Reading, Berkshire. Jon has a PhD and is the CEO of Pathfinders Neuromuscular Alliance.

Jon met his partner Tomas on OKCupid in 2016 and, in 2018, they got married. Jon and Tomas live together in a flat with their two cats, and enjoy travelling, drinking cocktails and baking. Jon is supported by a team of personal care assistants who provide round-the-clock care.

Jon says: “As a gay man, I found it really difficult coming out and telling my carers and parents about my sexual identity. Even though they were accepting, I was nervous and anxious and tried to hide that part of myself. It was only as I became independent and moved into my own place that I felt able to talk about my identity.

“The confidence I gained from becoming more independent gave me the courage to start dating. When I first spoke to Tomas, he was living in Sweden so I didn’t expect anything to happen. But we met up multiple times and there was great chemistry. It took a bit of figuring out but we’re now living together as a happily married couple.”

Dealing with rejection

Make sure your teenager understands that rejection is part of the journey towards finding good romantic relationships. It happens to everyone – both disabled people and non-disabled people.

Rejection feels awful. But we can only move forward if we are willing to find out who is interested in us and who isn't. If we are too scared to hear no, we are stuck where we are.

Talk to your teenager about how to tell if someone likes another person. You can point out obvious flirting and body language in TV shows or movies – things like looking away when a person sees somebody they like, hair twirling, touching and laughing.

Giving your teenager advice about finding romance

Your teenager might not want your advice about finding romance. Most teenagers don't. But if they do, here's some of the advice you might give.

You may need to explain that love rarely happens without effort. If your teenager wants a partner, they need to make an effort to talk to new people. They should take every opportunity to do something sociable.

So, if your teenager feels lonely and doesn't know how to find a partner, talk to them about where they can meet more people. Are there clubs or activities they could attend where they might meet someone?

If your teenager is interested in someone, encourage them to get to know them before asking them out. They should talk to them in person and message them.

Talk to your teenager about how to manage their excitement and expectations, and not to come on too strong. Remind them that this person might not be a 'match' for them. So, they should just focus on getting to know them first and acknowledge that it might not end up in a relationship.

Keeping conversations short allows your teenager to get to know someone in a casual way. Help your teenager by suggesting possible conversation topics. At this stage, it's just like making a new friend.

Asking someone out on a date

When your teenager knows more about the person they are interested in, they should try asking them out. In heterosexual relationships, some girls still expect that boys will make the first move.

It's easy to overthink asking someone out. But your teenager should try to keep things as simple as possible.

Your teenager should have a plan for something specific they could do with a potential partner before asking them out on a date. Ideally, it's something that they know their potential date will enjoy.

Being bold and clear is best. The person they are asking needs to know they are being asked on a date.

Flexibility is important. If your teenager is able to change their plans or offer another activity, they may be successful.

Your teenager should also think in advance about what to do or say if the person says no. This could be a casual "Ah well, it was worth a try" before moving on.

Make sure your teenager knows not to be pushy or make the other person feel awkward for saying no.

If your teenager is rejected by somebody, let them know it's okay to be upset. Tell them they should be proud of having the courage to ask someone out. Try not to let them blame themselves or the other person.

Many articles online share tips for asking people out.

This **Science of People** (www.scienceofpeople.com/how-to-ask-someone-out) article is a good place to start.

Using online dating apps

Online dating apps can be another way for your teenager to meet partners.

Many people find it much easier to get to know someone online or through an app than face to face. It avoids some of the accessibility barriers that face-to-face dating can have. And it doesn't require quick responses or interpreting body language, which may be more difficult for your teenager.

Online dating can also present challenges. Some apps focus on a person's appearance first, which can be unappealing to people who struggle with confidence in how they look. Sometimes it also means people focus on the wheelchair or disability rather than people's interests.

Some people can also be ruder online than in person. So, they may ignore (ghost) or say inappropriate things to your teenager. Your teenager might experience more rejection as a disabled person.

Many popular dating apps are only available to over-18s. These include Badoo, Bumble, Hinge, Match, Plenty of Fish, OKCupid and Tinder.

Some apps, such as MyLoL, are targeted towards teens. You should take care to find out about the social apps your teenager may use and how these are monitored to keep young people safe.

Your teenager will need to decide how much to share about their DMD when creating an online dating profile. Some people with DMD talk about their disability on their profile. Others bring it up when they start talking to a potential match.

It's usually best to share basic information about DMD as early as possible. Don't overwhelm the other person with details unless they ask. But if it's a deal-breaker for them, it's better to find this out early on.

Make sure your teenager knows about the safety risks of online dating. You can find good resources about staying safe when using online dating here: www.brook.org.uk/your-life/online-dating-and-staying-safe

> Many people find it much easier to get to know **someone online or through an app than face to face.**

Disability and relationships

At some point, your teenager is likely to think about how their DMD affects their romantic relationships.

So, encourage them by telling them that many adults with DMD are in successful relationships. Some are married. A few even have children.

Having DMD doesn't make relationships impossible.

Understanding why dating can be difficult

Finding romance can be harder as a disabled person. There can be a stigma associated with disability and dating.

People who are mainly attracted to athletic physical appearance or ability are less likely to date someone with DMD.

Some people may avoid dating a disabled person because they are worried about what other people may think. Teenagers particularly may fear becoming less popular or getting bullied for being different if they date someone with DMD.

Others may be worried about their lives becoming more difficult if they are in a relationship with someone with DMD. They might assume the person with DMD can't do things they want to do. They might assume that they will have to become their partner's carer.

Dealing with the extra challenges

Your teenager may face more challenges in finding non-disabled partners. But there are plenty of non-disabled people who would date someone with DMD.

They may also find a relationship with another disabled person. If they are attracted to each other, their shared experience and understanding of disability might bring them closer together.

Your teenager may find it a little difficult to find love, and they may experience more rejection along the way. You will need to help them deal with rejection without letting it defeat them.

Encourage them to focus on making the most of the qualities they have and finding someone who appreciates these.

Young people with DMD have plenty to offer a potential partner. They can draw on their own experiences to empathise with others. They can be excellent listeners. And, because of the challenges involved, they are more likely to value romantic relationships when they find them.

Spotlight

Mark Chapman

Mark Chapman is 51 and lives in Edinburgh.

He’s lived independently for over 30 years and is supported 24/7 by personal assistants. The disability campaigner co-founded DMD Pathfinders, now known as Pathfinders Neuromuscular Alliance. He’s since retired in his role to concentrate on other activities. He’s been ventilated with a tracheostomy for 25 years.

Mark says: “I lived with my girlfriend Corinna, who had Spinal Muscular Atrophy, in my 20s while we were studying at college and university. It was a great life experience before we went our own ways. I have many fond memories of that time together. Sadly, she died aged 30.

“I enjoy my life as a single person, fortunate to have close friends and a supportive family, as well as keeping active with many interests, such as socialising, cinema, concerts, genealogy, the arts, computers, design, politics, animals and travel.

“I’ve learnt that living with a complex condition brings many challenges which can be overcome, including occasional periods of poor motivation and low mood. If you push the boundaries and insist on good support, there’s no reason a contented and fulfilling life can’t be achieved.”

Having a good life as a single person

Because dating with DMD can be challenging, your teenager may spend long periods of time without a partner. Starting relationships can be especially challenging if socialising is difficult for them.

So, it’s important they know how to be happy and have a good life as a single person.

The media constantly bombards us with messages that we need a partner to be happy. Try to combat these with examples of people you know who are living happily on their own.

If your teenager feels lonely and unhappy, they may see finding a partner as the only solution. But the more they fixate on this notion, the less likely it is they will find someone.

Help your teenager to understand that spending time with friends, trying new experiences, going to new places, meeting new people and generally having fun are the best ways to find a partner. And if that still doesn’t help them find a partner, they will have a life they enjoy living.

Tackling loneliness and social isolation

Focus on tackling loneliness first. Try to find opportunities for your teenager to make new friends and spend more time with the friends they have. Invite their friends over. Arrange a trip to the cinema. Get them involved in sport.

They will feel less lonely if they are close to their friends and spend time with them.

Online friendships can also be important. If your teenager enjoys gaming, encourage them to join a game with a social aspect. Guilds or teams in some online games allow players to play with the same group of players every time. Do what you can to facilitate opportunities for your teenager to socialise with these groups.

Online groups can be a source of strong friendships. Try to treat these in the same way as you would your teenager’s in-person friendships. Avoid belittling them simply because you can’t see them.

> Try to find opportunities for your **teenager to make new friends.**

Your teenager and sex

Talking to your teenager about sex

Just like other teenagers, sex will be something most teenagers with DMD think about a lot.

So, ideally, you will have had age-appropriate conversations with your child before they reach their teens.

Disabled people have campaigned to have their sexuality acknowledged and respected. Just like a non-disabled person, their sexuality is part of them. They want, need and deserve love, physical affection, sex and intimacy.

You should acknowledge to your teenager that having sex is a real possibility. Don't assume it's out of the question because of their DMD. Instead, talk about it as something your teenager will do in the future.

Taking a sex-positive attitude

Sex positivity is a way of thinking and talking about sex as a healthy part of life that should be enjoyed. Sex should be discussed without judgement, shame or awkwardness.

Using a sex-positive attitude with your teenager makes it more likely they will have a healthy attitude towards sex. This means they are more likely to ask questions and tell you if they have worries or problems.

So, try to acknowledge it as a positive activity, that makes us feel good and allows us to intimately connect with a partner. Don't just talk about the risks and dangers of unsafe sex.

Talk about positive attitudes towards sex and why they are important. You could talk about sex as an equal partnership which feels good for both parties. You could talk about furthering intimacy by respecting your partner's privacy, likes and dislikes and trust.

You can still make sure your teenager understands about sexually transmitted diseases (STDs), safe sex, pregnancy, consent and legal age. This will help them stay safe and teach them how to be respectful of their potential partner.

Take opportunities to talk to your teenager about sex when it comes up. It doesn't have to be a single, formal talk. Discussing something that happened in a TV programme or a game could be a useful springboard to talk about sex.

Encourage your teenager to ask questions about sex. Don't worry if you're doing most of the talking. By talking about sex openly, you're showing your teenager that it is a topic you are willing to discuss.

Spotlight

Tom and Charlotte Hardwick

Tom and Charlotte Hardwick are a married couple in their 30s. They both live with Muscular Dystrophy and Tom has DMD.

They met through online dating and live together in a bungalow in Nottingham with their dog. They are supported by a team of 11 personal care assistants 24 hours a day which enables them to live fulfilled and happy lives. They enjoy watching films, having a good giggle together, entertaining and volunteering. As Christians, they find meaning in their faith and being part of a loving and supportive church community.

Tom says: “My parents looked after me very well and we had a fantastic relationship. But when I reached my twenties, I had zero independence and sank into depression. I needed to become my own man. Moving in with Charlotte and getting a care package gave me something to live for.”

Charlotte says: “Sex is great fun! But it’s so much more also. It’s time alone where we get to explore each other’s inner being through physical touch and trust. It is a sincere declaration of our love. Without the trust in and care we receive from our PA team, we wouldn’t be able to enjoy sex and that would inhibit us from having a fulfilling adult relationship.”

Age of consent

In the UK, the age of consent for sexual activity is 16.

It is the same for everyone, regardless of their gender identity or sexual identity, and whether the sexual activity is between people of the same or different gender.

Sex and DMD

Your teenager may also have concerns about the impact of sex on their breathing, cardiac or bone health.

So, you may need to reassure them that DMD doesn't stop them from being able to have sex. If they are worried, encourage them to raise the issue at their next clinic appointment.

The key to good sex as a disabled person is communication and creativity. When they are looking for a partner, your teenager should seek someone who will be patient and understanding. The partner should be willing to think creatively about overcoming physical barriers.

Speak with your teenager about how to communicate with a partner. Talk to them about how to explain DMD and what help they need.

Talk about what it might feel like for their partner – they might also be nervous and unsure about what to do. And they might have concerns of their own. So, encourage your teenager to be patient and kind, and to listen to what their partner wants.

> The key to good sex as a disabled person **is communication and creativity.**

Sex education at school

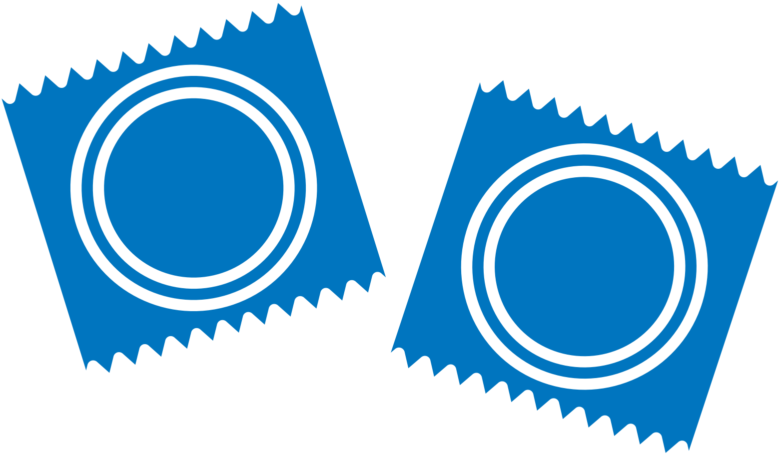
Your teenager has the right to be included in sex education lessons at school, and to have any adjustments made to make these accessible to them.

But they may need to ask for specific information which is not covered in standard sex education classes.

Your teenager may want to ask about different sexual positions (for example, in a wheelchair, hoist or specialist bed). They may want to ask about how they would manage different types of sex, or about fitting condoms, adaptive aids to help with positioning or transferring, or vibrators that can allow them to masturbate if they have weaker arms.

If your teenager's school doesn't have this information, you can offer to look it up together. They will probably prefer to do this alone, but you could direct them to high-quality resources online:

- **The Outsiders Trust** (www.outsiders.org.uk) provides peer support and resources on sex and relationships for disabled people.
- **Pathfinders Neuromuscular Alliance** (www.pathfindersalliance.org.uk) provides information and advice on a range of issues, including sex and relationships.
- **Disability Horizons** (www.disabilityhorizons.com) features articles about disability and sex.
- **Spokz** (www.spokz.co.uk) sells a range of different sex and positioning aids.



Supporting your teenager as a parent

Setting boundaries with your teenager is important when it comes to sex and romance.

As well as agreeing how your teenager can have privacy, you will also need to think about what you are comfortable with in your own home.

It’s highly likely your teenager will masturbate at home. They may struggle with cleaning up after themselves. If this causes a problem with hygiene or staining clothes, it may be necessary to help them clean up.

If your teenager needs help cleaning up afterwards, you may be able to suggest solutions – for example, having a ‘code word’ they can use when they need help getting cleaned up, or giving them time to themselves right before they have a shower or bath.

Your teenager shouldn’t be embarrassed about masturbation. But it’s likely they will feel awkward anyway.

Because they have DMD, they may not be able to keep it private. So, help your teenager to feel comfortable asking for help with cleaning up by not drawing attention to it when they do ask. Using humour to make light of the situation could end up making them feel more embarrassed.

If there’s no problem, sometimes it’s better not to say anything at all. Your teenager may have figured out an appropriate way to masturbate and clean up afterwards without needing to ask. So, pointing out that you know could be embarrassing.

Having sex with a partner

If your teenager has a partner, you will also need to think about appropriate boundaries. This might include rules about their partner staying overnight and having sex.

Your teenager will need to learn how to communicate with you and their care workers about how they wish to be supported when they are with a partner.

Your teenager may live with you for longer because of the barriers to living independently. They may also be less able to visit their partner's home because of a lack of accessibility. So, banning sex altogether could prevent your teenager from having a successful relationship.

Try to consider how you can best support your teenager when they have a partner with them. That could include giving them time and space to be alone, keeping doors closed or helping to hoist them onto a bed.

They will also need a way to ask for help while maintaining their privacy. Connecting to smart home devices in different rooms can be a way for your teenager to call for help without impinging on their privacy.

If their partner stays the night, you will need to speak to your teenager and their partner about how that can work. You should ask your teenager and their partner about the best way to make sure your teenager gets the help they need overnight.

Their partner may be willing to help with some of their care. You and they will need to decide whether they need a separate bed, and how that might impact on your teenager's care.

Try to build a constructive relationship with your teenager's partner. This will be essential in enabling your teenager to have a relationship if they are living at home.

Also, make sure your teenager understands about the need for contraception if they don't want to have children or are not ready to start a family at the moment. They could get their partner pregnant or, in the rare cases of girls with DMD, become pregnant themselves. So, they will need to use birth control properly.

> Try to consider how you can best support **your teenager when they have a partner with them.**

Pornography, sex therapists and sex workers

Why we included these topics in the book

Duchenne UK's aim for this book is to help people think through many different aspects of their lives and make informed decisions.

Some disabled adults use pornography, sex therapists and sex workers. So, we felt it was important to include reliable information about these topics too.

We acknowledge that this may be challenging and uncomfortable reading for some people.

Your values and beliefs

Your values and beliefs should be the starting point for any discussions with your teenager. We encourage you to think about your own beliefs about pornography and sex work before you speak with them.

Pornography and sex work can raise complex questions about empowerment, rights and exploitation of people working in the industry.

You will need to have thought about your own feelings about this. Then, if your teenager asks, try to have an open conversation about your own values, benefits and risks.

Pornography

You can set up parental controls on the internet, the television and their phone to stop your teenager accessing pornography or age-inappropriate content.

Pornography should only ever be watched by people who are over 18. But many younger teenagers do find ways to access it. So, talk about this with your teenager in a frank manner.

If you don't want your teenager accessing pornography, you could talk to them about the risks of exploitation and the false messages given in pornography. Try to explain your values and attitudes, and why they are important.

Talk to your teenager about the differences between pornography and sex in real life. You can find more information on talking to your teenager about porn here: www.nspcc.org.uk/keeping-children-safe/online-safety/online-porn

> If you don't want your teenager accessing pornography, you could talk to them about **the risks of exploitation and the false messages given in pornography.**

Sex therapists, sex surrogates and sex workers

Your teenager may ask about sex therapists, sex surrogates or sex workers. The names are similar, but the roles are very different.

Sex therapists talk about the psychological issues that may be impacting on sex. They are qualified counsellors, doctors or healthcare professionals. You can find out more from the NHS at bit.ly/nhs-sex-therapy

The College of Sexual Relationship Therapists (www.cosrt.org.uk) is the UK professional body which keeps a register of psychosexual relationship therapists.

Sex surrogates are sex workers who work with licensed sex therapists. Sex surrogates use sex to help disabled people to learn about their own bodies and build confidence.

The School of Intimacy, Consciousness and Self-Awareness (www.icasa.co.uk) provides sex surrogacy services.

Sex workers provide sex in return for payment. Paying for sex is legal, provided the sex worker is not being coerced. Soliciting for sex in a public place or advertising sexual services is illegal.

Sex work can be truly consensual for the sex worker. However, many sex workers are controlled by violent gangs. Clients may not be able to tell whether a sex worker is being coerced or not.

The TLC Trust (www.tlc-trust.org.uk) maintains a list of sex workers who specialise in working with disabled people.

Whatever you choose, you and your teenager both need to be comfortable with what happens in your own home. So, try to agree on what is appropriate together.

Appropriate behaviour with care staff and professionals

When your teenager is supported by paid care assistants, they will need to be aware of appropriate behaviour with them. This will protect both your teenager and the professional carers.

Your teenager should understand how they should treat their care staff.

If you employ care staff through direct payments, it will be your responsibility to ensure employees are safe at work. This includes being free from sexual harassment.

Sexual harassment includes sexual comments or jokes, inappropriate touching, sexual advances or displaying sexual photos or videos.

You should talk to your teenager about how to avoid making care staff feel uncomfortable. This includes not flirting, joking or using sexual innuendo.

If you use a care agency, ask if they have any information about sexuality. Some hospices have policies on sexuality.

There is no obligation for care staff to help with any activities that make them uncomfortable.

Make sure your teenager understands that care staff can help with positioning or cleaning up after sexual activity. But they must not be involved in the activity itself.

You should talk to care staff in your home about the appropriate boundaries you have agreed with your teenager. If this includes help with cleaning up after masturbation or sex, the member of care staff must be comfortable with doing this. They have the right to say no.

Your teenager may develop feelings for care professionals. It can be quite common to confuse someone caring for you professionally with caring intimately for you.

Try to discourage your teenager from spending too much time alone with a member of care staff they may be attracted to. Encourage them to spend time with friends and family too.

> You should talk to your teenager about how to avoid making care staff feel uncomfortable. **This includes not flirting, joking or using sexual innuendo.**

Having a family

Some adults with DMD go on to have children themselves. This could be a possibility for your teenager in the future.

Parents with DMD need extra help in order to look after their children. For example, the local authority could fund a personal assistant to help with childcare activities. This could allow your teenager to be a good parent to their children.

If your teenager wants to start a family, talk to them about what that might look like. Talk to them about the rewards and challenges of raising a family. Ideally, they should only start a family if they want to, not just because they want to seem more ‘normal’ or because they feel it is expected.

Encourage your teenager to get involved in volunteering with young children or looking after children in the family. This will give them a better understanding of what’s involved in childcare and help them to decide if they want a family in the future.

Worries about passing on DMD

Your teenager may be concerned about passing on DMD to their children. They can get good advice from their doctors because we know how the genes are passed on.

Genetically, sons of people with DMD will not have DMD themselves unless their partner is a DMD carrier.

However, daughters of people with DMD will carry the faulty dystrophin gene. They can then pass DMD to their own children.

Your teenager should speak to their neuromuscular clinic about getting genetic counselling. Then, they and their partner will have the information they need to decide if they want to start a family.

Support for parents with DMD

If your teenager does start a family, they can get support from:

- **Enabled2parent**, an advice service for disabled parents – www.enabled2parent.org
- **The Disability, Pregnancy and Parenthood website**, which has resources for disabled parents – www.disabledparent.org.uk

Spotlight

Mitch Coles

Mitch is 29 and lives in Bristol. He has two children, Aubrey, 5, and Ethan, 3.

They enjoy playing outdoors and interacting with nature, as well as getting their hands dirty baking cakes or making arts and crafts.

Mitch is assisted by a parental support worker who, under his direction, enables him to take care of his son and daughter. The support worker is a specialist in addition to his own personal carers.

Whether it's talking about dinosaurs and unicorns or teaching his kids how to tie their shoelaces, Mitch loves being a parent.

Mitch says: "When I was younger, I assumed I would have the same opportunities in life as anyone else. My doctors, on the other hand, never spoke to me about having a family or encouraged me to think about the future. But I'm pretty stubborn! For me, having children was just the natural next step in my life.

"Being a parent with DMD can be tiring and you have to adapt your parenting style, but I wouldn't change it for anything. I love being able to teach the kids new skills and seeing them progress through different milestones. Above all, I love having fun and reliving my own childhood!

"My kids mean everything to me. They keep me going and taking care of them gives me a sense of purpose."

Chapter 7

Chapter 07 – Home

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In a nutshell

1

You can create a positive home

Your home is a haven for all of you, but some things may cause your teenager difficulty.

Small changes can ensure they feel safe and comfortable. Some parents worry that their home will become too like a hospital. But it is entirely possible to make it feel homely.

2

Assistive technology can help your teenager to do things for themselves

Assistive technology performs functions that disabled people find difficult to do themselves. It includes smartphone apps, voice activation and devices that control appliances and utilities.

3

Equipment and adaptations to your home will make life easier

Life can be easier for your teenager and you if they have the correct adaptations and equipment, both at home and at school.

> Equipment and adaptations will **increase your teenager's independence.**

Small changes can ensure they feel safe and comfortable.

Adaptations to your home can help make life easier.

Download Muscular Dystrophy UK's 'Adaptations Manual'.

www.musculardystrophyuk.org

4 You can get good advice about equipment and adaptations

Your local authority's occupational therapist should provide you with personalised advice about the equipment and adaptations to your home that your teenager needs.

They should help you apply for grants to pay for them. And, if your home cannot be adapted, they can provide you with a medical referral for priority social housing.

Muscular Dystrophy UK also has excellent advice about equipment and adaptations, which you can download from their website.

5 Transport schemes can help you get about more easily

You may be able to get an adapted car through Motability. Under this scheme, you can exchange all or some of the mobility part of your benefit for a lease on an adapted car of your choice.

Your local authority can give you access to disabled parking spaces through its Blue Badge Scheme. Some also provide transportation to and from school to give teenagers more independence.

> Ask your local authority for an occupational therapist sooner rather than later **because they often have long waiting lists.**

For more information about financing adaptations and equipment

In this folder, you can find an overview of the financial support available to families with DMD in Chapter 8: Financial Support. This includes specific support for adaptations and equipment.

On our website, you can find our *Guide to Financial Support and Work for DMD Families* which has detailed information. **www.duchenneuk.org/resourcesforparents/supporting-your-teenager**

Equipment for home and school

Your teenager may find it helpful to use the following equipment:

- Specialist chair
- Easy-grip cutlery
- Easy-grip pens
- Bathroom accessories
- Electric profiling bed
- Ventilation devices to aid breathing
- Arm supports (Neater arm support)
- Assistive technology

Ask your occupational therapist for advice.

An electric profiling bed will enable your teenager to lift and lower their bed themselves. This will reduce the strain on your back.

Arm supports support the elbow which enables them to move their forearm and maintain functionality.

Occupational therapists (OTs) are good at recommending the best equipment to meet their needs from the many options available

Funding for equipment

Your teenager will need different specialist equipment over time as their needs change.

Funding varies across the country. Some local authorities fund equipment as a matter of course. Others take these decisions to a panel. Unfortunately, in other places, families need to pay for equipment. Some charities will award grants for equipment.

Many DMD families fundraise for themselves. They often use GoFundMe or JustGiving to raise money for equipment or adaptations. Friends and the local community are usually happy to help. Some families also contact their local newspaper and have received generous donations from readers.

More information about financial support

Chapter 8: Financial Support

Guide to Financial Support and Work for DMD Families for more detailed advice about financial support.
(www.duchenneuk.org/resourcesforparents/supporting-your-teenager).

Assistive technology

Assistive technology could help your teenager to do more for themselves. It comes in many forms, including smartphone apps, voice activation and devices to control appliances and utilities.

They may be able to use assistive technology to control the heating, turn on the washing machine or even find out what's in the fridge. They could also use it to open doors, answer an intercom and operate electric devices, such as lamps, televisions, gaming systems, security systems and electric profiling beds.

Evoassist is a widely-used app which can control many devices if they are set up for it. It can work with showers and machines that wash hair so disabled people can manage their own personal care.

Voice-activated systems, such as Apple HomeKit, Amazon Echo and Google Home, are increasingly popular. Microsoft's voice-activated features can help your teenager use Word, Teams, Outlook and Excel.

Advice about assistive technologies

Your teenager's OT can recommend that they have an environmental control assessment. Then, they can receive advice and product recommendations tailored to their needs and goals.

Before investing in any assistive technologies, you'll need to research them thoroughly. Ask sellers:

- What this technology does itself
- How much it costs
- Which devices, appliances and utilities it works with and their costs
- How easy it is to install
- How easy it is to use

Adapting your home

Daily life will be easier for your teenager if you are able to adapt your home to meet their needs.

They'll be able to be more independent and do more for themselves. And this will help them develop their skills and confidence.

Adaptations that your teenager will need now

Ramps and handrails on steps can help to prevent stumbles and trips. Lifts can work for multi-storey properties. Small lifts (called through-floor lifts) don't take up as much space as you might think.

Your OT can give you advice about the different types of equipment available:

- Higher seats and handrails can make using the toilet easier and safer
- Bath chairs to help them to get in and out of the bath
- Chairs in the shower to make it easier for them to wash
- Bathroom handrails to provide balance and support
- Ceiling track-hoists can aid in moving around

Wet rooms may be a better answer, but they'll need to work for the whole family.

Adaptations that your teenager will need when they start using a wheelchair

As your teenager comes to rely on support from their wheelchair, they may want to use it within your home. Then, the doors may need widening and the light switches will need to be moved to the right height. This will support their independence.

Voice-activated devices, such as wireless switches and Alexa-type devices, are helpful too.

Renovations and moving house

Over time, your teenager's needs will change. Then, they'll require more equipment and adaptations to your home.

Ideally, you only want to adapt your current home or move house once. So, if you think about your teenager's long-term needs at an early stage, you are likely to be better off practically and financially.

If you live in social housing, it can be more difficult because you are reliant on your local authority's budgets. If you speak with them at an early stage, the decision process will hopefully be easier.

Advice and funding for equipment and adaptations

You can get advice about the best equipment and adaptations for your teenager from your teenager's social worker, occupational therapist and muscular dystrophy charities.

The process is the same for people who live in their own homes, rented homes and social housing.

Personalised advice from your local authority

Your local authority should refer your teenager to their OT team. If they don't, you should make the request yourself.

OTs often have waiting lists. And the process for adapting your current house, or moving to a new house, can take many years. So, it's best to get an OT for your teenager sooner rather than later.

OTs have two different roles:

- Social care occupational therapy – Equipment and adaptations in the home
- Healthcare occupational therapy – Bodily function

In some local authorities, these two roles are both performed by the same person. In other local authorities, they are performed by different people.

Assessment and report

The social care occupational therapists will assess your family home by looking at whether it is suitable for your teenager over the long-term. For example, they'll see if it has level access or steps, and if the shower and bathing facilities are safe for them

Once they have finished their assessment, they will write a report recommending adaptations and equipment. The report will describe your teenager's specific needs and the best ways to meet them.

The report will be sent to you and your landlord, housing association or council housing office if you are a tenant. Then, you'll be able to plan changes to your current home, or move to a new home.

Your OT will help you to apply for grants for adaptations and equipment.

Applying for a Disabled Facilities Grant (DFG)

www.gov.uk/disabled-facilities-grants

You can apply to your local authority for a Disabled Facilities Grant (DFG) to help meet the costs of adapting your home to your teenager's needs.

Once you've applied, your local authority must give you their decision within six months.

Your OT will guide you through the application and adaptation process. If your OT is not helpful or doesn't listen to you, ask to be transferred to a different OT. You will need the support of a competent and empathetic professional during this process.

Your grant must be approved before you begin any building works. Grants cannot be awarded after building work has begun.

If you are a tenant, you must also have permission from your landlord, housing association or council housing office. If you own a leasehold property, you'll need permission from your freeholder.

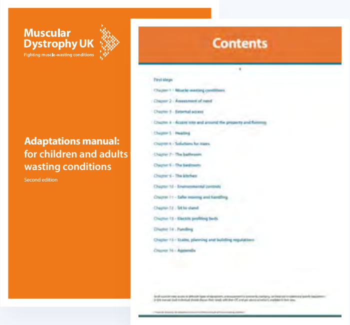
Funding for minor adaptations costing less than £1,000 is not means-tested. Larger grants are means-tested. Your benefits will not be affected if you receive a Disabled Facilities Grant. Some charities, such as Independence at Home (www.independenceathome.org.uk), also provide grants for adaptations.

If your home cannot be adapted to meet your teenager's needs, your OT can give you a medical referral for priority social housing. If you live in a housing association property, the local authority may fund them to do everything from the occupational therapy assessment to hiring people to do the adaptations.

If your situation is urgent, you may be able to get NHS adaptations or equipment.

General advice from charities and other organisations

You can get good general advice about equipment and adaptations from charities. But before spending money on changes, it's best to speak to your teenager's OT.


Muscular Dystrophy UK
Fighting muscle-wasting conditions

Adaptations manual:
for children and adults
wasting conditions
Second edition

Contents

Muscular Dystrophy UK

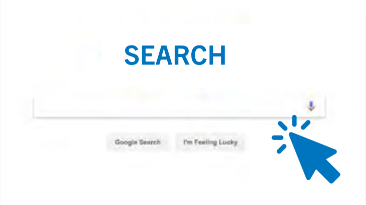
www.musculardystrophyuk.org

Muscular Dystrophy UK have produced manuals about equipment, adaptations and wheelchairs which many families have found extremely helpful.

Their '**Adaptations Manual**' is a detailed guide to assessment of needs and solutions for stairs, bathrooms, bedrooms and kitchen.

Other sources of advice

- **Contact a Family** – www.contact.org.uk
- **Carers' alliance** – Google the name of your local authority + carers' alliance
- **Disabled Children's Register** – Google the name of your local authority + disabled children's register
- **Home Improvements Agencies (can help with adaptations)** – Google the name of your local authority + home improvement agency



Other DMD families

You can get good advice from other parents what works and doesn't work.

See Chapter 16: Contacts for information on DMD community groups on social media.

Pathfinders Neuromuscular Alliance

www.pathfindersalliance.org.uk/advice-assistive-technology

Pathfinders have a useful guide to assistive technology, including mounting smart-phones and tablets to your wheelchair.

> Assistance dogs can increase the well-being of the whole family.
> **These dogs provide companionship and emotional support.**

Assistance dogs

From the time, when your teenager is about 8-10 years old, they might be able to get an assistance dog.

These dogs provide companionship and emotional support. They also help in practical ways, such as picking up things from the floor.

Assistance dogs can increase the well-being of the whole family.

You can find out more from Assistance Dogs UK.

www.assistancedogs.org.uk

Transport

You can get help from the government with transport, including a car, parking spaces and school transport.

Motability car

www.motability.co.uk

If your teenager receives the high level of Disability Living Allowance (DLA) or the enhanced mobility component of the Personal Independence Payment (PIP), then you are eligible for Motability.

Under this scheme, you can exchange all or some of the mobility part of your benefit for a lease on an adapted car of your choice.

If your teenager uses a powered wheelchair, then you can get a wheelchair-accessible vehicle. You'll also need to think about what sort of vehicle will suit you best. For example, you might need a bigger vehicle to transport your teenager's equipment if you want to go on holidays. Or you might not be able to have a tall vehicle if you have low bridges near your house.

Motability cars include insurance for two drivers, breakdown assistance, services, repairs and replacement tyres. The scheme can also provide grants for adapting a vehicle. For example, they could pay the extra costs of a car that can be driven from a wheelchair.

You should double check the insurance to see if it covers personal assistants and carers as well. Most insurers do provide open policies.

As your teenager grows up, being able to go out in their own vehicle with a carer will give them independence. They'll be able to go to college, work, appointments and socialise with their friends more easily. Once they are 18, they may be able to learn to drive their adapted vehicle for themselves.

Queen Elizabeth's Foundation for Disabled People has useful resources and advice on the mobility section of their website:

qef.org.uk/our-services/qef-mobility-services

Blue badge for disabled parking spaces

www.gov.uk/apply-blue-badge

You probably already have a blue badge so you can park in disabled parking spaces.

If not, you can apply for one through your local authority. Then, you'll be able to park in disabled spaces which are bigger and more convenient.

School transport

Some local authorities provide transportation to and from school to give teenagers greater independence. Take a look at your authority's local offer or speak to your teenager's social worker.

Chapter 8

Chapter 08 — Financial Support

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In a nutshell

1

You’re entitled to support from the Government

Until your son or daughter is 16, the Government will pay you a Disability Living Allowance (DLA) because you are looking after someone. When they turn 16, they’ll receive a Personal Independence Payment (PIP) instead.

If you are not working or on a low income, you may also receive Carer’s Allowance, Universal Credit or other benefits.

You may also be eligible for a motability car from the Government or be exempt from road tax for your own car.

2

You’re entitled to support from your local authority

By law, your local authority must provide health, education and social services to disabled people. You’ll be entitled to direct payments, short breaks and disabled facilities grants as part of your social care support. You may also be able to get a reduction in your council tax.

You might be able to apply for grants from charities as well – especially if your teenager needs new equipment.

3

You can access new support as your teenager grows up

The benefits and support available will change to meet your teenager’s changing needs.

They may receive personal budgets for health, social care or education. They may be able to get a wheelchair or receive a contribution towards one from the NHS. And they may be eligible for grants for adapting your home.

If you are on a low income, you may receive Carer’s Allowance, Universal Credit or other benefits.

You’ll be entitled to direct payments from your local authority.

Talk to other DMD parents about combining work and care.

As your teenager grows up, they may want to take a greater role in making decisions about the type of support that will work best for them.

4 You can get help accessing financial and care support

You can get advice about benefits from your local authority and charities which support disabled people and those on low incomes.

5 Your work is important too

Your teenager's DMD has an impact on your work as well as your family life.

Many parents find that work has social as well as financial benefits. So, many parents of teenagers and young adults with DMD continue to work.

We can put you in touch with other DMD parents so you can speak to them about combining work and care. Please email us at support@duchenneuk.org.

Important note

The information in this chapter was correct at the time of writing in 2021. But benefits change frequently. So, we recommend that you look up the most up-to-date information on the internet.

Alternatively, contact Duchenne UK (www.duchenneuk.org) or Pathfinders Neuromuscular Alliance (www.pathfindersalliance.org.uk) for advice.

Use this chapter as a checklist

In this chapter, we've provided you with a list of benefits and support. You can use it to check that you are getting all the help that is available to you.

We've also included information about organisations that can advise you about benefits and support. So, if you have questions about how the system works, you know where you can find the answers.

Find out more in our PDF Guide

Our *Guide to Financial Support and Work for DMD Families* contains detailed information about the different benefits and support available to you and your teenager as they grow up.

You can download the Guide from our website at: ***www.duchenneuk.org/resourcesforparents/supporting-your-teenager***

Financial support from the Government

The Government has a range of benefits which could help you.

You will have to apply for the benefits (except for child benefit). You can find information about eligibility and application processes for each benefit on the internet.

Benefits calculators (www.gov.uk/benefits-calculators) can help you work out what support is available to you.

Financial support for all disabled people and their carers:

- **Carer's Allowance (comes with National Insurance credits)** – www.gov.uk/carers-allowance
- **Disability Living Allowance (DLA)** for children under 16 years old - www.gov.uk/disability-living-allowance-children
- **Personal Independence Payments (PIP)** for people aged 16 years or older - www.gov.uk/pip
- **Motability Scheme for transport -** www.motability.co.uk
- **Road Tax Exemption** - www.gov.uk/financial-help-disabled/vehicles-and-transport
- **VAT exemptions** - www.gov.uk/financial-help-disabled/vat-relief

Financial support for people on low incomes:

- **Universal Credit** – www.gov.uk/universal-credit
- **Pension Credit** - www.gov.uk/pension-credit
- **Cold weather payments** - www.gov.uk/cold-weather-payment

Universal benefits:

Child Benefit – www.gov.uk/child-benefit (means-tested for high earners)

Support from your local authority

By law, your local authority must provide services and support to your teenager and you.

So, contact them early so you have time to get everything set up properly. Don't wait until you are struggling.

The people in your teenager's care team – such as their social worker, occupational therapist, physiotherapist or a specialist nurse - can help you access support.

They'll assess your eligibility and arrange direct payments and other types of support. They can also help you to navigate the benefits system.

Services

- **The Local Offer in your area** – Google 'local offer' + [the name of your local authority]
- **Social care assessments** – Google 'social care assessments' + [the name of your local authority]
- **Occupational therapy for social care (aids, equipment and home adaptations) and healthcare (physical functionality, such as help walking)** – Google 'occupational therapy' + [the name of your local authority]
- **Short breaks** – Google 'short breaks' + [the name of your local authority]

Financial support:

Direct payments to parents – www.gov.uk/apply-direct-payments

Personal budgets for health, social care or education – Google 'personal budget' + [the name of your local authority]

Housing:

Disabled Facilities Grant for making adaptations to your home – www.gov.uk/disabled-facilities-grants

Council Tax Reduction – www.gov.uk/apply-council-tax-reduction

Local Housing Allowance – www.gov.uk/guidance/local-housing-allowance

Council housing – www.gov.uk/council-housing

> "Having a social worker allowed us to employ a personal assistant for our son. This enables him to go out independently from our family and socialise with friends. Our social worker has also helped us when we were having problems with housing adaptations and transport to school."
>
> DMD parent

Support from the NHS

When your teenager's mobility changes significantly, ask their Occupational Therapist to refer them to NHS Wheelchair Services.

Electric wheelchairs are provided by the NHS, not your local authority.

Your GP can provide extra support to you if you register as a carer at their surgery.

They can provide advice and refer you to social services and local voluntary agencies. They may be able to arrange home visits or double appointments so that it's easier for you to see them. You can also get free health checks so you can look after yourself better.

Find out more at https://bit.ly/carersuk-your-gp

Support from charities

You may also be able to get financial support, including grants for wheelchairs, family breaks and equipment, from charities such as:

Family Fund - www.familyfund.org.uk

Promise Dreams - www.promisedreams.co.uk

Turn2Us Funds - www.turn2us.org.uk/Get-Support/Turn2us-Funds

Appointeeship, deputyship and power of attorney

If your teenager has a learning disability, you may need to manage their money on their behalf.

You'll need to apply to become their appointee or deputy. You can find out more:

Appointee - www.gov.uk/become-appointee-for-someone-claiming-benefits

Deputy - www.gov.uk/become-deputy

Power of attorney - www.gov.uk/power-of-attorney

Special Educational Needs and Disability Information Advice and Support Service (SENDIASS)

Every local authority has a Special Educational Needs and Disability Information Advice and Support Service (SENDIASS). It supports parents and carers of young people (0-25 years old) with special educational needs or disabilities, as well as the young people themselves.

Local authorities must provide this service by law.

Your local SENDIASS will offer free, confidential and impartial advice and support. It is run at arms-length from the local authority itself. They will work with you, your teenager and professional staff to provide the best possible support.

They can provide you with advice and support on:

- Education, Health and Care Plans (EHCPs) and the assessments for them
- Social care and health matters

They can also help you to:

- Understand complicated documents and reports
- Complete paperwork
- Attend meetings with you to ensure your views are heard

You can find your local SENDIASS through your local authority or on Google.

> They will work with you, your teenager and professional staff **to provide the best possible support.**

Charities that offer advice about benefits

Charities that specialise in advice about benefits:

Turn to Us - www.turn2us.org.uk

EntitledTo - www.entitledto.co.uk

Policy in Practice - www.policyinpractice.co.uk

Charities that offer advice on a range of matters, including benefits:

Carers' UK - www.carersuk.org

Citizens' Advice Bureau - www.citizensadvice.org.uk

Contact a Family - www.contact.org.uk - a national charity which supports families who have children and teenagers with disabilities.

Your local independent living centres - search online for 'independent living centre' + [the name of your local authority]

Bank accounts for your teenager

Your teenager should have their own bank account once they start receiving payments from the Government or local authority.

Separate accounts make it easier for you to see what's their money and what's yours. This reduces the risk of tensions with the local authority and family members.

So, even if you manage their money for them because they are young or have a learning disability, we still encourage you to set up a separate account for them.

Parents' work

Families with DMD tend to change their work and childcare arrangements over time, depending on their own needs and the needs of all their children.

You may be able to get help with childcare from:

- **The Government** - www.gov.uk/help-with-childcare-costs
- **Your local authority** - contact them directly to find out about short break services, direct payments and childcare for disabled children

If you'd like to speak to other DMD parents about combining work and care, please join our Facebook group or email us at support@duchenneuk.org.

Download

You can download the *Guide to Financial Support* and *Work for DMD Families* from our website at:

www.duchenneuk.org/resourcesforparents/supporting-your-teenager

Chapter 9

Chapter 09 – Holidays and Fun

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In a nutshell

1

You can still lead a good life with DMD

As fellow DMD parents, we want to assure you that your teenager with DMD and your whole family have many happy days in front of you.

We've shared our best recommendations in this chapter. We hope you'll find them helpful.

2

Music, sport, Scouts and pets

You'll find many wonderful opportunities for your teenager to play sports from swimming and hydrotherapy to adventure sports, like sailing, skiing and flying.

Many sports organisations for disabled people offer subsidised places at reduced costs.

Your teenager may also enjoy singing, learning an instrument or joining Scouts in their local area. And they may be able to get an assistance dog who will provide them with friendship and practical help.

3

Arts, graphics, gaming and social media

Most teenagers enjoy online gaming and using social media. Your teenager may also enjoy art, graphics, photography, writing and other artistic pursuits.

4

Family holidays

As your teenager's physical needs change, consider using specialist holiday companies and holiday camps for disabled people. Some offer subsidised places too.

5

Grant-giving and wish-granting organisations

Starlight Children's Foundation, Make a Wish and other smaller organisations grant wishes for holidays and special treats to teenagers with serious illnesses.

Some DMD families have used their wishes to go on amazing holidays to Disney and other places.

Starlight Children's Foundation also holds a wonderful summer party with rides, games and celebrities.

Living a good life for your teenager, your family and yourself

Many teenagers and adults with DMD and their families lead good lives with friends, hobbies and holidays.

Many organisations provide music, sport, holidays and adventures suitable for your teenager.

In this chapter, we have shared some of our favourites, but there are many more out there. You can find them on the internet or through your local council's advice service.

> My advice to other disabled people would be, concentrate on things your disability doesn't prevent you doing well, and don't regret the things it interferes with. Don't be disabled in spirit as well as physically.
>
> – *Stephen Hawking*

Hobbies and sport

Teenagers with DMD should have opportunities to learn music and play sports which they might enjoy.

For us as parents, it can be bittersweet watching our teenager playing an instrument or a sport which we know they won't be able to do so forever. So, the temptation for us is to 'protect' them and ourselves from this future loss.

But our teenagers benefit greatly from developing their abilities. Not only will they have fun, they'll also develop their confidence, concentration and social skills.

Music helps develop their sensory, motor, social and expressive skills. And the right kind of physical activity is an essential part of strengthening and protecting their muscles.

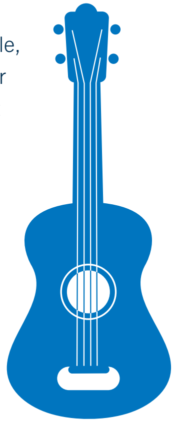
So, we encourage you not to anticipate the loss of your teenager's abilities before it happens. Let them enjoy music and sport now, and worry about future activities when the time comes.

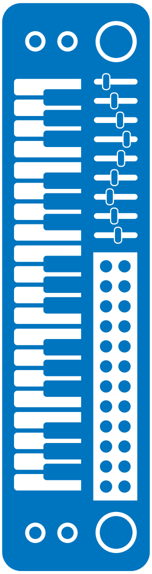
Music

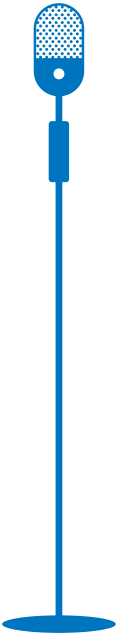
Your teenager's own interests are the best guide when you are investigating different instruments and choirs.

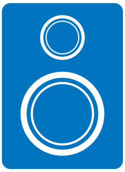
If you can, let them try out a few so they can see which one they enjoy the most.

- **Learning an instrument** – Teenagers with DMD can enjoy playing the ukulele, keyboards, recorders, flutes and other instruments. Learning any instrument will enhance your teenager's life.
- **Learning singing** – singing provides a good workout for the lungs and improves posture as well as being enormous fun. Singing in a choir or a band also develops teenager's social skills and lowers stress levels.









Arts and graphics

Your teenager can choose from many artistic hobbies.

They may enjoy drawing, painting, pottery, model building or Lego. Or they could try creating graphics on their computer. They can use adaptive computer programmes so they can continue their interest for many years.

Art galleries and museums are often accessible, so can make inspiring days out. All the same, it's best to check their accessibility on their website before you visit.

Scouts, Explorers or Girl Guides

Many teenagers with DMD have had lots of fun and adventures in their local pack at weekly meetings, regional competitions, excursions and camps.

Some have reached high levels or received special commendations.

Scouting is an inclusive activity open to all young people, regardless of their mental or physical ability. You can see from their website that they try hard to make their activities available to all.

Many young people will require some special consideration to enable them to fully participate in all Scouting activities. By identifying an individual's additional needs and providing them with appropriate support, we can include more young people in Scouting.

So, take a look at your local pack and see how suitable the pack and location is for your teenager. Each county has a specialist SEN adviser and they can advise you which packs in your local area are the most suitable.

You do need to think about the future when you look for a pack. As your teenager progresses through Scouts, Explorers or Girl Guides, they'll need a location that will work for them as their needs change.

All the packs are staffed by volunteers. So, if your teenager needs extra support, you may need to volunteer yourself, or see if a friend or teaching assistant can attend pack meetings and camps.

> We encourage you not to anticipate the loss of your teenager's abilities before it happens.
> **Let them enjoy music and sport now.**

Sports

Your teenager needs to stay active to protect their health. So, it's important that they find a sport that they enjoy.

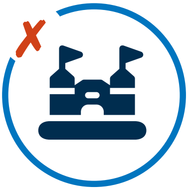
You'll probably find that it takes a bit of a negotiation between you and your teenager. We encourage you to tell them that they can choose what they do, but they can't choose to do nothing.

Your teenager may enjoy these sports:

- **Walking** – Depending on your teenager's ability, walking on a flat surface or indoors may still be possible with or without walking aids. Walking can aid in endurance, maintain balance and strength.
- **Swimming** – Helps teenagers to develop their muscle tone, balance and motor control. They can also stretch their muscles in a pool more easily than on dry land
- **Hydrotherapy** - Involves doing special exercises in a warm-water pool. The soothing warm water relaxes the teenager's muscles so they can exercise more easily. Some parents invest in an inflatable hot tub, like a Lay-Z-Spa, so their teenager can do hydrotherapy at home.

  Ask your teenagers' physiotherapist if they can refer them to local hydrotherapy services.

  Hydrotherapy is often offered at hospices – and this can feel off-putting for parents. But we encourage you to contact your local hospice and ask about their services for teenagers with chronic serious conditions. You may find they can provide other forms of support, as well as hydrotherapy, and many of their services are free.
- **Tomcat trikes (www.tomcatuk.org)** – Are specially designed for people with physical disabilities. But they are expensive. Many parents use GoFundMe or JustGiving pages to raise the money for a trike. Rotary clubs, charities, local schools and community groups have provided generous support to many families.
- **Horse-riding** –Helps teenagers to improve their posture, balance, co-ordination and communication skills. Teenagers can complete badges and ride in competitions which also builds their confidence. Riding for the Disabled Association (www.rda.org.uk) is the best place to start.



- **Boccia** (www.boccia.uk.com) – A competitive bowling game played from a wheelchair. Many levels are available. Some older teenagers with DMD have represented England at international level.

- **Wheelchair football** (www.thewfa.org.uk) – A fast-paced active team sport for people who use electric wheelchairs. It's fun for players and spectators.

- **Tai chi and other martial arts** – Develops teenagers body awareness and improves their general health through slow fluid movements

- **Sailing** – Suits teenagers with a wide range of abilities as they can sit down on the boat. Take a look at Sailabilty which is run by the RYA (www.rya.org.uk), the Disabled Sailing Association (www.disabledsailingassociation.org.uk) and Sailing for the Disabled (www.sftd-iom.com) to see if they offer classes near you. You may even find they have subsidised classes

- **Learning to fly** – Gives teenagers the opportunity to do something extraordinary which builds their confidence. Aerobility (www.aerobility.com) takes nearly 1000 disabled people flying every year. They offer half hour lessons which can make wonderful birthday treats

- **Ice-skating** – Many of the pop-up rinks that appear every winter will let teenagers skate in their wheelchairs. The chairs also give parents something to hang on to which is useful!

- **Skiing** – Helps teenagers to develop their motor skills and balance. Snowbility (www.snowbility.co.uk) and Disability Snowsport UK (www.disabilitysnowsport.org.uk) have centres in the UK

- **Disabled cricket, disabled tennis, disabled football and other sports** – Ask your local council about the sports and leisure facilities for teenagers with disabilities in your area. And also ask them about community buddy schemes that may support your teenager as they take part in sports and other activities

The Duchenne Family Support Group (www.dfsg.org.uk) run days out themselves. Also, other parents may be able to recommend activities near you.

> **Please remember that some activities can damage teenager's muscles** - especially two-wheeled scooters, bouncy castles, trampolines and rugby. These should be avoided.

Days out, amusement parks and attractions

Your teenager can have a great day out with family and friends at amusement parks and attractions.

Think broadly about the type of attractions that you could visit. You could try horse racing, Truckfest, motor racing, music festivals – to name but a few options. Try new things and encourage your teenager to have broad interests.

Many are fully accessible. But you should check in advance by looking at the attraction website. Many also offer discounted tickets to carers and fast-track passes for queues.

Photography

Photography can be a rich and enjoyable hobby for disabled people.

Cameras can be fitted with remote cords. Smart cameras have apps that can connect to phones. This way, creative and arty people can pursue their passion from their wheelchair.

The Disabled Photographers' Society (www.the-dps.co.uk) runs workshops, exhibitions and competitions.

Gaming

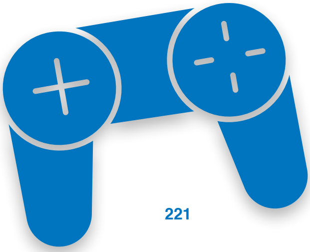
Many teenagers and adults with DMD are enthusiastic online gamers. Often, it's their favourite activity.

Some people with DMD also enjoy designing and building games of their own. Minecraft is particularly popular with many teenagers.

We know parents worry that their teenagers spend too much time on gaming, but it does have many benefits. So, try to find a good balance rather than discouraging it completely.

Gaming has many physical, social and psychological benefits for people with DMD. They can gently exercise their muscles which can help maintain physical ability. They can make friends, play games and have fun on an equal basis with their peers. And it provides a release from everyday life where they can choose who they want to be and what they want to do with complete independence.

Many gaming consoles are suitable for people with DMD. You can also get advice from Special Effect (www.specialeffect.org.uk), the gamers' charity. They will personally assess your individual needs and recommend the equipment which will suit you best.



Social media and blogging

Social media is a wonderful way for your teenager to make friends and socialise from your own home.

Instagram, Snapchat, TikTok, Facebook, WhatsApp, video-chats and other social media bring people together where they are. So, teenagers and adults with DMD can meet each other easily online. They can also meet other disabled people and non-disabled people. So, it can help your teenager to discover other people's perspectives on life.

Through social media and blogging, your teenager could share experiences, vent frustrations and document their life. Bloggers often challenge stereotypes and misconceptions. They can highlight specific problems, such as a local shop that's inaccessible. And they can campaign to raise awareness about the things that matter most to them.

Best of all, social media is fun.

Staying safe online

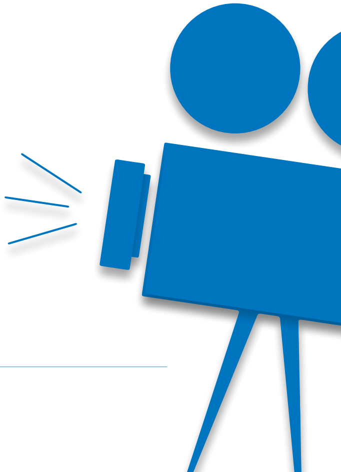
Sadly, the online world has some dangers for teenagers and adults. You should speak to your teenager about staying safe so they can protect themselves from bullies and predators.

You will be able to keep your son or daughter safe with a little planning and open conversations. So, don't let the bad behaviour of a minority of people put you or your teenager off enjoying the online world.

- Internetmatters.org (www.internetmatters.org) has advice, guides and resources for parents to help them keep their children and teenagers safe online. They have age-specific advice for pre-teens (11-13) and teens (14+).
- The NSPCC also has an excellent set of guides on these topics www.nspcc.org.uk/keeping-children-safe/online-safety

Movies with a CEA Cinema Card

The CEA card (www.ceacard.co.uk) is a national scheme which gives a free ticket to a parent or carer who is accompanying a person with a disability (8 years old or over) to the cinema.



Family holidays

Holidays are an important time for every family. You can relax and have fun together.

As your teenager's physical needs change, contact specialist holiday companies and charities. They have the facilities and services your family needs to have a wonderful holiday together.

- **Duchenne Family Support Group** (www.dfsg.org.uk)
  DFSG arranges days out and subsidised holidays in the UK and abroad for DMD families. All of them have adapted places for all ages and all family members. You can join DFSG for free. Then, you'll get automatic notification of their events.
- **When You Wish Upon A Star** (www.whenyouwishuponastar.org.uk) –
  A charity with properties in Cornwall, Alicante and Florida that are available for reasonable rents to families whose teenagers have serious conditions
- **Calvert Trust** (www.calvertlakes.org.uk) – An outdoor adventure centre for disabled people that runs family and individual holidays
- **Holidays with volunteers and carers**
  Holidays with Help provide respite care breaks for disabled people (www.holidayswithhelp.org.uk)
- **Holiday camps for teenagers and adults** – Including
  Over the Wall (www.otw.org.uk) – 8-17 years old
  Wood Larks (www.woodlarks.org.uk) – 10 years old - adult
  Camp Whizzkidz (www.whizz-kidz.org.uk) – 12-25 years old
  PHAB UK (www.phab.org.uk) – 8-30 years old
- **Holiday properties in the UK and abroad**
  Bond Holidays (www.bondhotel.co.uk)
  Break (www.break-charity.org)
  Calvert Trust (www.calvert-trust.org.uk)
  Revitalise (www.revitalise.org.uk)
  Hall Farm Cottages (www.hallfarm.com)
- **Cruises** - cruise ships often have profiling beds, wheelchair-friendly layouts and other adaptations

Your family can have wonderful holidays together.

- **Specialist travel agents** can be a good source of advice, but they might be more expensive than booking a holiday directly:

  Access Travel (www.accesstravel.com)
  Disabled Holidays (www.disabledholidays.com)
  Enable Holidays (www.enableholidays.com)
  Limitless Travel (www.limitlesstravel.org)

- **Skiing holidays** –

  Disability Snowsport UK (www.disabilitysnowsport.org.uk)
  Crystal Ski (www.crystalski.co.uk)
  Ski 2 Freedom (www.ski2freedom.com)

- **Sailing holidays** – Jubilee Sailing Trust (www.jst.org.uk)

> You can contact specialist holiday companies and charities **which have the facilities and services your family needs to have a wonderful holiday together.**

Grant-giving and wish-granting organisations

Across the UK, there are charities which specialise in granting wishes to children and teenagers who have serious illnesses and their families.

They provide opportunities for having fun and creating special memories. Some charities will also provide equipment, such as garden play equipment, sensory equipment or household items.

If you would like to apply for a grant for your teenager, these wish granting charities might be able to help:

Starlight Children's Foundation
www.starlight.org.uk

Make a Wish
www.make-a-wish.org.uk

When You Wish Upon A Star
www.whenyouwishuponastar.org.uk

Rays of Sunshine Children's Charity
www.raysofsunshine.org.uk

Promise Dreams
www.promisedreams.co.uk

Family Fund
www.familyfund.org.uk

Child Flight
www.childflight.co.uk

Dreams and Wishes
www.dreamsandwishescharity.org

Dreams Come True
www.dreamscometrue.uk.com

Dreamflight
www.dreamflight.org

Muscle Dreams
www.musclehelp.com/muscle-dreams

Willow Foundation
www.willowfoundation.org.uk

Travel advice

- **Tourism for all** (www.tourismforall.org.uk) provides free travel advice to disabled adults, teenagers and children, and their carers. They try to match holidays with your specific needs. They cover holidays in the UK and abroad offered by both commercial and voluntary organisations. They even offer discounts to their members.

- **Disability Holiday Guide** (www.disabilityholidaysguide.com) lists specialist tour operators for wheelchair users. They can also help you find travel insurance, accessible transport and mobility equipment.

- **Tryb4ufly** (www.tryb4ufly.co.uk) helps disabled people try seating and transfer options with an occupational therapist before they fly.

- **The Ceiling Hoist Users Club** (www.chuc.org.uk) keeps a list of hotels, B & Bs and self-catering accommodation with hoists. You can also find advice about using hotel hoists and information about hoist and sling suppliers on their website.

Travel insurance

The following firms have all been helpful to families with complex needs:

- Freedom Insure (www.freedominsure.co.uk)
- All Clear (www.allcleartravel.co.uk)
- FISH (www.fishinsurance.co.uk)

Remember to tell them everything about your condition, even seemingly minor unimportant details.

Holiday funding for your family

The social services team at your local authority.

- The Family Fund (www.familyfund.org.uk)
- The Family Holiday Association (www.fhaonline.org.uk)
- Helping Hands for Holidays (www.3hfund.org.uk)

Muscular Dystrophy UK's factsheet, Dream trips and wishes, has more suggestions for funding. (www.musculardystrophyuk.org/get-support/for-parents-and-families/dream-trips-and-wishes)

Travelling with medication

Your medication should be in a box labelled by the dispensing pharmacy. Ideally, you should also have a doctor's letter listing all your medication.

Always pack half your medication in your hand luggage and the other half in your suitcase. That way you'll have enough to keep you going for a few days if your suitcase gets lost.

Of course, you should also take:

- **Your teenager's medical alert card**
- **Your teenager's emergency plan**
- **The Duchenne Emergency App with your teenager's details uploaded**

See Chapter 13: Emergencies for more information about preparing for and responding to emergencies.

Ceiling hoists

You may want to take your own mobile hoist with you if the accommodation provider doesn't have one.

Before you travel, you should ask the accommodation manager about the clearance under the bed. Mobile hoists don't work with divan beds. However, you may be able to use 'elephant feet' to raise the bed and make space for the mobile hoist.

(www.completecareshop.co.uk/beds-and-bedding/bed-raisers/elephant-feet)

Chapter 10

Chapter 10 — Life Skills

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In a nutshell

1 Talk about the future

You can help your teenager by talking to them about what independence means to them and how they picture their future.

Shaping a good life starts with your teenager’s dreams and goals. You might be surprised with what’s possible even if what they want sounds difficult or impractical.

2 Encourage them to learn practical skills

You can help your teenager develop the practical life skills they’ll need in their adult lives.

Being independent doesn’t always mean doing things for themselves. It can also mean taking responsibility for managing things like diet, travel and money by having a friend or carer work with them.

3 Let them do it their way

You can help your teenager find their own way of doing things and feel good about becoming more independent.

This might mean making adaptations to your home or accepting they won’t do things the way you would. Helping them do it their way will make them feel better about their future.

4 Encourage them to learn from role models

You can help your teenager find friends and role models who can help them deal with new challenges.

Meeting other young adults who have overcome difficulties and shaped a good life for themselves can be hugely empowering. Also, it’s good to understand that non-disabled young people also have challenges, anxieties and struggles.

5 Show them how to be confident

You can help your teenager grow in confidence by reminding them they’re not defined by their disability.

By expanding their horizons of what’s possible, they’ll be able to steer their life in the right direction. Talk to other DMD teenagers and parents. Learn from adults with DMD. Seek out solutions first rather than immediately managing expectations.

Life Skills in this chapter

As we shape a good life for ourselves and our families, we need to develop some essential life skills.

This chapter covers many of the skills your teenager might need. It covers basic skills, such as eating well and doing online research, and more challenging skills, such as travelling without you and managing their own finances.

We appreciate that everyone is different and not everything in this chapter will be applicable to every family. So, just use this chapter to see what’s possible and then choose what’s right for you.

Preparing your teenager for independence

As your teenager moves into adulthood, you'll want to help them prepare for a more independent future at whatever level that's right for them.

Whether they continue to live at home or move away, they're going to need some practical life skills to help them cope.

See Chapter 12: Transition to Adulthood for more information about independent living options.

Deciding what independence means to your teenager

Independence will mean different things to different young adults.

For some, it could be moving away from home and managing their life with help from PAs. For some, it could be staying at home and taking on more responsibility for their own healthcare, education or employment. For others, it will be living in a residential care home.

Whatever the future brings, you can help your teenager develop the practical life skills they'll need to live independent adult lives.

Helping your teenager develop practical skills

There's no single right age to start talking to your teenager about living independently. But around 14 years old is a good guide.

To begin with, they might be reluctant to even talk about practicalities – especially if they're used to others making decisions for them. But, handled sensitively, becoming more independent should be an enjoyable experience for everyone.

Useful resources

www.preparingforadulthood.org.uk

This website has many valuable resources, including their Independent Living Guide and inspirational stories about how young disabled people became more independent.

www.scope.org.uk/advice-and-support/teaching-child-life-skills-living-independently

The Scope website teaches life skills for independent living to teenagers. It also has an online community where you can talk to disabled adults and their families.

Picturing what independence looks like

Ask your teenager how they picture their future:

- What interests them? What's important to them?
- Do they imagine themselves in work? Following a career? Or being a student?
- Do they like the idea of going on holidays with friends?
- How do they feel about needing more help from a PA as their disabilities increase?

See Chapter 12: Transition to Adulthood for more information about finding, employing and working with personal assistants.

Teenagers with learning difficulties

If your teenager also has learning difficulties, we still encourage you to spend time talking about their future.

Too often, well-meaning teachers, healthcare professionals, social workers and parents make decisions for people with learning difficulties. The common-sense answers about what they can and can't do aren't always right. Increasingly, people with learning disabilities are living independently and working in paid or voluntary employment.

So, ask your teenager about their dreams and what they want from life.

Take their answers seriously. Involve them as much as possible when making decisions about their future. And encourage them to develop their practical life skills so they can get the most out of life.

Ask your teenager about their dreams and what they want from life.

Managing frustration and anxiety

A large part of growing up is learning to manage our responses to things that anger or frustrate us.

If your teenager is struggling to learn a new task or do something on their own for the first time, it can lead to sudden outbursts, panic attacks or withdrawing into silence.

You can help your teenager manage anxiety by talking to them during calm periods. Reassure them it’s okay to feel frustrated. It’s how they manage that emotion that matters.

Ask them how they feel when they get anxious. Get them to talk about both mental and physical responses:

- Do they lash out or feel like lashing out?
- Do they feel sick?
- Does their head hurt?
- Does their heart race?

Getting to know these signs can make them less frightening when they happen.

Together, make a list of the things that make your teenager feel better. Maybe they have a favourite film they like to watch or an album they like to listen to. Perhaps there’s a friend they could invite over.

If your teenager experiences severe anxiety, you might also want to consider activities such as yoga, mindfulness and meditation.

Young Minds Website

www.youngminds.org.uk

This website has many valuable resources for parents and young people, including a detailed section on helping your teenager cope with anxiety.

bit.ly/young-minds-anxiety

Introduce new skills one at a time

You can do a lot to help your teenager do things for themselves. They might just have to do things a bit differently.

Sometimes doing things differently will mean having to adapt your home or buy specialist equipment, such as wheelchairs. Other adaptations can be more low-tech, such as moving things onto lower shelves.

Move at their pace. Start with a couple of easier things, like deciding what clothes they want to wear, and helping to set the table if they are physically able. Then, as their confidence grows, introduce more complex tasks like helping to prepare a meal.

Change routines slowly. Work on one thing at a time. Show them how to do it the first time and make it as much fun as possible. Learning new skills can be a sociable experience. Perhaps you can use the opportunity to chat, play music or involve other members of the family.

Let them find their own way of doing things. It might not be how you do it. But if it gets the job done, and they feel good about it, it will encourage them to do more.

Giving realistic feedback will help them learn and adapt their ways of doing things as their abilities change over time.

Learning from experience

When we're learning a new skill, most of us try, fail and try again. Teenagers with DMD need to feel comfortable with this process so they don't give up at the first failure.

It's frustrating when things don't go well the first few times we do them. But trying and failing is an important part of development. With 'useful failure' we learn what worked well and what we need to do next time to get a better result.

Remind your teenager of their previous successes. Be positive about things they've already learnt to do, such as playing a new computer game. Remind them they found this difficult to begin with but they did learn how to do it eventually.

Perhaps you can share some of your own experiences.

Tell them about the first time you drove a car, cooked a meal or put a load of washing on. Maybe you never got out of second gear, added salt instead of sugar, or washed a red sock with white shirts.

By demonstrating that everyone makes mistakes, you'll be reassuring them it's okay to get things wrong.

The benefits of doing household chores

Helping out with chores around the house has several benefits. It's good practice for your teenager and it helps make them aware of other people's needs.

Considering and helping others is a fundamental part of being an adult. But children and teenagers who need care have fewer opportunities to learn these useful skills.

If there are siblings in the house, share the chores as equally as you can. Your teenager might surprise you with how much they can do.

Making responsibility fun

Create a list of tasks. Aim for a mix of household chores and responsibilities, as well as more fun stuff. Some ideas include:

- Maintaining an indoor or outdoor herb garden
- Baking cookies
- Finding recipes online
- Making smoothies
- Writing shopping lists and choosing food at the supermarket
- Helping prepare vegetables for meals and washing up afterwards
- Setting a wake-up alarm and taking responsibility for getting ready for school
- Taking responsibility for personal hygiene and medication
- Taking responsibility for reminding carers to charge phones and wheelchairs
- Helping younger siblings do their homework
- Reading bedtime stories to younger siblings
- Walking the dog
- Cleaning out pets' beds and food dishes
- Volunteering for special needs groups

Be positive about things they've already learnt to do.

Housework aids and adaptations

It might be easier for your teenager to help out if you have some special cleaning aids.

Brushes with long handles, for example, are ideal for getting into hard to reach places. And cordless and lightweight vacuum cleaners are easier to manoeuvre.

You can see a range of helpful products on the www.abilitysuperstore.com and www.uksmobility.co.uk websites.

See Chapter 7: Home for more information about home adaptations and assistive technology.

The benefits of learning to cook

A good diet has a huge impact on your teenager's health. So, getting them involved in food and cooking at an early age will have big benefits for their future.

Learning to manage their diet is particularly important if they move away and their carer or PA also has limited cooking skills.

Setting a good example is the best way to encourage good behaviour.

A healthy diet is achieveable with planning and practice.

Remind everyone in the family that takeaways, pizzas and burgers are fine for occasional treats. But a balanced, healthy diet will make them feel better in the long run – and is surprisingly easy to achieve with planning and practice.

Involve your teenager in all aspects of food and nutrition as early as you can.

- Plan menus together
- Write shopping lists
- Go to the supermarket together
- Get them to choose the freshest looking products
- Let them help prepare vegetables and experiment with different foods and flavours

See Chapter 3: Health for more information about diet and nutrition.

Cooking aids and adaptations

You might need to make some adaptations to your kitchen and eating area to make it easier for your teenager to reach shelves and worktops.

Special non-slip chopping boards and clamps hold food in place during preparation. Food processors can be safer than knives. And 'one hand' storage containers make it easier to open and close by just pressing down on the lid.

There's a wide range of cooking and food preparation aids on these websites: www.abilitysuperstore.com/collections/kitchen-dining-aids and www.uksmobility.co.uk/kitchen-dining/food-preparation

Cooking and helping around the house will help your teenager to see they can help other people too.

See Chapter 7: Home for more information about home adaptations and Chapter 8: Financial Support for information about financial aid for adaptations.

See also our *Guide to Financial Support and Work for DMD Families* for more detailed advice about financial support. It's on our website at **www.duchenneuk.org/supporting-your-teenager-with-duchenne**

Making a life skills handbook together

A daily tasks handbook with step-by-step instructions might help your teenager remember and manage practical skills better. This can be particularly useful for teenagers with learning difficulties.

If your teenager has (or is likely to have) a carer or PA, the book could also include a section for them. It could list your teenager's specific needs, likes and preferences.

Making the book together will help make your teenager feel more involved. It could also motivate them to do more on their own.

Let them decide how they'd like to make it.

It could be a scrap book or folder with lists and pictures they've drawn or collected. Or they might prefer a whiteboard or planner on their bedroom wall. Some teenagers also like making 'how to' videos, which they could then share online.

The handbook could include step-by-step instructions on:

- How to make a recipe book of favourite meals
- How to use household equipment
- How to use the remote controls for the television and music players
- How to check bank balances and pay bills with online banking
- How to set up passwords for online banking
- How to plan a bus or train journey or book a taxi
- How to get to a friend's house, school or college

Leonard Cheshire 'Can Do'

You can find encouraging practical advice on how to help your teenager develop their skills and confidence on www.leonardcheshire.org

Leonard Cheshire has been supporting disabled people for more than 70 years.

Its 'Can Do' skills development programme might be particularly helpful for your teenager. All the projects focus on building confidence through fun and engaging activities designed around participants' interests.

www.leonardcheshire.org/get-support/learning/can-do

Learning from role models

Young people don't always listen to their parents' advice. They can see it as interfering or nagging. But if a friend or someone they admire says the same thing, they often see it more positively.

It's sometimes hard to accept that the lovely child who welcomed your advice and support for so long is now a 'stroppy teenager'. Reassure yourself it's just a phase and encourage them to mix with people who can be good role models.

Making friends with disabled and non-disabled teenagers with similar interests can help your teenager and you deal with new challenges. They might open up more and share problems.

It's also really good for teenagers with DMD to understand that non-disabled young people also have challenges, anxieties and difficulties.

Seeing how others have had to work hard to excel at something can give your teenager confidence to have a go themselves.

Where to find role models

Your teenager might already have good role models from school, clubs or clinics. But you can encourage them to explore other possibilities.

Pathfinders Neuromuscular Alliance is a UK charity run by and for teenagers and adults with neuromuscular conditions.

As well as finding advice and support on the website, you can read inspiring stories from other young adults.

The charity also runs live and online events where your teenager can meet other disabled young adults and their friends and families.

www.pathfindersalliance.org.uk/upcoming-events

Other organisations where your teenager might find suitable friends and role models include WhizzKidz. www.whizz-kidz.org.uk

Read inspiring stories from young adults on the Pathfinders website.

Connecting with role models through social media

Social media has made it so easy for teenagers to find others with similar interests, share content and have private or open discussions.

While newer platforms like TikTok are growing in popularity with teenagers and young adults, YouTube and Facebook are still the most popular.

Duchenne UK has several social media channels you and your teenager might want to follow. These include YouTube, Instagram and Facebook.

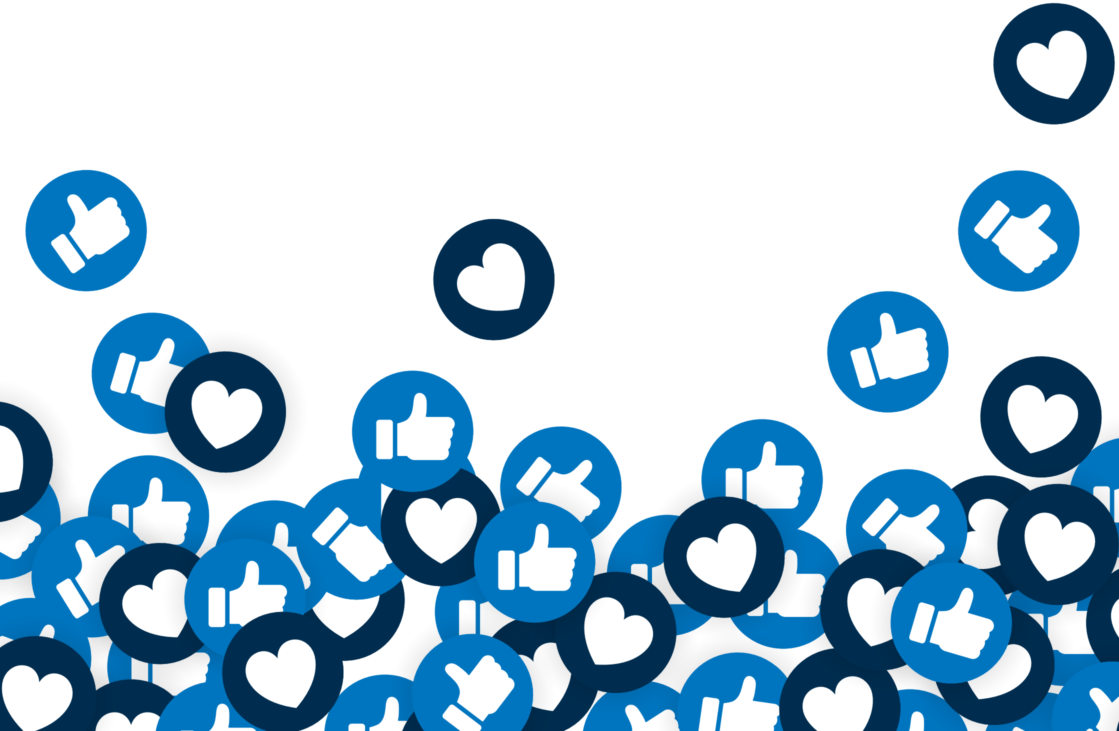
www.facebook.com/duchenneuk

www.instagram.com/duchenneuk

www.youtube.com/c/DuchenneUK

However, lots of parents worry about who their teenagers might meet online so it's wise to put some rules in place.

See Chapter 2: Your Teenager and Family for more information about social media and staying safe online.



Developing social skills

Helping your teenager develop the ‘hard’ practical skills of life is a crucial part of growing up. But ‘soft’ skills, such as speaking, listening, making friends and getting on with people, are equally important.

One of the best gifts you can give your teenager is confidence. Making them feel good about themselves and their decisions will be as valuable in life as showing them how to cook.

Remind your teenager that they’re not defined by their disability. They have a personality, talents, interests and ideas which are totally separate from DMD.

It’s tempting to want to protect them and shield them away from people who might hurt their feelings. But if they rely on you too much, they won’t learn to manage.

Speaking up for themselves

Your teenager will have spent much of their life with adult professionals. They will have seen doctors, nurses, teachers, social workers and carers talking to you about their condition and best interests. So, they may have learnt to become quiet or passive when spoken to by any adult.

> Look at your teenager if a health professional talks only to you.

You can encourage them to be more outgoing by involving them in conversations about them. If a health professional appears to be talking only to you, look at your teenager and ask what they think.

Use open questions such as ‘how do you feel about that?’ and ‘what would you like to happen?’. Open questions are questions that can’t be answered with a ‘yes’ or ‘no’.

Encourage them not to be afraid and to speak up if they’re unsure. Reassure them it’s okay to say they don’t understand and to ask questions. Show them that saying they’re anxious, uncomfortable or not sure is a good thing.

Difficulties with social communication

Many young people with DMD experience difficulties with social communication. They may also have learning difficulties, including being on the autistic spectrum.

If your teenager has learning difficulties and struggles to find the right word quickly, encourage them to take their time. And ask professionals to be patient with them.

By giving your teenager good social skills, they’re more likely to get on well with people – and have the confidence to speak up for themselves if they’re being criticised or ignored.

You can find some useful advice on communication skills on the Scope website.

See Chapter 6: Friendships, Relationships and Sex for more information about communication skills.

Researching things online

Being able to find things out for ourselves gives us a real sense of independence and empowerment. And, thanks to the internet, we can find information and advice on just about anything.

Most young people are extremely comfortable with computers, so encourage your teenager to research and understand information for themselves. This is especially important when they are making decisions about their own welfare and education.

Using keywords

When trying to find information online, the starting point is usually to type keywords and keyword phrases such as ‘best schools in my area’ or ‘cinemas with wheelchair access’ into a search engine.

But don’t just rely on Google. Help your teenager identify organisations and people they can contact for help. Work with them to figure out how to ask.

Making sure the source is reliable

Tell them that they can’t trust everything they read online – especially on social media. Encourage them to check sources and be wary of fake news.

There’s an excellent video by BBC disinformation specialist, Shayan Sardarizadeh, who gives some easy, practical tips. bit.ly/fake-news-bbc

Be wary of fake news – check online sources.

Help them make a list of useful websites they can use when they’re trying to solve problems such as:

- Trying to get somewhere new
- Looking at study options
- Finding out what treatments or equipment are available
- Researching days out or holidays

As well as Google, the following websites are good starting points.

www.youthaccess.org.uk

bit.ly/govuk-disability-work-help

See Chapter 7: Home for more information about adaptive technologies.

Travelling independently

Independent travel is an important part of your teenager's transition to adulthood. It's also important for you to have space in your life.

There might come a time when you're not able to run them everywhere yourself or travel with them on public transport. But travelling independently doesn't necessarily mean travelling alone. It means taking responsibility for travelling, usually with a friend or PA.

Travelling with a friend or PA

Using public transport alone as a disabled person can be a difficult experience. It can be both practically challenging and emotionally draining because you need so much assistance. So, having someone with your teenager as they venture out will make things a lot easier.

Perhaps, in time, they might feel confident and resilient enough to go out alone. But tell your teenager it's okay not to travel entirely on their own. Even adults with DMD prefer to travel with friends, family members or PAs.

Building their confidence step-by-step

Moving from taking them everywhere yourself to them travelling independently is best done gradually.

Involve your teenager in every part of the process. Begin by planning a journey together. Or ask a friend to get involved and let them work it out then run it past you.

Ask them to research timetables, routes, costs and accessibility. This will also help them develop their research skills which are vital for adult life. (See later section on useful transport information websites.)

Tell them it's okay to feel anxious. Ask them what concerns they have about travelling without you and reassure them that almost anything can be resolved with careful planning.

Tell them it's okay to feel anxious.

Independent travel options

Your teenager's first venture into independent travel is likely to be on public transport.

Choosing the right public transport will largely depend on where you live and accessibility. Buses tend to be more widely available than trains, especially in rural areas. Taxis can provide door-to-door access, but they're expensive.

You might be able to apply for travel subsidies from your local authority.

Of course, you can't always get where you want to go with public transport. Having a Motability car might be an option. See later section on driving and Motability.

Planning a journey

Travelling independently has become so much easier in recent years. Just about everything your teenager needs to know about planning a journey can be found online or by phoning a helpline.

When you and your teenager are planning a journey, ask these questions:

- Where is the nearest bus stop or train station to my destination?
- Is there wheelchair or level access?
- Is there assistance at the stations?
- What's the best way to get from the bus stop or train station to my destination?

Have a back-up plan in case things go wrong.

Back-up plans

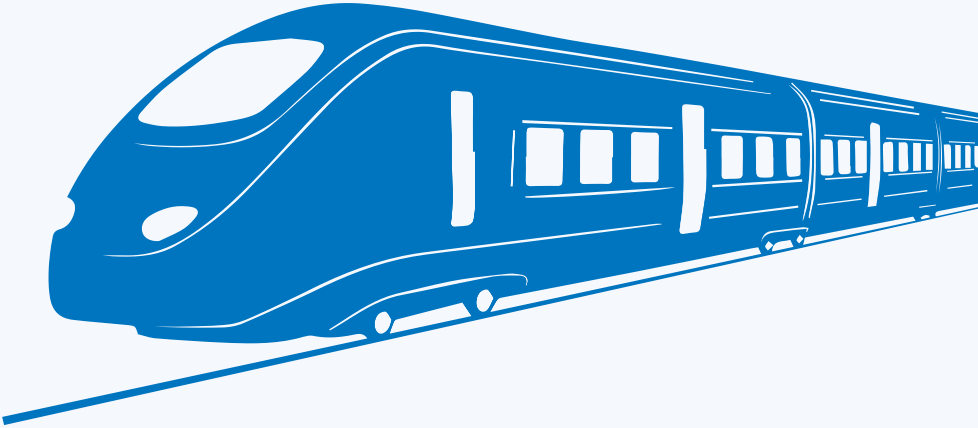
Of course, even the best plans can come unstuck. Trains can be cancelled. Buses can be delayed. Timetables can be changed. So, having a back-up plan if things go wrong is a good idea.

If your teenager has a smartphone, they should be able to check for delays and make alternative plans. Most train operators have mobile phone apps that show live timetables and updates.

Remind them to fully charge their phones before they leave home.

Useful transport planning websites

There is no shortage of transport information available online. And most websites have helpful pages about travelling as a disabled person.



Network Rail

The Network Rail site provides information about its stations, including their facilities and accessibility. But it isn't always up-to-date and might not include recent changes.

If in doubt, contact the station directly and ask what facilities are available.

Google Maps

Google Maps has a little known feature that provides wheelchair-accessible public transport routes. To access this feature:

- Open Google Maps and in the 'Search here' box enter your destination
- Select 'Directions'
- Select 'Public transport' icon (box with image of a train)
- From 'All modes' dropdown box, select the modes of public transport you want to use
- In 'Best route' dropdown box, select 'Wheelchair accessible'

This will provide you with your best wheelchair-accessible route. You can also find additional accessibility information on each leg of your journey, including what assistance should be available to you from transport providers. You can see this information by clicking on the box that reads '+Accessibility'.

Google updates the system regularly, based on users feedback. So if you find any problems with the directions or advice provided, do complete the feedback request to help others in future.

Moovit and Citymapper

The Moovit app is a remarkable tool. It helps people get round towns and cities using public transport. It gives directions to main streets and popular attractions, maps of local transport lines, and train and bus timetables.

Citymapper is similar to Moovit. But it also offers the Citymapper Pass, a card that can be used instead of tickets on all public transport.

Useful transport websites include:

www.google.co.uk/maps

www.networkrail.co.uk/communities/passengers/our-stations

www.thetrainline.com

www.traveline.info

www.tfl.gov.uk

www.moovitapp.com

www.nationalrail.co.uk

www.citymapper.com

Travelling by rail

In the UK, all train companies offer Passenger Assist, a national system for passengers who need a helping hand.

The train companies can arrange for their staff to:

- Meet your teenager at the station entrance
- Help them get around the station
- Provide a ramp and help them get on and off the train
- Help them with or carry their luggage

Book ahead

Your teenager should book Passenger Assist as far in advance of their journey as possible. They can call for free on **0800 0223720** or text **60083**.

The rules for how much notice your teenager needs to provide for assistance have recently changed and can be found on your local train operating company's website. Some train operators also offer turn-up-and-go provision which doesn't need to be booked in advance.

The train company which books their tickets will organise assistance for their entire journey, even if part of the trip is with a different operator.

Sometimes booked assistance doesn't show up. It's important your teenager knows how to alert the driver if they are stuck on the train. This can usually be done using an emergency button next to the wheelchair space on the train.

Wheelchairs and powered scooters

Most trains can accommodate wheelchairs if the size is within government regulations (700mm by 1200mm). But there are a few older trains with a maximum width of 550mm. There are also limits on the total weight of a person and their chair.

Because powered scooters come in a variety of types, sizes and weights, not every train operator can assure they'll be safe.

The best thing to do with both chairs and scooters is to get your teenager to check before they travel.

www.nationalrail.co.uk/stations_destinations/disabled_passengers.aspx

Travelling by bus and coach

By law, bus and coach drivers must give reasonable assistance to disabled people.

For example, drivers should help your teenager get on and off the bus or coach. But this doesn't mean physically lifting them or their mobility equipment. So, where possible, your teenager should ask for help when they book a ticket.

Where possible, ask for help when you book a ticket.

Wheelchair accessible buses and ramps

Most big towns and cities now have wheelchair accessible buses with automatic powered ramps operated by the driver. In other areas, the ramps might have to be fitted manually by the driver.

Wheelchair accessible buses usually have at least one wheelchair space with a padded backrest to stop the chair tipping backwards. But this space might also be used by young children in buggies.

The Equality Act gives wheelchair users priority over buggies. Again, it's wise to check with the bus company before venturing out.

www.disabledtraveladvice.co.uk/bus-travel-wheelchair-users.html

Travelling by taxi or minicab

In larger towns and cities, licensed taxis have to be wheelchair accessible. But this doesn't mean that all wheelchairs can fit into all taxis.

Some larger taxis with tail lifts can fit all wheelchairs. But many others can't accommodate larger wheelchairs. They either don't fit or they're too heavy for the ramps.

Not all taxi companies are aware of these issues so try out a few companies and vehicles first. When you find the right one, book them well in advance.

To find out if there are accessible taxis near you, contact the taxi licensing office at your local council.

www.gov.uk/transport-disabled/taxis-and-minicabs

Getting help with travel costs

bit.ly/citizens-advice-travel-costs

There are several ways your teenager can get financial help with travel and transport costs. These include:

- Bus passes
- Rail cards
- Blue Badges
- Cars, scooters or powered wheelchairs from Motability

Encourage your teenager to do their own research. That's good independent living practice. Your local authority or local council is usually their best starting point.

Disabled Persons Railcard

If your teenager receives Personal Independence Payments (PIP) or a Disability Living Allowance (DLA), they could be eligible for a Disabled Persons Railcard. This would give them and a travel companion a third off standard rail fares.

If your teenager doesn't qualify for a Disabled Persons Railcard, they could still apply for a Young Persons Railcard (16-25) or a Two Together Railcard. Both of these offer similar savings.

Find out more about railcards and eligibility.

www.disabledpersons-railcard.co.uk

Disabled Person's Bus Pass

Your teenager might be eligible for a Disabled person's bus pass.

Qualifying criteria varies depending on where you live, so you need to apply directly to your local authority.

www.gov.uk/apply-for-disabled-bus-pass

Healthcare Travel Costs Scheme (HTCS)

If your teenager is 16 or older, they might be able to claim a refund on travel costs to a hospital, doctor, dentist or other primary care health professional.

To qualify, they have to meet three criteria, including being referred to a specialist for further treatment or tests.

Your teenager might be able to get help with travel costs to clinical appointments.

bit.ly/NHS-healthcare-travel-costs

Cars and driving

Being able to drive is probably the most independent way to travel. But it won’t be suitable for everyone. It’s more likely that your teenager will have a friend, family member or PA drive for them.

However, having DMD doesn’t necessarily prevent someone from driving. Some adults with DMD do drive their own cars.

Sometimes controls have to be adapted or accessories fitted. But it may be possible.

You’ll find excellent advice on all aspects of driving with a disability on the Department of Transport website www.drivingmobility.org.uk/information/first-time-drivers

Applying for a licence

Teenagers can apply for a provisional licence at age 17. But if your teenager receives a mobility allowance, they can apply for a licence at age 16.

They need to apply for their licence online at www.gov.uk/apply-first-provisional-driving-licence. It costs £34 and they’ll need to provide an identification document, such as a passport.

Because of their DMD, your teenager will also need to fill in a medical questionnaire to support their provisional licence application. This can be downloaded from www.gov.uk/health-conditions-and-driving

Teenagers with DMD need to fill in a medical questionnaire when applying for a licence.

Learning to drive

You can find a list of specialist driving instructors in your area on the Disability Driving Instructors website.

Not all driving instructors are able to teach disabled drivers. They might not have the right type of vehicle or the right type of training.

Specialist driving instructors are more likely to be aware of your teenager’s needs and have access to cars with special controls.

Learning to drive can be expensive (as much as £2,000). So, you may want to apply for a grant.

Further advice on driving lessons and funding:

www.disabilitydrivinginstructors.com/driving-advice/first-time-drivers/help-with-funding-driving-lessons

www.disability-grants.org/funding-for-driving-lessons.html

www.disabledmotoring.org

Adapted vehicles and Blue Badges

Whether your teenager learns to drive, travels in the family car, or is driven in their own car, you might need to modify the vehicle.

Most cars can be adapted for drivers or passengers with disabilities. Typical accessories include:

- Hand controls to operate the accelerator and brake
- Steering wheel knobs that help turn the wheel more easily
- Ramps, hoists and tail lifts for easier access
- Rotating seats
- Adapted mirrors
- Safety belts and harnesses

You or your teenager can also apply for a Blue Badge so you can park in the most convenient bays at shops and leisure facilities.

As the badge is linked to the holder and not the vehicle, your teenager can use it with any car and any driver, so long as they're in the car at the time. This includes taxis and hire cars.

Contact your local council or find out more at:

www.gov.uk/blue-badge-scheme-information-council

Motability

If your teenager receives a higher rate mobility allowance, they might qualify for the Motability Scheme.

Motability is a national charity that helps disabled people get mobile by exchanging their mobility allowance for a lease on a new car, scooter, wheelchair-accessible vehicle or powered wheelchair.

Your teenager may be able to learn to drive the car themselves. Or they can choose up to three people who can drive on their behalf. The car can be adapted for accessibility and wheelchair storage.

You can choose up to three people to drive a Motability car.

See Chapter 8: Financial Support for information about financial support for transport costs, including Motability.

See also our *Guide to Financial Support and Work for DMD Families* for more detailed advice about financial support. It's on our website at

www.duchenneuk.org/supporting-your-teenager-with-duchenne

Insurance, breakdowns and emergencies

If your teenager has a Motability vehicle, insurance and breakdown cover is included in the lease. Privately-owned cars will need their own insurance and breakdown cover.

It can be difficult to get insurance as a disabled driver. However, it's illegal for a car insurance company to charge extra because of a disability, but they can charge extra for a vehicle based on its value. And the value may be higher because of its adaptations.

Also, if you need an insurance policy that allows multiple people (including PAs) to drive the vehicle, this will be more expensive than having just one driver.

Your teenager is legally obliged to disclose information about their disabilities and any modifications to the vehicle. Some providers will ask many extra questions.

Your teenager might get better results contacting companies, such as Fish, that specialise in insuring disabled people. These insurance companies can often insure mobility equipment in the vehicle and get your teenager an adapted vehicle to drive if theirs is off the road.

www.fishinsurance.co.uk/products/car-insurance

As well as needing motor insurance, your teenager should also think about breakdown insurance so they can get help in an accident or emergency.

You can find out more about motor and breakdown insurance at

www.disabledmotoring.org/insurance/motor-insurance

Getting along with other people

Your teenager may have experienced other people's reactions to their DMD throughout their childhood. But independent travel may be the first time they have to manage it on their own.

Reassure your teenager that most people, especially bus drivers and station staff, are really friendly and willing to help.

As mentioned earlier in this chapter, you can do some practice runs together before they go out without you.

You could even ask people they pass along the way to look out for them (for example, people in a corner shop or café).

Seeing the good intentions

It might help to explain to your teenager that most people have good intentions.

An offer of help to manoeuvre the wheelchair or pick up a dropped bag is usually a positive thing – even if your teenager doesn't need help.

Sometimes well-intentioned offers of help can be difficult to deal with. Your teenager might feel uncomfortable saying they're fine. They may accept help that actually makes the situation more difficult for them.

So, tell them it's also okay to thank someone and then decline their offer of help. They can be polite but firm with people who are well-meaning.

Asking for and dealing with help

Many young people with DMD experience difficulties with social communication. As a result, other people may feel they're being rude or aloof if they forget to say please or thank you.

There is a range of strategies that could help your teenager develop their communication skills.

See Chapter 6: Friendships, Relationships and Sex for more information about communication skills.

Explain to your teenager that asking for help or refusing an offer of help isn't rude. One way of dealing with this is to practise some useful phrases in advance:

- I'm fine thank you. But thanks for offering.
- It's actually easier for me to move at my own pace. But thank you for offering.
- Excuse me, can you help me with my wheelchair?
- Excuse me, I've dropped my phone. Can you pick it up for me?
- Excuse me, I need some help. I don't know where to find the…

ASD Social Cues

ASD Social Cues is one of the many strategies used to help teenagers with DMD manage communication, especially if they have Autism Spectrum Disorder (ASD). bit.ly/asd-social-cues

Dealing with antisocial behaviour

Occasionally, your teenager might experience antisocial behaviour. This is usually because of other people's ignorance or their own emotional problems.

If this is likely to be an issue, you can discuss possible unpleasant situations before they happen and come up with a list of ways to deal with them. Being prepared makes it easier to respond.

You might want to roleplay different scenarios with them. Or you could talk through difficult experiences so they can learn from them and respond differently next time.

You could also come up with some stock phrases together that your teenager feels comfortable saying.

You can talk through different scenarios and practise responses.

Humour can also be a good deflection. The website www.wish.com has some amusing t-shirts with slogans such as "I'm in a wheelchair as I have toothache". Some teenagers with DMD enjoy wearing these.

Recognising and reporting discrimination

If your teenager is harassed or discriminated against because of their DMD, this is a crime.

They or you might want to make a formal complaint to the police. You can find information on www.citizensadvice.org.uk/law-and-courts/discrimination/hate-crime/disability-hate-crime

Managing money

One of the most important skills of independent living is managing money.

Children and teenagers who've been given some financial responsibility are usually better at managing personal, household and family budgets in adulthood. This could be particularly useful when it comes to managing care packages and personal assistants.

The age ranges below are only a guide. Some children and teenagers will take an interest in money earlier or later. Encourage them to start as early as possible.

See Chapter 8: Financial Support for information about financial support from the Government, local authorities and charities.

See also our *Guide to Financial Support and Work for DMD Families* for more detailed advice about financial support. It's on our website at **www.duchenneuk.org/supporting-your-teenager-with-duchenne**

Pocket money for 10 to 14 year olds

Many parents find that giving even a small amount of pocket money from an early age is a good way for young people to practise managing money.

The amount you give them isn't as important as its regularity. According to the Money Advice Service, teenagers who get a regular fixed amount of money keep better track of their income and spending than those who get money 'as and when' they want it.

A set amount every week will teach them how to budget. They might have to choose one thing over another or save up to buy something more expensive. So, they learn to plan their spending.

You can help your teenager to manage their money by:

- Getting them to write down what money they have and how they spend it
- Encouraging them to save by offering to contribute towards something they want if they save an agreed amount first
- Giving them extra pocket money in return for doing chores

Bank accounts and prepaid cards for 15 to 18 year olds

As your teenager gets older, they might want their own bank account so they can manage their money better, shop online or withdraw cash from ATMs.

Most banks offer current accounts to young people age 11 to 18. They're similar to adult accounts. You can pay money into them and take it out. But they don't have overdraft facilities so your teenager can't spend more than is in the account.

Most banks offer current accounts to young people.

If your teenager has a mobile phone, they might want to download the bank's app to their phone so they can manage their money on the go.

You'll need to help them fill in the application form. Some banks allow you to do this online. You'll still have to go into a branch to provide identification and complete and sign the form.

You can read more about opening a young person's bank account at bit.ly/childrens-bank-accounts

Prepaid cards

If you or your teenager are uncomfortable with having a bank account, you could consider prepaid cards instead.

Prepaid cards are like debit cards, but they're not linked to a bank account. You use them to pay for things in person or online. Like pay-as-you-go mobile phones, you put money into them before you use them and top them up when the money runs out.

Prepaid cards are a good way to budget. If they're lost or stolen, you only lose the amount on that card.

However, pre-paid cards usually come with fees or charges or both. So, you need to look at the costs carefully.

You can read more about prepaid cards on the Money Advice Service website. bit.ly/money-advice-prepaid

Managing personal finances for 18 to 21 year olds

By this age, young people want to manage their own finances, especially if they're working, attending college or living away from home.

The amount of money they have to manage will depend on the financial support they receive from the Government and local authority, and their earnings from work.

Your teenager will be eligible for:

- Personal Independence Payments (PIP) and other financial support from the Government
- Direct payments and personal budgets from the local authority

See Chapter 8: Financial Support for information about financial support from the Government, local authorities and charities.

See also our *Guide to Financial Support and Work for DMD Families* for more detailed advice about financial support. It's on our website at **www.duchenneuk.org/resourcesforparents**

Managing direct payments and personal budgets

Your teenager has a choice over how money from their personal budget is managed.

Following a needs assessment, the council will provide a care and support plan, including a personal budget. This is the amount of money the council thinks their care will cost.

Your teenager can choose to let the council manage all, part or none of their personal budget. If they decide to manage all or part of it themselves, they'll receive money as a direct payment.

How direct payments are used

If your teenager chooses direct payments, the payments can only be used for the things agreed in their care and support plan. These include hiring a personal assistant or carer.

Local authority managed care tends to use a small range of care providers. With direct payments, your teenager has control over who provides their care.

However, they'll then have employer responsibilities. So, they'll have to document their accounts. They will need to set up a separate bank account for the direct payment.

You can read more about managing direct payments on the Scope website.

www.scope.org.uk/advice-and-support/managing-direct-payments

See Chapter 12: Transition to Adulthood for information about employing personal assistants.

Managing money for a teenager with learning disabilities

Some teenagers with DMD need a parent or the local authority to manage their money for them. In such cases, you will need a separate bank account for them – or possibly a joint account where you are the other signatory.

Choose a bank that provides support for people with learning difficulties so they can access their money if they need it. This might include support such as:

- Providing information and letters in easy-to-read formats
- Allowing different forms of ID if a person doesn't receive bills in their name
- Allowing you to bank in a branch rather than only online or by telephone banking
- Using a chip and signature card if a person has difficulty recalling their PIN number

Depending on your teenager's abilities, you might also need to consider applying for appointeeship, deputyship or power of attorney (POA). This will give you the legal power to make decisions about their financial affairs.

> See Chapter 8: Financial Support or the *Guide to Financial Support and Work for DMD Families* for more information about appointeeships, deputyships and power of attorney.
>
> You can download the Guide from **www.duchenneuk.org/supporting-your-teenager-with-duchenne**

Making budgets go further

Your teenager may be able to find better deals than their current suppliers by doing some online research. They could save on insurance, mobile phones, gas and electricity.

The following websites offer free and independent advice that could help a young adult with a small income save hundreds of pounds each year.

Gas and electricity

energycompare.citizensadvice.org.uk

Mobile phones and tariffs

bit.ly/which-mobile-tariffs

General money saving deals

www.moneysavingexpert.com

Supermarket loyalty cards

Look at your local supermarket's website

Budget planning

Whatever stage your teenager is at, it’s a good idea to teach them how to budget.

The word ‘budgeting’ can sound off-putting. But it’s basically just recording what money comes in and what money goes out.

It could be as simple as a notebook, where your teenager writes ‘incoming’ down one side and ‘outgoing’ down the other. Or they could use a spreadsheet, such as Excel, on a computer. Or a budgeting app on their smartphone.

Depending on your teenager’s circumstances, the outgoing column could include:

- Clothes
- Music
- Gadgets or equipment
- Snacks or meals while out with friends
- Cinema tickets
- Sport or events
- Phone
- Rent
- Heating
- Council tax
- PA fees

The income column could include:

- Pocket money
- Gifts
- Allowances
- Wages
- Benefits
- Interest on savings

Whatever tool they use, the aim of budgeting is to see how much money they have and how much they need. Good budgeting is the best way to manage money and avoid getting into debt.

The Money Advice Service offers a free online budget planner.

www.moneyadviceservice.org.uk/en/tools/budget-planner

General information on helping your teenager manage their money

You can find lots of good advice on helping teenagers manage money at bit.ly/managing-money-teens

Chapter 11

Chapter 11 – Work

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In a nutshell

1 Encourage your teenager to prepare for the future

Adults with DMD often live into their 30s, 40s and beyond. So, your teenager needs to prepare for an independent adult life.

Talk to them about what they want to do as an adult. Encourage their interests and hobbies. If something seems too difficult, try to focus on solutions rather than problems. Show your teenager what is possible for adults with DMD.

2 Help your teenager to set their own goals

Currently, adults with DMD are employed in a range of different jobs, managing their work around their health and well-being. Others are dependable and productive volunteers, bringing significant value to charities.

For many, doing something meaningful gives them purpose and self-esteem. Others find meaning in family, friends and hobbies. It is up to your teenager to decide what type of life they want to have.

Don’t necessarily expect less for your teenager because they have DMD.

You can usually find a way to make things work and help your teenager to have the life they want.

3 Develop your teenager’s skills from an early age

Employability skills will help your teenager to thrive as an adult with DMD in their work and personal life. Support them to develop these in their daily life.

Valuable skills include talking about themselves, understanding others, self-evaluation, responding to feedback and working in a team.

4 Make the most of their education

Schools and colleges can provide excellent support for you and your teenager, including careers advice. Make the most of these opportunities while you have them.

Your teenager will find it easier to get work or volunteering opportunities if they have different experiences to draw on. Seize the opportunity for them to join school trips, competitions, activity holidays, sporting events, work experience placements and internships.

5 Know the rights of disabled people in work

Disabled people face additional barriers finding work. Not all workplaces are accessible and not all employers are good at supporting disabled people. Prepare yourself and your teenager for this.

By law, employers must support your teenager and not discriminate against them. They must make reasonable adjustments to workplaces, procedures and job roles to allow your teenager to work.

How to use this chapter

You'll find detailed advice on dealing with different stages of preparing for work and volunteering in this chapter.

We recommend you consider using the sections as you need them:

- **During secondary school, including the lower grades, read:**
    - Preparing your teenager for work and adult life

It talks about developing skills and building experience which will be useful in work or voluntary roles and can be started at an early age.

- **In the later years of secondary school or college, read**:
    - Helping your teenager to identify goals
    - Exploring work and volunteering options for your teenager

They talk about making plans and show your teenager the different options open to them.

- **When your teenager is actively looking for work, read:**
    - Getting started in employment and work experience
    - Applying for volunteer roles, employment and experience
    - Making work and volunteering work for your teenager
    - Understanding the rights of disabled employees.

We have mostly used 'teenager' to refer to the person with DMD in this book. However, your teenager may be a young adult by the time they start volunteering or working.

Please bear this in mind while reading the chapter.

Preparing your teenager for work and adult life

Preparing for work and volunteering is an important part of every teenager's journey to adulthood. Young people with DMD are no different.

You can support your teenager by helping them to develop their skills and access opportunities to gain experience.

Employers are more likely to recruit people who have experience of team-working and problem-solving as well as soft skills such as speaking up for themselves, self-reflection, empathy and understanding.

Your teenager will find these skills incredibly helpful in other areas of their life too, including relationships with family, friends and colleagues. You can help your teenager to develop these skills throughout adolescence.

Teenagers develop soft skills through observing adults, receiving guidance and practising what they have learned. So, model the behaviour you want to teach. Explain what you're doing and why. And give them the opportunity to practise.

> You can help your teenager to develop their skills **and access opportunities to gain experience.**

Interacting with others

Working well with clients, colleagues or customers is essential in any job. These skills can be nurtured by helping your teenager learn how to communicate and understand other points of view.

Communication skills

People need to be able to speak about their skills, hobbies and interests in order to find work. This requires being able to speak to people they do not know very well.

It may be that communication is an area that your teenager really struggles with, as do many young people with DMD. You may need to help them to communicate with others effectively.

You can help your teenager to prepare for social situations. Work with them to identify topics of conversation they can talk about with their friends. Help them to write a script for both important and casual conversations or prepare some conversation starters. Encourage them to make a home scrap book to provide visual prompts of things they have been doing so they can talk about them.

Your teenager can further develop these skills by giving presentations at school, talking to professionals or participating in performing arts. The more they do this, the easier it will become.

Empathy and understanding

Employers look for applicants who are empathetic and can understand different points of view. Often, this means putting others' needs first.

Teenagers with DMD have many needs themselves, and they are used to being cared for by parents, family members, teaching assistants and healthcare professionals. Dealing with problems that other people don't have can make it more difficult to empathise with other people. So, it can sometimes be challenging for them to think of others and their needs.

Thinking about others

From an early age, you should talk to your son or daughter about other people they know and the problems they might be experiencing.

Encourage your teenager to think about the people and things they are grateful for, which other people might not have. Talk to them about how they can help others.

Expect them to listen to other people and ask questions, as well as talk about their own interests and needs.

This may be an area your teenager struggles with, especially if they have autism. You can help them by brainstorming topics they might talk about to people in different situations and roles. Also, ask your school for resources for teaching teenagers with autism about how to identify what other people are feeling.

Helping other people

Practically, volunteering in their community can help your teenager to understand the needs of others.

Closer to home, ask them to carry out household chores and help family members. Accessible chores might include preparing dinner, washing or drying up at a table, fixing home IT problems or tidying surfaces.

Your teenager will see that they have a lot to give when they help others.

> Encourage your teenager to think about the people and things **they are grateful for, which other people might not have.**

Responding constructively to feedback

Employers expect employees to assess and evaluate their own performance and respond constructively to feedback from others.

Self-awareness and self-reflection

Your teenager can develop their self-awareness through schoolwork, extracurricular hobbies and interests.

Graded assessments in their schoolwork or music tests can give your teenager feedback on their performance. You can help them to develop self-evaluation skills by talking to them about results they receive and the things they learned from these results.

In their hobbies, encourage your teenager to look at role models performing at the highest levels to help them evaluate their own performance. If the hobbies are more difficult for someone with DMD, look for role models with DMD or similar conditions. Talk to your teenager about the time and effort it takes to become successful.

Ask your teenager about the times they were pleased with their performance. Help them to think about what was going on around them at the time.

Encourage your teenager to consider what their perfect performance looks like. Then, ask them to score themselves on a scale from 1 to 10 and think about what is going well and what they are happy with. Then, ask them what they could do to improve by a single point on the scale.

> Ask your teenager about the times **they were pleased with their performance.**

Using a growth mindset to build your teenager's skills

Encouraging and challenging your teenager helps them to become resilient as an adult. So, don't give your teenager an easy ride to compensate for the challenges of DMD. Instead, use a growth mindset to develop their full potential.

A growth mindset is the belief that people can develop their abilities with time and practice. So, focus on the effort your teenager is making rather than what they achieve.

Success in any hobby or interest is a journey that takes time. Your teenager should be praised for effort, perseverance and progress (however small). This is important for all young people, especially those with learning difficulties who will need time and encouragement to find their niche.

Every mistake or less successful attempt should be seen as an opportunity to learn. Teach your teenager to value mistakes as well as successes.

> A growth mindset is the belief that people **can develop their abilities with time and practice.**

See Chapter 2: Your Teenager and Family and Chapter 5: Education for more information about growth mindsets.

Giving encouragement and feedback to your teenager

Praise is essential to your teenager. Without it, they are less likely to succeed.

Look for anything you can genuinely praise, such as a single mistake they have corrected or a new approach they have tried. Or even just making another attempt.

This doesn't mean you shouldn't give constructive feedback. Shielding your teenager from every criticism can leave them unprepared for work as an adult. Although difficult to hear, constructive feedback can be incredibly valuable in helping them to identify areas for improvement.

How to give constructive feedback

Teenagers will be most invested in a solution where they have thought of it themselves. So, ask them what they are hoping to achieve and how they think they can do this.

You may need to nudge them towards thinking about possible solutions, but try not to give advice unless they ask for it. Allowing your teenager to identify solutions helps to build their problem-solving skills.

Ask their permission before giving your own feedback about how they can improve. Do they want advice on how they could make something even better?

Reflect on any feedback before you give it. Ask if it is necessary. Will your feedback help them to improve? Is it something they are unaware of? Does it give them a way forward?

Make sure you consider the timing and context when giving feedback. Try not to give your teenager feedback in front of others.

Acknowledge their journey when giving feedback. Use the term "yet". In other words, "you're not there just yet", or "you haven't quite nailed that yet". Make sure your teenager understands that with time and hard work, they may succeed in the future.

> Teenagers will be most invested in a solution **where they have thought of it themselves.**

Help your teenager to identify unreasonable feedback

Sometimes, negative feedback can be unfair or based on unrealistic expectations (for example, comparing a beginner to a professional). Often, these unrealistic expectations may come from your teenager themselves.

You can help your teenager to reflect carefully on feedback they have on themselves or that they receive from others.

Make sure they balance negative and positive feedback and don't just focus on the negative. Ask them if they think the feedback could help them improve.

Dealing with change and solving problems

Adapting to change

Adapting to change is a critical part of living with the gradual deterioration of DMD. Teenagers will often need to find new ways to carry out day-to-day activities.

Adapting to change can be difficult for teenagers with DMD. Helping your teenager to have new experiences and to leave their comfort zone can help them become more adaptable. Remember to praise them when they've responded flexibly to a change.

Supporting your teenager to try new things

Making small changes to your teenager's routine can eventually help them feel more comfortable with bigger changes. For example, change the order of getting dressed or eating breakfast in the morning.

Changes need to be made carefully, particularly for teenagers with autism. Start with very small, easy changes. Reward them for coping before introducing a bigger or more difficult change.

Try to talk with your teenager about their worries when they're doing something new. Ask them what they expect from a new situation and what they might find stressful.

Ask your teenager what would make them feel more comfortable about doing something new. For example, they might want to try something in private first, or visit a venue before an event to reduce anxiety. Encourage them to think in advance about conversations they may have and what they can say or talk about.

Problem-solving skills

Your teenager can develop problem-solving and technical skills in video games with a puzzle element. Strategic board games, jigsaw puzzles and crafting hobbies, such as Lego or model building, can also help.

Computer-based activities involving coding or 3D printing can be exciting and accessible ways to develop these skills too.

Losing abilities because of DMD can be frustrating and exhausting. So, treating the loss of ability as a problem to be solved can sometimes help. You can focus on finding equipment and technology to help and learning new skills to do things differently.

> Helping your teenager to have new experiences and to leave **their comfort zone can help them become more adaptable.**

Helping your teenager to know when and how to ask for help

For a young person in work or volunteering, knowing when they can solve problems on their own and when to seek help is an important skill.

When your teenager has a problem, rather than giving them the answer, encourage them to find it for themselves. Work with them first to search for help on the internet, for example using Google or YouTube.

If they have a problem they cannot solve themselves, encourage your teenager to say what they need and ask for help from family members, teachers and healthcare professionals.

Online discussion forums, social media, your local authority and charities are all useful sources of support. Encourage your teenager to contact experts, organisations and charities themselves so they become more comfortable asking for help.

If your teenager is nervous or shy, you can build confidence gradually. Start by asking them to write down the problem and sit down together to email, message or telephone the people they're asking for help.

Asking for help from colleagues is often helpful when receiving feedback about job performance. Employers don't want employees who do a poor job instead of asking for help from their manager.

See Chapter 10: Life Skills for more information about teaching your teenager to ask for help.

Gaining suitable experience

Your teenager should try to gain CV-building experience while at school and college. This should include both work experience and extracurricular activities.

Experience of team-working

Your teenager can gain experience in team-working by participating in games, sport and team activities. These should be fun and give them an opportunity to compete with others at a similar level of ability.

Joining non-disabled peers during mainstream sport activities can help them to feel included. But this will become less enjoyable as their physical ability declines.

Disability sports organisations can help your teenager to take part in team sports with other disabled young people. Disability Sports, such as powerchair football and boccia, are popular with many young adults with DMD. They can be casual or highly competitive.

Computer games can be an excellent source of experience in team-working. Not all computer games are equally constructive, so make sure you understand what games your teenager plays. Where possible, encourage them to play co-operative games with people they know.

> Disability Sports, such as powerchair football and boccia, **are popular with many young adults with DMD. They can be casual or highly competitive.**

Adventure and outdoor challenges

Team activities such as orienteering and adventure challenges may be included as part of school trips.

These encourage teenagers to move outside their comfort zone and develop skills in problem-solving and team-working. Speak to your school about how they can make activities and trips more accessible.

Outdoor activity centres specifically for disabled youngsters can provide opportunities to participate safely. The Calvert Trust is one example (www.calvert-trust.org.uk).

Experience of following instructions and completing tasks

Following instructions and completing tasks is vital for succeeding at work. Your teenager can get useful experience by doing chores, participating in school projects and academic competitions, or volunteering for charity.

Supporting young people with autism and learning difficulties

Teenagers with additional diagnoses of learning difficulties and autism need extra support to be independent.

Skills such as speaking up for themselves, being part of a team, identifying goals, solving problems and asking for help are still important.

We have tried to suggest some inclusive activities above. You may be able to identify additional resources or training online which can help.

The National Autistic Society (www.autism.org.uk) provides advice and contacts which may help.

Speak to your school or an education professional who's experienced in working with people who have learning difficulties and autism. Then, you can work with them to support your teenager.

Helping your teenager to identify their goals

Developing goals and ambitions for work and volunteering

Getting a job or voluntary role can be incredibly empowering to young people. Then, they can develop skills, build self-esteem and find their place in society. This helps them become successful, independent adults.

Paid work also gives young people greater financial freedom. They're able to buy the things they want and access better housing, travel and holidays.

Thinking about what's possible

With the use of assistive technology, adults with DMD can perform any task which is computer-based. They can do things such as teach, train others, deliver speeches, run focus groups, conduct research, direct films and chair meetings.

Adults with DMD are employed as writers, CEOs, charity workers, lawyers, graphic designers, software engineers, video streamers, finance officers and consultants - to name just a few! Many more volunteer their time for charity.

With a support worker to assist them, adults with DMD can be employed in many jobs that have a physical element as well. (Support workers are a type of personal assistant provided by the Government's Access to Work scheme.)

Education and transition plans

Education and transition plans agreed for your teenager may include support to help them prepare for employment. Including work experience in transition plans can make it easier for young people to get the right support.

Plans are typically agreed with your school, local health body, social services and/or local education authority. Plans differ significantly between countries in the UK, and have different names:

England: Education, Health and Care plans (EHCPs)

Wales: Individual Development Plans

Scotland: Coordinated Support Plans

Northern Ireland: SEN statements

> Including work experience in transition plans **can make it easier for young people to get the right support.**

Making choices in education

When your teenager is choosing courses in education, encourage them to consider what they want from work in the future.

You should acknowledge that their wishes and needs may change. Most young people consider different jobs before choosing one. Most teenagers don’t know what they want to do when they grow up.

Support in school and college

Careers advice, careers fairs and work experience organised by schools and colleges can help young people to think about their future.

See Chapter 5: Education for more information about careers advice.

Your teenager should access all the support available from their school or college while they are still in education. After they leave, it will be harder to access skills development and to find careers advice.

Work experience at school and college

Work experience should be available to teenagers from key stage 4 onwards (GCSEs and A levels or their equivalent). It is a required part of 16-19 study programmes.

You should speak to your school or college early to ensure plans will be in place for your teenager.

Support for students with special educational needs varies. So, you should ask about work experience opportunities when choosing schools and colleges.

Sources of careers advice outside school

We encourage you to speak to adults with neuromuscular conditions at Pathfinders Neuromuscular Alliance (www.pathfindersalliance.org.uk). They can tell you how they manage in work.

See Chapter 5: Education for more information about:

- careers advice (including distinguishing between good and bad advice)
- education and transition plans

Exploring work and volunteering options for your teenager

Note - By the time that your son or daughter is looking for work, they'll probably be a young adult. We've continued to refer to them as 'your teenager' for consistency with the rest of the book.

Different working arrangements

Jobs vary hugely in the type and amount of work involved.

Full-time and part-time roles

Traditional full-time roles from 9am to 5pm may suit some people with DMD. But they can be exhausting.

Part-time roles ranging from a few hours a week to a few days a week suit many people with DMD. More and more employers offer flexible hours or job-sharing options. These can often be requested as reasonable adjustments. (Under the Equality Act, disabled people have a right to reasonable adjustments at work).

Self-employment and freelancing

If your teenager has an idea for a business or service, they can consider self-employment. Self-employment can range from running a full-time business to doing occasional freelance work.

Freelancing is one of the most flexible ways to work. Your teenager can take on work as their energy and health allows. Some people use it to gain work experience or build a portfolio. Others do it as their full-time job.

Your teenager will need to bear in mind that they'll need to generate new work if they are self-employed or a freelancer.

Supported employment for young people with learning difficulties

Supported employment can provide opportunities for young people with learning and behavioural difficulties in a range of different roles. These can be accessed through a supported internship. Details of how to apply can be found in the next section of this chapter.

> More and more employers offer flexible hours or job-sharing options. **These can often be requested as reasonable adjustments.**

Spotlight

Sam Waddington

Sam works as the Southampton Hate Crime Network Co-ordinator at a user-led organisation for disabled people.

He is 24 years old and lives in Hampshire. He studied journalism at the University of Winchester.

In his role, Sam works with community groups to support people where they have experienced hate crime. Sam works part-time, doing 18 hours a week over four days, usually based in the office.

Sam says: “When I left university, I knew I wanted to find a role where I could have a direct impact on the community. My mum told me about a nearby organisation that supported disabled people, which sounded great. So, I got in touch to ask them about volunteering opportunities. I started volunteering on a project to tackle hate crime.

“After volunteering for just over 6 months, a paid role became available on the project so I decided to apply. Although I’m usually nervous about interviews, I found this process a lot easier because I had volunteered and got to know the interviewers first.

“I really enjoy my job and the responsibility I have to ensure people get the support they need at a traumatic time. I hope to be able to continue this work well into the future.”

Alternatives to paid work

Fluctuating health, fatigue and pain can sometimes make work difficult. So, not everyone is able to work all the time, even with adjustments.

Your teenager should decide what's best for them at the moment. This doesn't have to be a permanent decision.

If your teenager doesn't feel able to manage work, they could consider volunteering and using their skills to help charities.

Volunteering

Volunteering is often an extremely rewarding and highly valued way for a young person to use their time and skills. Volunteers make a massive contribution to society and improve people's lives.

So, volunteering should not be considered only as a second-best or temporary option.

Using volunteering as a route to employment

Volunteering can also be a way for your teenager to prepare for work. They can test what they can do and see how they cope in a professional environment. They'll get excellent experience which they can include in their CV and job applications.

If there is a specific organisation that your teenager wants to work for, volunteering can be a way to show their potential.

Your teenager may be able to access training opportunities with the organisation while they're volunteering. This will give them a chance to learn about the organisation and different jobs that people do which will help them in any future job application.

Organisations should set clear expectations about opportunities to move from volunteering into employment. Be careful to avoid organisations that exploit young people with vague promises of future employment.

> Volunteering should not be considered only **as a second-best or temporary option.**

Getting started in employment and work experience

Your teenager should think about the fields of work they might be interested in when looking for jobs or volunteering. They should also think about where and how much they want to work.

Your teenager should review their preferences each time they are looking for a role. They may change their mind about what they are looking for as they gain experience or their condition changes.

Consider approaching specific companies or organisations that work in the field they are interested in. They may offer volunteering, work experience, internships or paid roles that your teenager may be interested in.

Internships

Internships are paid placements in an organisation which can last between a few months and two years.

Some large companies provide internships for graduates where they can work in different areas of the company.

Internships are very competitive because they can lead to permanent employment. Taking part in extracurricular activities at school, college or university will help your teenager to write a good internship application.

Mainstream internships

You can search for internships using most mainstream job sites, such as Indeed, Total Jobs, Reed or Monster.

Some job agencies specialise in offering internships, such as:

- **PlacementUK:** www.placement-uk.com
- **Step:** www.step.org.uk
- **Gradcracker:** www.gradcracker.com
- **Stem graduates:** www.stemgraduates.co.uk/jobs

Internships for disabled graduates

Some organisations provide internship opportunities specifically for disabled graduates. These include:

- **EmployAbility** - internship opportunities and skills workshops
  www.employ-ability.org.uk
- **Leonard Cheshire** - Change 100 programme
  www.leonardcheshire.org/what-we-do/working
- **Civil Service** - Summer Diversity Internship Programme (SDIP)
  www.faststream.gov.uk/summer-diversity-internship-programme/index.html

If your teenager goes to university, they should be able to access both mainstream internships and internships for disabled graduates. However, specialist schemes may offer them greater support and be more adaptable to their needs.

Supported internships

Supported internships are offered by some schools and colleges to provide extra support for young people with an Education, Health and Care Plan (EHCP) or a statement of Special Education Needs (SEN). Your teenager's school or college can tell you about this.

Supported internships are a work placement with an employer that lasts for a minimum of six months. They include structured training and skills development. They may also involve study for qualifications needed for the job.

The British Association for Supported Employment (www.base-uk.org) maintains a list of providers of supported internships and employment. They can also provide advice about securing a supported internship for your teenager.

Permanent employment

Your teenager can use job search websites to find a range of part-time or full-time opportunities.

General job sites:

- **Indeed**
  (www.indeed.co.uk)
- **Reed**
  (www.reed.co.uk)
- **Monster**
  (www.monster.co.uk)

Sector specific sites:

- **University jobs**
  (www.jobs.ac.uk)
- **Charity jobs**
  (www.charityjob.co.uk)
- **Public sector jobs**
  (www.jobsgopublic.com)

Your teenager can also use disability-specific sites, such as:

- **Disability Jobsite**
  (www.disabilityjobsite.co.uk)
- **Evenbreak**
  (www.evenbreak.co.uk)

Disability-specific sites may be more likely to have a role that can meet their needs.

Recruitment agencies

Recruitment agencies connect jobseekers to opportunities which cannot be found elsewhere. They can be an excellent way to be considered for multiple jobs with just one application.

When choosing a recruitment agency, your teenager should consider the job opportunities they offer carefully. Some agencies try to push job opportunities that don’t match the candidate’s needs.

The Recruitment and Employment Confederation maintain a list of recognised recruitment agencies (www.rec.uk.com/jobseekers).

Pluss is a recruitment agency that specifically supports disabled jobseekers (www.pluss.org.uk).

Jobcentre Plus

Your teenager can get help finding a job or developing new skills at their local Jobcentre Plus. Anyone over 16 is entitled to free help and advice from a Jobcentre Plus adviser if they're unemployed and looking for work.

The Jobcentre can assign a work coach to them. The coach will carry out an employment assessment and help identify suitable work. They can also refer them to support organisations and a specialist work psychologist if appropriate.

Jobcentre Work Coaches are different from Access to Work Job Coaches, who may be provided once a young person has a job.

Jobcentres can also help your teenager to access out-of-work benefits they may be eligible for.

They may be able to get Universal Credit if they're over 16, studying full-time, have limited capability for work and are receiving Personal Independence Payment.

Self-employment and freelancing

Government advice services provide support to people who want to become self-employed.

Service providers vary by region:

- **England** – Business Support Helpline www.gov.uk/business-support-helpline
- **Wales** – Business Wales www.businesswales.gov.wales
- **Scotland** – Business Gateway www.bgateway.com
- **Northern Ireland** – InvestNI www.investni.com

The Prince's Trust's Enterprise Programme also provides mentoring and support to young people over 18 who want to be self-employed. (www.princes-trust.org.uk)

The New Enterprise Allowance provides small grants and mentoring to people on Universal Credit or Employment and Support Allowance who want to set up their own business.(www.gov.uk/government/collections/new-enterprise-allowance-campaign)

> Anyone over 16 is entitled to free help and advice **from a Jobcentre Plus adviser if they're unemployed and looking for work.**

Freelancing agencies

Freelancing is one of the most flexible ways to work. Some people use it to gain work experience or build a portfolio. Others do it as their full-time job.

Freelance sites allow people to look for opportunities and promote their services:

- **People per hour** www.peopleperhour.com
- **Upwork** www.upwork.com
- **Freelancer** www.freelancer.com

Some companies specifically offer opportunities to disabled freelancers:

- **Podium** www.appbytap.com

Volunteering

Volunteering hubs can provide information about local charities. They're also known as Community and Voluntary Sector organisations (CVS organisations).

Consider contacting charities you know to ask about what opportunities are available.

Take a look at websites that list volunteering opportunities around the UK:

- **Do-It** (do-it.org)
- **Volunteering Matters** (volunteering matters.org.uk)

Making employment and volunteering work for your teenager

Your teenager will need to consider how suitable any job or voluntary role is for them. They should look at the following things.

Accessibility of the workplace

Workplaces will need to be accessible to a wheelchair to accommodate employees with DMD. All the places your teenager needs to use at work need to be accessible.

Accessible toilet facilities are essential. Adults with DMD may require hoists or changing facilities during the day. Some organisations can adapt their bathrooms or make rooms available.

Employers may be required to make physical adjustments to the workplace to make them accessible. In some old buildings, adaptations may not be possible because of cost or listed status.

Location

Your teenager will need to think about how they travel to and from work. A long commute to work can be exhausting and unsustainable in the long run.

Relocating for a permanent volunteer position or job is possible. However, this brings additional challenges and costs.

If your teenager is living on their own, they'll need to organise a care package and accessible accommodation. This can take many months. Their employer would need to discuss temporary working arrangements for them while this is put in place.

If your teenager is doing a temporary work experience placement, their local authority may fund a care package. They'll need to discuss this with the local authority.

Working from home

Working from home became commonplace during the Covid-19 pandemic. It is now a viable option in many jobs. Working from home can also be requested as a reasonable adjustment by the employer where this is practical.

> Employers may be required to make physical adjustments **to the workplace to make them accessible.**

Spotlight

Zak Richardson

Zak is 19 years old and lives with his family in Northumberland. He has two sisters and loves socialising, music and cars.

Zak volunteers as a young leader at the gym club that his sisters attend. He leads warm-up games for 5–6 year-olds, takes official photos and manages the badge listings.

Zak recently started volunteering at his local Community Hub where he is learning how to be a waiter at the café.

As well as DMD, Zak also has processing difficulties which affect his reading, writing and maths. He attends Tyne Metropolitan College where he learns independent living skills, including numeracy and literacy.

Zak says: "I started volunteering at the gym club to get experience for a job, meet new people and keep busy. And I get to go for lunch afterwards!

"I'm proud to be a volunteer. Volunteering is great fun and everyone is friendly. The other members have made everything accessible for me and encouraged me. The club helped me find my PA, Kieran, who supports me in the role.

"In the future, I want to work with cars and music, but at the moment I'm trying different things."

Your teenager should weigh up the pros and cons of homeworking before taking on a job.

Working from home can have significant benefits. It can eliminate commuting and travelling to meetings.

It can open up jobs from more organisations across a larger geographic area. It can support a more flexible working schedule. Also, it ensures that your teenager would have access to toileting and personal care facilities without having to negotiate workplace adjustments

Working from home can have disadvantages too. It can sometimes feel more isolating and provide fewer social opportunities to mix with colleagues, such as going out to lunch or the pub. Where other colleagues all work in the office, working from home might make it harder for your teenager to build good working relationships.

Also, it can be harder to concentrate on work if your home is busy. So, your teenager will need to have private space at home where they can work.

Managing work hours

Working part-time, having flexible hours or job-sharing can make employment more accessible for your teenager.

People with DMD may experience fatigue which can limit the amount of work they are able to do. As washing, dressing and toileting become more difficult, it can be harder to work fixed hours.

Small changes to your teenager's routine can sometimes make it easier to manage their work hours. (For example, they could change the time they bathe or shower to shorten their morning routine.)

Talking about disability

It's up to your teenager how much they share about their disability with their colleagues at work. But knowing how to talk about their disability and answer questions will help them make that choice.

When talking about disability, your teenager should only share what they are comfortable with.

Your teenager should think about what they want colleagues to know. Telling them how their disability affects them at work can make things easier. For example, they could tell colleagues they find online documents easier to use than paper copies or that they need a lower shelf in the fridge.

> When talking about disability, your teenager **should only share what they are comfortable with.**

Your teenager should make sure that their manager understands the impact of their disability. This will ensure they get the right help and support to succeed at work.

Writing a blog or a one-page profile to share with colleagues can be a good way to share information. Then, they won't have to repeat themselves and colleagues will understand how they can support them. It can also be a good ice-breaker if they invite colleagues to say hi.

Colleagues and members of the public are naturally curious about disability. Talking about their disability can be a good way to build a rapport and avoid awkwardness. But there is no obligation to do this.

Some people may also ask inappropriate or personal questions that your teenager doesn't want to answer. They should know how to give a polite but firm response to unwanted questions.

On the other hand, some people may feel awkward talking with your teenager. They may avoid talking to them for fear of saying the wrong thing or bothering them when they are busy. Your teenager may wish to start a conversation with them to break the ice.

Your teenager should make sure they talk about other things too, not just DMD. Colleagues should understand there is more to them than their disability.

Extra support

If your teenager has learning difficulties or autism, they may still be able to work, but may require extra support.

They may need quiet spaces, clearly defined roles and colleagues trained to provide appropriate support.

Organisations such as the National Autistic Society (www.autism.org.uk) and the Autism Training Company (www.autismtrainingcompany.co.uk) provide training to employers on how to support autistic employees.

Access to Work

The Government's Access to Work scheme can provide funding to disabled employees who require extra support at work.

This can open up job opportunities that might seem too difficult to manage. People can apply to Access to Work once they have a job offer.

Access to Work support can include:

- **Assistive technology** - voice recognition software, switches to operate smart phones, eye-gaze devices, headsets, keyboards and mice
- **Larger equipment** - wheelchairs, mobility devices and hoists etc.
- **Funding for travel costs** - taxi fares where public transport is not accessible
- **A support worker** to help with work-related tasks
- **A job coach** to teach job skills and workplace norms

Equipment is only provided where it is necessary to enable the employee to work. Access to Work does not provide support for volunteers or people doing unpaid work experience.

Support workers

Support workers can assist with physical tasks such as notetaking, using equipment and getting around the workplace.

Access to Work will usually only fund a support worker to help with work-related tasks. Employees with DMD may require a separate personal assistant (PA) to help with personal care tasks while at work. They may be funded by social services.

Job coaches

A job coach is a specific type of support worker who primarily assists people with autism, learning difficulties or mental health conditions.

Job coaches can help people learn how to carry out tasks efficiently, safely and logically. They can also teach soft skills, such as coping strategies at work, communication and interpersonal skills.

Applying for volunteer roles, employment and work experience

Writing good applications

CVs, cover letters and application forms

Young people need support when they are writing applications. So, your teenager will need you or their teacher to check that they've communicated their qualifications, experience and strengths effectively.

The CV or application form may be their only opportunity to demonstrate they have the required experience and should be considered for the position. This could be work experience, volunteering placements and extra-curricular activities such as sports teams, competitions or awards.

Other sources of experience

Young people can use their hobbies and interests to show they have the skills that the employer wants.

Hobbies can demonstrate teamwork (for example, team-based computer games), commitment (for example, learning a language, coding or design) and a desire to improve yourself (for example, learning skills from YouTube videos).

They can use the experience they've gained from having DMD positively in an application. Young people with DMD develop communication skills and learn to manage people by talking to healthcare professionals and working with care assistants. By adapting to DMD, they show problem-solving skills and resilience.

> Young people can use their hobbies and interests **to show they have the skills that the employer wants.**

Tips for writing good applications

Your teenager should:

- Follow the application instructions guidelines precisely - this demonstrates their ability to follow instructions
- Include a cover letter that's specific to the position they're applying for (unless instructed not to) – this shows they have made an effort
- Read the job description thoroughly and identify what an employer is looking for
- Explain how their skills, experience and interests match the requirements in the job description
- Describe why the position interests them

You and your teenager can get more advice about writing good applications online from Scope, the disability charity: (www.scope.org.uk/advice-and-support/writing-cv)

Preparing for interviews

When your teenager is invited to a job interview, they'll need to prepare well.

They may need your advice and guidance to do this. The best place to start is with the job description and application materials.

Find out about the organisation

Your teenager will need to research the organisation by looking at its website or online news stories.

They should learn about the organisation's aims and objectives, how it works and the opportunities and challenges it faces.

Glassdoor (www.glassdoor.co.uk) has information about the recruitment processes and employees' experiences in different companies.

Your teenager should also research the kind of work that will be required. For example, if they are applying for a role in marketing, they could research how to run successful marketing campaigns.

Think about common interview questions

In interviews, your teenager will need to talk about their strengths and weaknesses, achievements and hopes for the future. They'll need to explain how they handle conflicts, disagreements and mistakes.

Most interviewers ask applicants to provide examples that demonstrate they can do the different tasks in the job description. It can be difficult to think about these on the spot. So, they should think of examples when they are preparing for their interview.

They should also think of examples that demonstrate they have good general working skills, such as working in a team, resolving a conflict, speaking up about something and completing difficult tasks.

Then, they should organise their examples into proper answers to interview questions using the STAR structure:

- **Situation** – what was the context?
- **Task** – what needed to be done?
- **Action** – what did they do?
- **Result** – what happened after they took the action?

You can support your teenager by helping them to research information and practise answering interview questions.

Rejection will happen

Many jobs have lots of applicants. Even good candidates get rejected. So, your teenager may have to make a large number of applications to succeed in finding a suitable role.

Job interviews can be stressful. They make most people feel anxious. Your teenager may have several unsuccessful interviews before they find the right position.

Dealing with rejection

Rejection hurts. So, talk to your teenager whenever they experience rejection from a potential employer.

Remind them that it is difficult for everyone to find work. But if they persevere, they can succeed.

They'll get valuable experience from every application they complete. Unsuccessful applications and interviews should be seen as opportunities to practise and learn. So, encourage them to consider if their failed application was missing something and think how this might be improved.

Wherever possible, your teenager should request feedback from an organisation after an unsuccessful application. Unfortunately, not all employers respond to these requests. So, encourage them not to take it personally if they don't get a response.

> Unsuccessful applications and interviews **should be seen as opportunities to practise and learn.**

Getting a job

Securing a work experience placement, internship, volunteering position or job is a tremendous achievement for any young person with DMD.

Take time to celebrate this. Make a fuss of them. Bake a cake. Tell the whole family. Most of all, enjoy the moment.

Starting a job

Starting their first job will be a daunting time for your teenager. It can be a steep learning curve to adapt to workplace norms and become skilled in their role.

They may need some extra support to settle in. Reassure them that everyone takes time to learn a new job. Let them know it’s okay to ask for help if they don’t understand something.

Preparation is key. Your teenager should research the job as completely as possible. They should contact Access to Work as soon as they receive a job offer. It will take a few weeks before the assessment takes place.

They should meet with their line manager as soon as possible to discuss the logistics of the job and any support they will need. Visiting the workplace is essential to determine accessibility of the office space, furniture and toilet facilities.

Your teenager will need to know how to communicate with their manager. They must ensure they understand what is expected from them in the first few weeks. And ask for regular feedback at the beginning to make sure they are getting things right.

Success in their first job is not just about your teenager’s own performance. They also need to work with their team members. Encourage them to speak to their team and get to know them. Making friends can help ease the transition process.

> Your teenager should contact Access to Work as soon as they receive a job offer. **It will take a few weeks before the assessment takes place.**

Understanding the rights of disabled employees

Sadly, disabled people are more likely to experience barriers in the workplace. This makes it harder for them to find and keep a job.

Under the Equality Act, employers have specific duties:

- They must not directly discriminate against someone because they are disabled
- They must also make reasonable adjustments for disabled applicants and employees to ensure they are not disadvantaged

Telling an employer about your disability

Disabled people can choose if and when to tell their employer about their disability.

Employers are only allowed to ask applicants about their condition before they get the job in some circumstances. They could ask whether DMD would prevent them from doing something essential to the job. And they can ask whether an applicant would require any reasonable adjustments.

Some people prefer not to mention their disability in the job application to avoid the risk of being discriminated against. Others talk about their disability openly and the skills they have as a disabled person in their application.

If your teenager is invited to a job interview, they will need to tell their employer if they need any reasonable adjustments.

For an interview, reasonable adjustments might include:

- Conducting interviews in an accessible location
- Allowing applicants to be supported by a personal assistant at the interview
- Adjusting the evaluation process (for example, allowing applicants to use assistive technology or have extra time to complete assessments)
- Changing the time of the interview

When a disabled person starts work, the employer is also required to make reasonable adjustments for them. The new employee will need to discuss with their employer what they need.

Reasonable adjustments at work might include:

- Providing flexible working hours
- Allowing working from home
- Providing a nearby parking space
- Allowing time off for hospital appointments
- Providing equipment or furniture to make the workplace accessible

The Access to Work scheme may fund support that a disabled employee requires if the employer doesn't consider it something they can fund.

Extra support from employers

Some employers recognise the value of disabled employees and their support goes beyond the legal requirements.

Importantly, these employers also often provide work experience opportunities for young disabled people.

Many employers who go the extra mile to support disabled employees can be found on the Business Disability Forum (www.businessdisabilityforum.org.uk).

The Disability Confident Scheme (www.gov.uk/government/collections/disability-confident-campaign) is another way in which businesses demonstrate commitment to supporting disabled employees. Employers on this scheme guarantee to offer an interview to every disabled applicant who meets the minimum criteria for a job.

Guaranteed interviews can ensure qualified disabled applicants have the opportunity to demonstrate their suitability for the job. This can be important where applicants haven't had the same opportunities to gain experience as non-disabled applicants.

Using the Equality Act to enforce your rights

Disabled young people have rights, so they should expect employers to support them.

If your teenager experiences discrimination as an applicant or employee or they cannot get reasonable adjustments, they should first talk with the organisation. Problems can often be resolved this way.

> Guaranteed interviews can ensure qualified disabled applicants **have the opportunity to demonstrate their suitability for the job.**

If they still experience disability discrimination or the organisation fails to make reasonable adjustments, they can use independent arbitration or an employment tribunal.

The Equality and Human Rights Commission (www.equalityhumanrights.com) has useful guides about what you can expect from employers and how you can challenge discrimination.

What can you expect when you volunteer for an organisation?

Volunteers do not have the same rights as paid employees.

Disabled volunteers should not be discriminated against. However they do not have a right to reasonable adjustments. Volunteers cannot use the Access to Work scheme either.

When volunteering, young people should look for organisations which are accessible, supportive and understanding of disabled volunteers.

Chapter 12

Chapter 12 –
Transition to Adulthood

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In a nutshell

1 You can help your teenager manage their transition to adulthood

Your teenager will need you to help them plan, prepare and access support as they transition from childhood to adulthood. This will give them the best chance of success.

As they grow up, they'll be able to make more decisions for themselves and take on more responsibilities for their own life.

2 Your teenager can choose to have personal assistants or care workers

As your teenager becomes an adult, their personal care should be provided by someone other than their parents or guardians.

They can choose to have either their own personal assistants (PAs) or care workers from an agency.

If they choose to have PAs, they'll become their legal employer. Your local authority will provide funding and advice. Some charities also offer support and advice to people who employ PAs.

3 They can live independently in the family home or their own home

Your teenager may want to live in their own home, the family home or shared accommodation when they are an adult.

As they enter their late teens, you should look at different housing options with them. Then, together you can decide which option will suit them best.

You may need to push hard to get the type of home that your teenager wants. Sadly, it's not always straightforward.

You may find you have mixed feelings as your teenager becomes an adult. That's ok.

4 You'll also need to manage your own transition as a parent

If you start early, you'll be able to take things slowly. Your teenager will gradually be able to take on more responsibilities for themselves and you'll be able to let go a little at a time.

You may find that you have mixed emotions or struggle to let go as your teenager becomes an adult. That's ok. Try to make space for your own feelings and make sure you get the support you need too.

5 You'll have a new relationship once your son or daughter is an adult

As your teenager grows up, they'll be able to take on more responsibility for their lives and use PAs for personal care. So, you'll be able to just be 'Mum' or 'Dad'.

This gives you the opportunity to develop a new adult-to-adult relationship. You can enjoy being together and doing things for fun.

Transition planning

Transition to adulthood is just as important for a person with DMD as it is for every other teenager. But it's more complex for them than most teenagers.

As they grow older, the wishes of the person with DMD should increasingly drive decisions. They need and deserve choice and autonomy. Then, they can shape their lives as they want to live them.

Our job as parents is to encourage their independence and help them access the support they need.

In this chapter, we're looking at three big decisions that you and your teenager need to make as a family – employing personal assistants, deciding where to live, and managing your own transition as a parent.

Our job as parents is to encourage their independence.

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More resources to support transition

Transition to adult services

When people refer to 'transition to adulthood', they often mean the transition to adult health and social care services.

See Chapter 3: Health for more information.

Life skills

You can help your teenager prepare for adulthood and independence by developing their practical and financial skills.

See Chapter 10: Life Skills for more information.

Personal assistants or care workers

As your teenager gets older, they should begin preparing to accept personal care from people other than their parents or guardians.

Some teenagers are more comfortable with this change than others. Others can become quite anxious and want their parents to carry on indefinitely. If your teenager is worried, gradually get them used to the idea and talk about the greater independence that they'll have.

Note on wording

In this chapter, we have used 'care workers' for paid professionals. This is to distinguish them from parents, guardians and family members who are often unpaid carers.

We have continued to refer to your son or daughter as a teenager in this chapter. However, they may be an adult when they make some of these decisions.

Two options for care workers

Your teenager will have two options:

- **Using a home care agency** who supplies care workers
- **Directly employing their own personal assistants (PAs)** and either recruiting themselves or recruiting them through a specialist agency

Your teenager will need to decide which option will work best for them.

Employing their own PAs

PAs are people who provide care where you live. Some people with DMD have only one PA. Others need multiple PAs.

- PAs have legally-set breaks and maximum working hours. So, if your teenager needs more care than can be provided during one PA's working hours, they will need two or more PAs. (You can find out more at www.gov.uk/browse/employing-people)

If they have their own PAs, your teenager can choose the people who provide their care and set their responsibilities. They can help your son or daughter to live with greater independence as a teenager and adult.

Your teenager will be the PA's employer. Legally, the PA will have employment rights, so your teenager will have employment responsibilities. But don't let this put you off. Your local authority can introduce you to organisations who can support you as an employer.

We recommend that they look at the excellent advice about working with PAs provided by:

- **Scope** bit.ly/scope-PAs
- **Disability Rights UK** bit.ly/disabilityrightsuk-PAs
- **Skills for Care** www.employingpersonalassistants.co.uk

Most adults with DMD employ their own PAs so they can choose who supports them. This enables them to lead a more independent life in their own home.

Using home care agencies

A home care agency will send one or more care workers to support your teenager. They may send different people on different days.

Agencies are typically arranged through the local authority. Typically, they are less work for your teenager than employing PAs because the agency recruits and manages the care workers. They can be particularly good for complex needs. But your teenager will have less control over who is providing their care and what kind of support they receive.

Home care agencies should be able to provide the hours of support your teenager needs. But they may not always be able to provide this support at the times or on the days when your teenager needs them. This will depend on their capacity. This can cause problems with work, education and social activities. You and your teenager should discuss this at the initial meeting with the home care agency.

The local authority will explain their services if your teenager chooses to use them.

Getting funding for PAs or care workers

Your local authority will provide the funding for your teenager's PAs or care workers.

You or your teenager will need to apply for funding by requesting a social care assessment from your local authority. At the assessment meeting, you and your teenager can discuss the type of support they need. After the meeting, they'll receive a copy of the assessment detailing the care and support that they are entitled to.

Sadly, getting funding can be difficult. Local authorities vary in what they offer, so do check what's available in your area. Some local authorities try to give as little as possible – usually because of constraints on their budget. So, you may need to push hard to get what your teenager needs, especially if you feel that the local authority is not treating them fairly.

You may need to push hard to get what your teenager needs.

Your rights as a parent or guardian

You have the right to be part of discussions with the local authority about how much care your teenager receives – even if they are over 18.

You may feel pressured to look after your teenager yourself. If so, you may need to strongly state what you can and cannot manage yourself. You may need to make the case that the local authority should take your teenager's social needs into account too.

If you get a carer's assessment from the NHS, you may be able to use this to argue for more support for your teenager. You can find out about carer's assessments on bit.ly/NHS-carers-assessments

You can also get advocacy support from:

- **Carers Trust** (bit.ly/carers-trust-advocacy)
- **Carers UK** (bit.ly/carers-uk-advocacy)
- **Muscular Dystrophy UK** (bit.ly/MDUK-advocacy)

Your teenager’s personal budget

You and your teenager will need to discuss the specifics of the care and support plan. You’ll also need to agree hours and personal budget with your local authority.

Your teenager will have the choice to receive a personal budget in three ways:

1. **Direct payments** – the local authority gives them money to pay for services as agreed in their care and support plan
2. **Commissioned services** – the local authority arranges services on their behalf, such as commissioning an agreed home care agency to provide care
3. **A mixed personal budget** – the local authority arranges some of their care and they arrange and pay for the rest with a personal budget

If your teenager wants to top up this money, they can use some of their Personal Independence Payment (PIP), Disability Living Allowance (DLA) or their own income.

Your teenager may also be assessed to see if they meet the criteria for an NHS continuing healthcare budget for long-term complex healthcare needs.
bit.ly/NHS-continuing-healthcare

Working with personal assistants

If your teenager decides to employ PAs themselves, they will need to recruit them. They can either recruit them by themselves or work with a specialist agency.

Either way, they should begin by defining their PA's role. If they use a specialist agency, they can help your teenager with this.

Defining their PA's role

Your teenager can ask their PA to perform tasks to help them maintain their independence. Their support plan with the local authority will describe their care and support needs so it's a good place to start.

They may choose to ask a PA to perform some or all of the following tasks – or other tasks that meet their particular needs:

- Supporting their work, training or education
- Providing mobility in their home and the wider community, including driving
- Accessing health, leisure and social services in the community
- Escorting them to social events, meetings and days out
- Providing personal care and hygiene, such as washing, dressing and toileting
- Helping them with medication
- Shopping, washing, ironing and cleaning

They'll need to clearly define their PA's tasks in the job description. If they clear about what they want, they are much more likely to have a positive and productive

relationship with their PA.

Recruiting a PA themselves

Their local authority or approved external agency will support them as they recruit and employ a PA.

These are the steps that they'll need to go through if they directly employ a PA:

1

Write a clear job description which describes:

- **Your goals and the type of life you want to lead** – this will help your job stand out from other care jobs and is likely to attract potential PAs who want to support someone who is pursuing their goals
- **What the job involves** – what tasks they want the PA to perform
- **The hours** – could be a few hours or 8 hours each day (or night)
- **The pay**
- **Skills required**
- **Qualifications required**
- **Experience required**
- **Checks they need to pass** (for example, the right to work in the UK and Disclosure and Barring Service)

As your teenager is writing their job description, they should think about the must-haves and the deal-breakers. What do they really want their PA to be or do? What are the things that are unacceptable to them? Sometimes, PAs need space to develop and improve, especially if they are new to this type of work.

Your teenager will be more likely to find a PA if they are open-minded about the type of person they want. If they have too many must-haves, they may find it difficult to recruit someone.

2

Look for a PA by:

- **Asking their local authority** about a personal assistant register or brokerage service
- **Advertising in the local newspaper,** online job sites, job centres, PA registers or social media

3

Keep themself safe by:

- **Asking for a Disclosure and Barring Service (DBS)** check to see if the candidate has a criminal record (the candidate needs to apply and pay for this)
- **Asking for at least two references**
    - **a professional reference** from a previous employer
    - **a personal reference** from someone who has a position of trust (for example, a teacher or youth club leader) who has known them for two years or longer

4

Interview candidates by:

- **Selecting the candidates** who have the right skills, qualifications, experience and checks on their CVs
- **Contacting them** to arrange a time to meet
- **Writing questions**
- **Asking a family member** or friend to sit in on the interview
- **Taking notes during the interview**
- **Noticing how they feel about each person** – make sure they feel comfortable with them
- **Deciding who is the best person for their job**

We recommend that your teenager has a face-to-face meeting with every person they interview. Ideally, they would meet candidates in person. If that's not possible, video interviews are a good second choice. Both are much better than telephone interviews.

Using a specialist agency to find PAs

If your teenager uses a specialist agency, they will help recruit and manage the PAs. But your teenager will still be the PAs' employer.

During the recruitment process, the agency will help your teenager to define the role and find the right PA. They may even train them on caring responsibilities – but this will depend on the agency.

After your teenager has chosen their PAs, the agency will manage the payroll, holidays and rota. They may even be able to act as a mediator if there are problems between your teenager and their PA.

Different agencies offer different services. So, your teenager should check the exact services that an agency offers before agreeing to use their services.

Your teenager may want to look at using these agencies:

- **AskJules** (www.askjules.co.uk) – specialises in providing PAs to young disabled people at home, university and work. They match people by their interests, academic background and age. If your teenager goes to university, they can arrange for their PAs to also be their university support workers.

  Young adults with DMD have used their services. One young man with DMD used their PAs when he was studying at university and highly recommends their services.

See Chapter 5: Education for more information about support workers at university.

- **UKCIL** (www.ukcil.com/employers) – finds PAs for disabled people who wish to live at home
- **PA Pool** (www.papool.co.uk) – helps employers and PAs through its specialised user introduction site
- **Purple Match** (www.wearepurple.org.uk/purplematch2) – provides advice for employers and PAs. They also list PA vacancies
- **Possibility People** (www.possabilitypeople.org.uk) – provides free, independent information to support disabled people, their families and their carers in Brighton, Hove, East Sussex and West Sussex

> "AskJules enabled me to find the right personal assistants who could support me living independently while I was at university away from home. **They took the pressure of findings PAs and made employing them easy and stress free."** Benjamin James

Employing a PA for themselves

Your son or daughter can get the support they need to be a responsible employer from:

- **Their local authority** – they are legally obliged to provide advice and information about employing PAs to disabled people (often local authorities use a direct payment support service to provide this service)
- **Skills for Care** (www.skillsforcare.org.uk) – they have useful templates for employing PAs and may be able to provide funding for training
- **Low Incomes Tax Reform Group** (www.disabilitytaxguide.org.uk) – they provide resources and information for anyone who employs a PA

When they hire a PA, your teenager will be the PA's legal employer. This can sound daunting, but the groups listed above can help you.

Their legal responsibilities will be:

- **Creating an employment contract** which describes the job requirements, hours, pay, holiday, notice period and probationary period (best done before they start and must be done within two months of starting)
- **Checking they have the legal right to work in the UK** before they start work (keep a copy of their document)
- **Avoiding discriminating against job applicants** because of their age, disability, gender reassignment, marital and civil partnership status, pregnancy or maternity status, race, religion, beliefs or sex
- **Paying the national minimum wage or more,** including holiday pay, sick pay, maternity or paternity pay
- **Running a payroll to pay employer's tax and national insurance** – they can use a payroll service or accountant
- **Setting up a pension if the PA is 22 years old or older** – their local authority can help them with this
- **Meeting GDPR requirements** to keep employees' personal data safe
- **Maintaining their PA's health and safety** by carrying out a risk assessment or providing training
- **Taking out a specialist PA employers' insurance policy** to cover them if their PA has an accident at work, injures someone else or they take you to an employment tribunal – much better than a general employer's policy

If they are not using a payroll service, your teenager will need to register as an employer with HMRC at www.gov.uk/register-employer. They'll only need to do this once before they employ their first PA.

We also recommend that they minimise risks to themself by:

- **Paying their PA by bank transfer either weekly or monthly** – it's best to use a payroll service, not cash
- **Developing a back-up plan** – making alternative arrangements if their PA is sick or on holiday so they are not left without care (for example, being registered with a home care agency that can offer last-minute care workers)

If things do go wrong with a PA, your teenager should get advice from their employers' liability insurance provider. Their legal advice service can guide your teenager through disciplinary and supervisory processes and other employment issues. If your teenager follows their advice, they will be indemnified against any legal claim.

Hiring self-employed PAs

Some PAs are self-employed. They are responsible for paying their own tax and national insurance.

Your son or daughter will need to check that they are legally self-employed before they hire them. If they're not sure, they can use the Government's Employment Status Indicator at www.gov.uk/guidance/check-employment-status-for-tax.

If the PA is not genuinely self-employed, it can cause problems with your teenager as well as the PA. For this reason, some local authorities prohibit hiring self-employed PAs.

Skills for Care has an excellent resource about self-employed PAs - bit.ly/skills-for-care.

Being someone's boss

Your teenager may find it strange to suddenly become someone's employer and manager.

They can get support from other disabled people who employ a PA. They can find useful resources and a safe forum for sharing experiences on www.beingtheboss.co.uk.

They can also get support from Scope (bit.ly/scope-PAs). Their online resources cover building a relationship with their PA, managing them and addressing problems.

Getting more out of life with a PA

PAs can help your teenager to go to more places, do more things and enjoy life more.

The relationship with their PA is fundamentally a working relationship. But it can and should be friendly and happy. It's good if they enjoy each other's company. Sometimes, PAs become friends with people and stay in touch after they leave the job.

That being said, your teenager still needs to develop their own friendships and relationships. Eventually, the PA will leave their employment.

Here’s a few tips to help your teenager work well with PAs:

- The PAs do need to do what your teenagers asks them to do unless it’s unsafe or unreasonable
- They don’t have to be in constant conversation 8 hours per day with the PA because it’s not a social visit
- The PA can be part of conversations and events with their friends and colleagues
- The PA can and should step back and let them enjoy conversations and events on their own
- They should develop a special signal so they can discreetly tell the PAs that they’re ready for them to leave the conversation
- Both your teenager and the PAs should respect professional boundaries
- They should speak up if they don’t like the way the PA is doing something
- They should ask for help from family members, friends or the local authority if the PA is bullying or mistreating them

Most of the time, the PAs need to fit in with your teenager. It’s not your teenager’s responsibility to fit in with the PAs. But your teenager should bear in mind that PAs also have their own lives.

From time to time, they will get sick or have personal problems. These shouldn’t dominate their working relationship with your teenager, but every so often they may need to be understanding and flexible.

Choosing where to live as an adult

People with DMD live happy independent lives in their own homes, their parents’ or guardians’ homes and shared accommodation.

Your son or daughter should explore different options for independent living as they go through their late teens and early twenties. This will help them choose.

Encourage your son or daughter to consider some or all of the following options:

- **Your family home** – probably with adaptations
- **An annex** – a self-contained flat or cottage within or attached to the family home
- **Accommodation** on a university or college campus during academic studies
- **Their own home** either by themselves or with a partner, friend or carer – in local authority housing, housing association accommodation, private renting, shared ownership or privately-owned
- **A care home or supported living scheme** – a group home designed for independent living with extra support, such as a warden or dedicated care staff
- **Shared living schemes** – living with a carer either in the carer’s home or their home

You can find advice about these choices at:

- Your local authority
- Citizens advice bureau (www.citizensadvice.org.uk/housing)
- Scope (www.scope.org.uk/advice-and-support)
- Shelter (www.shelter.org.uk)

Preparing for Adulthood has excellent guides for young disabled people. Their ‘No place like home’ guide advises them on finding the right housing choice for them. www.preparingforadulthood.org.uk/downloads/independent-living

Choosing the options that are best for them

Adults with DMD are living good lives in different types of accommodation.

Your teenager’s decision will depend on their needs and preferences. They are able to change their living arrangements as their needs and preferences change, such as wanting more privacy.

You may find that your teenager lives away from the family home for a while and then returns to live with you. That's fine. Many teenagers and young adults do this. Often, they change their housing because their study, work or social arrangements have changed. Teenagers and young adults with DMD should also feel comfortable about moving back home if they want to do so.

Adults with learning disabilities should still be encouraged to find the best living arrangement for them. Some choose to live in the family home or an annex. Others prefer to live in a care home or a supported living scheme. If your teenager has a learning disability, help them to explore different housing options and thinking about what they'd like.

Living in the family home

Some young adults with DMD prefer to live at home with their parents and other family members. They can still be independent with the right care package.

If they choose to remain at home, your son or daughter will need more privacy and independence. You'll need to think about how that can be arranged.

Adults with DMD are living good lives in different types of accommodation.

We recommend that you discuss and agree some new ground rules for living together which cover meals, privacy, chores, contributing to upkeep, bedtimes, night-time care, using the kitchen, having their own set of keys, accessing the car, returning from a late night, working from home and having friends and partners to stay.

Your teenager may need PAs or care workers to give them the lifestyle they want. Then, you will also need to think about how you accommodate care workers in your home.

You and your teenager will be able to get advice on adaptations to your home from their local authority and local Independent Living Centre. They may want to ask how others have adapted their homes. The local authority will also be able to advise you about funding.

Having a good occupational therapist (OT) who is on your side is essential when you are doing adaptations. If you're not happy with them, ask your local authority to change your OT.

See Chapter 7: Home for more information about adaptations.

See Chapter 8: Financial Support or the *Guide to Financial Support and Work for DMD Families* for more information about funding for adaptations.

You can download the Guide from www.duchenneuk.org/supporting-your-teenager-with-duchenne

Living away from the family home

If your teenager wants to live in their own home, they'll need to plan carefully. They'll need a home that is practical and suitable for their needs where they'll be happy.

These are some of the things they should consider:

- **Their own personal tastes and preferences** – what type of home would they like to live in
- **Location** – access to family, friends and community and medical facilities that they use regularly
- **Transportation** – ease of moving through the neighbourhood
- **Public transport to get to work, education, family and friends** – not all PAs are able to drive
- **Accessibility** – including any necessary home modifications
- **Space and facilities for care workers** – so they can work comfortably and safely

Sadly, local authorities can be difficult about providing enough care hours so an adult with DMD can live independently. If they carry out an assessment when your teenager is living at home, they may say there are limits on how much care they can provide. That might make it difficult for your teenager to move out.

Sometimes, local authorities cite financial restrictions or say they have allocated the maximum amount of money to one person. However, they have discretion to provide more money if it's needed. They may not tell you about these discretionary funds. You might have to ask.

However, local authorities have a duty of care and can't leave people without any care. So, if your teenager is over 18 and is determined to move out, the local authority would have to step in.

This can become like 'a game of chicken' with each side waiting for the other side to back down first. The local authority may be stubborn and hope that you will provide the care or give up on trying to get a home for your teenager.

When your teenager is over 18, the local authority cannot force you as parents to provide care. If they provide care, it is unlikely to be for 24 hours a day and 7 days a week. It may not even be enough to meet your teenager's needs or keep them safe. If that's the case, then you have grounds for appeal.

You might have to ask about discretionary funding.

Alternatively, they may threaten to place your teenager in a care home because they won't fund enough care workers in their own home. You may need to lobby and involve the media if the local authority threatens care homes against your teenager's wishes.

If your son or daughter is an adult and is already in their own place, then it's much harder for local authorities to refuse to provide care.

In reality, you may need to fight hard to get the result you want. If you are not happy with the care that your teenager is offered, you may need to provide some care yourself – at least in the short term while you appeal.

Care homes and supported living schemes

Some people with DMD prefer to live in a care home or a supported living scheme. Then, they can have more independence while still being fully supported.

Care homes can be a good choice both for adults with learning disabilities and those without them. It can be a good way of living with other people of similar ages.

A care home may be one large building or have bungalows around a courtyard. Residents have their own bedroom and bathroom. Often, they share communal areas, such as dining rooms and lounges. Sometimes, there is no communal area, but care is available on call.

The staff will be care workers, not nurses. So, they may be worried about how to use machinery, such as hoists. You may need to teach them how to do things for your son or daughter.

A good care home will provide a safe friendly home with enjoyable activities. Residents should have opportunities to socialise with each other and their families.

Look for care homes that are either specifically for young people or cater for all ages. Care homes that are for older people only may not be suitable. You can find out about care homes near you by looking at the local offer from your local authority and neighbouring authorities.

> **"I live in my own rented flat which has a great view of the Humber River.** My room has big bay windows allowing me to get lots of fresh air and see everything. I receive Universal Credits and Personal Independence payments which I manage myself."
>
> **Andy Elliott**
> **37 year-old man with DMD**

When you are visiting a potential care home, we encourage you to ask:

- Do they have the necessary equipment, especially a profiling bed, ventilator, cough machine, feeding tube and a ceiling hoist?
- Will they be able to provide the type of care your teenager needs – for example, physiotherapy stretches and regular repositioning to avoid pressure sores?
- Can your teenager come and go independently?
- Will they have transport and access to care workers?
- Are there set times when they have to get up or go to bed?
- Would they be able to go to work or volunteer?
- What are the rules on having friends and family to visit?
- What are the rules about partners staying over?
- How are meals organised?
- Is there anywhere that your teenager or their care workers can prepare food?

You may want to look at Leonard Cheshire who is a reputable provider of homes for disabled people - www.leonardcheshire.org/get-support/living/find-care-home

Getting support as you look for suitable housing

In reality, finding suitable homes can be a long and difficult process. We encourage you to fight for what will work best for your son or daughter when they are an adult.

Please use the resources in this book and get advice from people in the DMD community to help you, especially:

- The Duchenne Family Support Group (www.dfsg.org.uk)
- Pathfinders Neuromuscular Alliance (www.pathfindersalliance.org.uk)

See Chapter 1: Introduction for more information about the social model of disability and how it can empower you to fight for what your teenager needs.

Duchenne UK project about housing

Duchenne UK and Pathfinders Neuromuscular Alliance are running a project about housing for people with neuromuscular conditions, including DMD.

The project team are identifying the current issues in providing independent housing for people with DMD. They are working with the DMD community, housing organisations and experts to understand the issues and find better solutions for the future.

If you would like to find out more about this project, please check for updates on Duchenne UK's website at www.duchenneuk.org/housing-support.

Managing your own transition as a parent

Accepting your son or daughter's increasing independence and letting them make their own life choices can be difficult when they have DMD.

From the time of diagnosis, we've wanted to protect them and look after them. But, as they get older, we have to let them have their own life and independence.

We also have to acknowledge our own limits. As we get older, we may develop health problems or back pain which prevents us caring for our son or daughter ourselves. Or they may outlive us. So, we need to make sure they can manage without us.

It's ok to find this a struggle. Most parents of people with DMD struggle in some way with their teenagers' transition to adulthood. We all have mixed feelings as our son and daughter becomes more independent.

Here are our thoughts on how the parents can help with the transition. We hope you find them useful.

Start early

Start working on the transition early while your son or daughter is in their mid-teens. This will help them to develop the life skills they'll need when they are adults.

Help your teenager develop their confidence

Your teenager will need the confidence to ask for what they need and speak up when something is wrong. They need to know what's acceptable behaviour and what's not.

When they are confident and competent, you'll know that they can manage their life when you become too old to look after them. This is important otherwise they may suddenly become responsible for themselves if you unexpectedly become ill or pass away.

The more you support your son or daughter to make their own choices, decisions and mistakes, the more they'll grow in confidence. So, listen to your teenager as well as talking to them. Gently push them into doing things for themselves so they can learn what works and doesn't work.

Help them to socialise without you. Support them in trying new things and developing hobbies. Encourage them to have a passion for something. Encourage them to make friends and have a girlfriend or boyfriend. Try not to limit them.

Suggest that they join Pathfinders Neuromuscular Alliance (www.pathfindersalliance.org.uk) so they can meet other teenagers and adults with DMD. They'll see the many things that people with DMD are doing for themselves and others.

See Chapter 10: Life Skills for more information about helping your teenager to develop the practical skills, emotional control and confidence they'll need in adult life.

Help them to manage their emotions

Your teenager will need patience as they navigate their way through the social care system. Anger and frustration can get in the way.

Help them move through bad feelings: acknowledge the problem, express their feelings and move on.

See Chapter 10: Life Skills for more information.

Help them to develop resilience and perseverance

As parents, we can help our teenagers most if we let them develop the skills to cope with life's bumpy road.

So, we encourage you to avoid over-facilitating, over-protecting and always smoothing the path. We can't always make it better. We have to allow for things not to work and for our teenager to be upset and learn from mistakes.

When we develop our own resilience and perseverance, we also model it for our teens. So, have a go at things together so they can develop the confidence to do things by themselves. Push yourself and them to make things happen. Stay out in the evening. Catch trains, buses and taxis. Go out with friends. It can be exhausting because nothing's simple. But it will show that you are not going to let difficulties or the fear of things going wrong stop you from enjoying life.

Encourage your teenager to take on important responsibilities

Show that you see them as a capable adult by encouraging them to:

- Plan days out and holidays
- Research things and organise them
- Book and attend medical appointments
- Manage their medication
- Develop their emergency care plan
- Manage their finances
- Employ their own PAs
- Complete their own forms and paperwork

Start small when they're young and build from there. For example, you could just ask them to research a day out and then plan it together.

Accept that your teenager won’t always do things your way

You may feel anxious about the changes your son or daughter is making. It’s important to accept that they will probably want to do things their own way rather than your way.

They will make different choices to the ones you would have made. And they may even make mistakes. This is all part of letting them manage their own lives.

Many parents find handing over medical decisions particularly difficult. That’s ok. Remind yourself that it’s better if your son or daughter can manage their own health when they’re an adult if that’s possible

So, if appropriate, begin by stepping back. Let your teenager participate in conversations and, eventually, lead conversations. Keep your questions to the end. When they are older, wait outside the room and ask them about the appointment later.

Some parents use phrases like ‘I do not agree with your decision, but I respect it’ when they are having sensitive discussions with their teenager. This gives them a way to acknowledge their teenager’s views and right to make decisions while still saying their own views.

Arrange extra support for teenagers with learning disabilities

If your teenager has learning difficulties and will always need support, encourage them to participate in conversations with healthcare professionals. You can talk through decisions with your teenager and make sure their views are heard.

As your teenager gets older, consider using an advocacy service for people with learning disabilities. Parents are not the only ones who can advocate during conversations with healthcare professionals, the local authority and other services. If your teenager begins using an advocacy service, you may feel more comfortable letting go.

Accept that risks are part of life for your teenager

You and your teenager may worry a lot about risks and want to remove them. However, it’s likely that you’ll have different perspectives about what’s sensible for them.

Your teenager will worry about falls and injury. This may make them anxious about going out or socialising with other young people. Help them to manage these risks by encouraging them to use their wheelchair and other equipment that reduces the risk of falls.

We encourage you to talk with your teenager about how risks can be reduced without restricting their autonomy or ability to access opportunities. So, support them to take ‘sensible risks’.

See Chapter 2: Your Teenager and Family for more information about the teenage brain.

Welcome the assistance of PAs

PAs are the route to independence for your teenager. It's better for them to start working with PAs in your home (unless they don't need the support yet).

You may need to encourage your teenager to accept help from someone other than you. Some teenagers need time and support to make this change.

Give yourself time to get used to having PAs in your house. It can be difficult to have someone in your space, especially if you have a small home. They are an employee, not a visitor so you don't need to chat to them all the time. With good will on both sides, you will find PAs are enormously beneficial to your teenager and the whole family.

Give them space to do their job. It can be strange to let someone else provide personal care for your son or daughter. But this will take the strain off you. This is the way to independence for both parents and teenagers.

Make space for your own feelings

You may find you feel emotional about passing on your caring responsibilities to another person. If you can, talk to your partner, a counsellor, a close family member or a friend so you can feel supported.

Every parent responds to letting go as their teenager grows up in their own way. Some find it more of a struggle than others. You may have your own health challenges (for example, arthritis). So, don't suppress too much. Find a way to express your feelings and thoughts. If you can, talk with someone who also has a teenager with DMD. They'll understand best.

Your fellow DMD parents in the Duchenne Family Support Group can be particularly helpful. You can find them at www.dfsg.org.uk.

Most of all, remember that you're helping your teenager to become an independent, self-directed adult who can function happily and well in the world.

Helpful resources

Websites

www.preparingforadulthood.org.uk

bit.ly/transition-information-network

bit.ly/supporting-childrens-transition

Publications

Action for Children (www.actionforchildren.org.uk), *Supporting young people to a successful adulthood* (especially pages 6, 17 and 23)

Murdoch Childrens Research Institute (www.mcri.edu.au), *Transitioning from childhood to adolescence*

Google books (books.google.com), *Emerging Adulthood: The Winding Road from the Late Teens through the Twenties*

Your new relationship once your teenager is an adult

You'll have a new adult-to-adult relationship with your son or daughter as they take on more responsibility and use personal assistants to provide care.

You should have more opportunity to be just 'Mum' or 'Dad' when you don't have to provide all the personal care or manage medical stuff. You may have to work at making this happen. It can be tempting for your teenager to fall back on you. And you may have to resist making too many decisions for them.

Encourage and help them to take charge of decisions and plans. They should lead, and you should support. Avoid doing things for them.

Encourage and help them to take charge of decisions and plans.

These are our thoughts on this transition:

- Young adults still need advice and assistance
- Your teenager may continue to need help navigating tougher challenges, for example getting a care package, moving into their own place or finding work
- Everybody goes at their own pace and some people need longer to become independent – and that's ok
- Some young people move out of the family home and move back in – that's ok too
- There's no single right option that will work for every person
- Your teenager's choice about what's best for them is likely to change as they get older
- You may need to keep an eye on things from afar for a while

Make the most of your new relationship with your son or daughter:

- Enjoy your new relationship
- Enjoy doing things together – for example, you could watch films together, go to the pub or a restaurant together without having to be a care worker, especially if a PA is with you
- Enjoy your own friendships, hobbies, work and interests – tell them about them so they start to see you as a separate person
- Relationships between parents and adult children should be two-way with giving and receiving on both sides
- So, let your teenager look after you if they want. For example, they could treat you to a coffee or arrange a special outing for you. This will make you both happy

Chapter 13

Chapter 13 — Emergencies

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How should we prepare for emergencies?

People with DMD experience everyday illnesses and accidents. But, because their muscles are weaker, some things are more serious for them than other people.

So, you should prepare now so you can respond properly to an emergency if it occurs by:

Preparing an emergency plan

We recommend that you read the emergency guidelines in the *2018 DMD Guide for Families*.

Your doctor can also refer to the emergency advice in the *Care Considerations for Duchenne*. It is written specifically for doctors.

You can find links to both documents at www.duchenneuk.org/care-consideration-guidelines

* * *

Downloading the app

We recommend that you download the Duchenne UK 'In Case of Emergency' app and keep it up-to-date with your teenager's latest medical details. If your teenager uses a smartphone, they should have the app on their own phone.

Full details about the app can be found at the end of this chapter.

* * *

Getting a DMD Alert Card

The DMD Alert Card has detailed advice about DMD for ambulance staff, nurses and doctors so they can provide the right treatment during an emergency.

You can download an electronic copy at: www.duchenneuk.org/dmd-emergency-support

Who needs to know these emergency procedures?

Everyone who cares for your teenager needs to know how to take care of them in an emergency.

This includes grandparents, family, friends, teachers, carers and healthcare professionals.

You should give them a printed copy of this chapter, the DMD Alert Card and your teenager's documented emergency plan.

You should also make sure they have all your contact details so they can reach you quickly.

✓ Grandparents

✓ Family and friends

✓ Teachers

✓ Carers

✓ Healthcare professionals

What is an emergency for a person with DMD?

For doctors and paramedics

If you are treating a person with DMD, you should refer to **www.duchenneemergency.co.uk**

It is written by doctors for doctors. It has the best and most up-to date information about the clinical needs of people with DMD.

For parents, carers and family & friends

If your teenager with DMD has a healthcare emergency, use this information to advise paramedics and doctors about their clinical needs. We recommend you keep printed copies of this page to make this easy.

Misses a steroid dose	Give them steroids as soon as possible and seek medical advice.
Vomits and cannot take a steroid dose	Your teenager needs a steroid injection (hydrocortisone) to replace the lost steroid dose ASAP. **Call 999 or go to the hospital:** • If you have been trained to give injections, give the injection yourself while you wait for the ambulance. • If you have not been trained, then tell the paramedic staff that your teenager needs a steroid injection. • When you arrive at the hospital emergency department, tell the doctors that intravenous steroids are required until oral steroids can be taken again. Inform the doctors that they need to follow local adrenal insufficiency management pathways.
Develops a chest infection	Must be treated seriously and early with antibiotics and physiotherapy.
Breaks a bone	**If they break a bone, they need to go to hospital:** • Refer the doctors to the *The Care Considerations for DMD* • Avoid prolonged immobilisation whenever possible. So, internal fixation is preferable to casting as it helps to preserve muscle • Consider alternatives (e.g. surgery), if clinically indicated **You should also contact:** • Their neuromuscular specialist • Their physiotherapist to ensure close follow-up

Abdominal pain	Abdominal pain requires prompt investigation by a GP. It could indicate severe constipation or peptic ulcers. If symptoms rapidly get worse, **call 999**.
Needs an anaesthetic	**Because DMD affects the breathing muscles, doctors need to make special arrangements when they administer anaesthetics:** • Intravenous only • Local anaesthetics are safe (usually safer than inhaled anaesthetics) • Succinylcholine and depolarising muscle relaxant must never be given • Inhaled anaesthetics should be avoided • Neuromuscular blocking drugs should be avoided • Oxygen needs to be administered carefully
Breathing difficulties or distress	Breathing distress, especially gasping for breath – **call 999**. Consult www.duchenneemergency.co.uk for specific advice if the person with DMD is: • Younger and still ambulant • Older and no longer ambulant • Needs a ventilator Breathing difficulty – look for subtle signs that could indicate lung problems, such as early morning headaches, fatigue, daytime sleepiness, reduced appetite and weight loss. Consult your GP or neuromuscular consultant as soon as possible.
Adrenal insufficiency	Teenagers and adults who take steroids are at risk of adrenal insufficiency when they are sick or injured. So, they may need to have extra steroids to stop them becoming dangerously unwell. For more information, see our information leaflet, *Adrenal Insufficiency*, at www.dmdcareuk.org/information-leaflets
Heart problems	Any repeated abnormalities in cardiac rhythm (e.g. a fast heartbeat) should be promptly investigated at hospital – **call 999**.

Call 999

Show DMD App

Inform about steroids and other medication

Provide details to all medical and hospital professionals

What should we do in an emergency?

In an emergency, call 999.

People with DMD need expert medical treatment in an emergency. It’s dangerous to treat them yourself or rely on information on the internet.

What should you tell the emergency services?

You need to tell the emergency services that your teenager has DMD and, therefore, requires special treatment and:

- Show them the **Duchenne UK In Case of Emergency app**
- Tell them about your teenager’s steroids and other medication

This includes ambulance officers, nurses, doctors and other hospital professionals.

Duchenne UK

Duchenne UK Emergency app

We recommend that you download the Duchenne UK In Case of Emergency app and keep it up-to-date with your teenager's latest medical details. If your teenager uses a smartphone, they should have the app on their own phone as well.

You can store all the key facts about your teenager on the app, including:

- Contact and family details
- Medical team details
- Clinical trial enrolment
- Clinical information, including their diagnosis, allergies, steroid treatments, medications, respiratory status, cardiac status, gastro-intestinal problems and other problems
- Medical equipment, such as respiratory equipment, ventilators, positive pressure machines, cough assist machines and nebulisers
- Photos of recent clinical letters from their neuromuscular consultant and other specialists
- Instructions for use of oxygen
- Instructions for use of anaesthetics, including anaesthetics to avoid
- Emergency procedures for DMD patients using ventilators

Remember you and your teenager are the experts on DMD, especially how it affects them personally. Some emergency staff and healthcare professionals know little or nothing about DMD. So, you can and should share this medical advice with them.

Where to get the app

You can download the app from our website at www.duchenneuk.org/dmd-emergency-support.

You can also find it in the app store for your Apple or Android phone.

GET IT ON Google Play

Download on the App Store

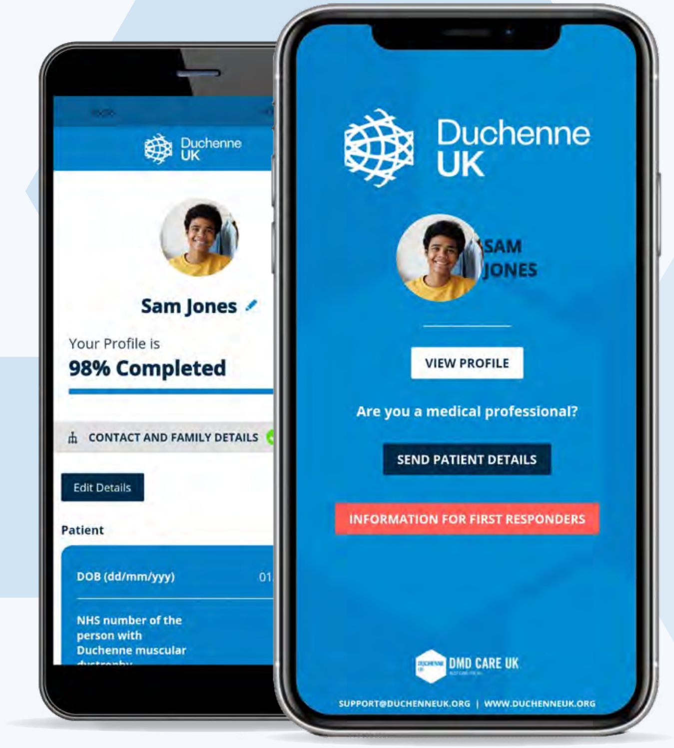
How to use the app

In an emergency, you can show the information on the app to ambulance officers and hospital doctors.

You can also email a PDF with your teenager's detailed medical information straight from the app to the doctor in charge.

As a precaution, you may want to email the PDF to the people who might need to access this information if you are not with your teenager during an emergency. This might include:

- Your teenager's school
- Grandparents
- Your teenager's close friends' parents (if he or she spends time at their house)



Your Profile is
98% Completed

Patient

DOB (dd/mm/yyy) 01

NHS number of the person with Duchenne muscular

Are you a medical professional?

SUPPORT@DUCHENNEUK.ORG | WWW.DUCHENNEUK.ORG

Emergency procedures for people using ventilators

If your teenager uses a ventilator, you need to tell the ambulance officers and hospital doctors about particular emergency procedures.

You need to give them this information:

- Your teenager's name
- Your teenager's medical condition – DMD
- Their use of ventilators – dependent or occasional use
- If they can breathe unaided and for how long (approximately)
- How long their ventilator batteries will last (approximately)
- The equipment and supplies that need to be taken with them, including the ventilator and its power cable and batteries, the cough assist machine, the suction machine and the correct-sized catheters etc.
- Contact numbers of your teenager's respiratory consultant and specialist team, including their on-call and emergency numbers

You need to give them these instructions:

- Your teenager should not be given oxygen alone (unless there's a specific medical reason to do so and it must be used together with non-invasive ventilation)
- Their oxygen saturation levels should be monitored during the transfer to hospital
- If they require manual ventilation at any time with an ambu-bag, the ambulance staff must ask them if they are bagging too hard or too soft, too fast or too slow

You should take this equipment to the hospital if you can:

- your own masks
- the specific ventilator equipment you prefer using
- spare equipment

Oxygen and non-invasive ventilation

If oxygen is given alone, it will cause carbon dioxide levels in the blood to rise to dangerous levels.

So, using non-invasive ventilation with oxygen is much safer.

Chapter 14

Chapter 14 - Research and Clinical Trials

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In a nutshell

1 We're helping to develop new treatments for this generation of DMD patients

Duchenne UK are tackling some of the biggest barriers to getting new treatments to this generation of patients.

We're funding dozens of research projects and clinical trials. We're also working with pharmaceutical companies to accelerate the approvals process for new treatments by government regulators.

2 Doctors are making huge progress in treating DMD

In the last five years, the landscape has changed for DMD. There are now clinical trials taking place which are testing gene therapy, steroid alternatives and other approaches, including repurposed medicines, which could all lead to better treatments.

3 Your teenager may be able to join a clinical trial

Your teenager may be able to participate in a trial where they receive potential treatments which are being tested to see if they are safe and effective for people with DMD.

And they may be able to join a study where the effects of DMD on their body are observed so doctors can understand the disease better.

Making an impact

Duchenne UK is ambitious and determined.

Between 2012 when we were established and 2021, we have committed:

- **£13.9 million** to research, access and support in total
- **£9 million** to research, including **£4.5 million** to clinical trials
- **£3 million** to the DMD Hub and expanding clinical trial infrastructure

Key facts:

- **30 posts** funded in the DMD Hub
- More than **300 children and teenagers with DMD** enrolled on to trials since 2015
- **11 sites** running clinical trials (up from 2 in 2015)
- **109 projects** funded since 2015 (including clinical trials)
- **24 live research projects** including 5 clinical trials in 2021

4 You can get information about clinical trials

The DMD Hub Clinical Trial Finder has information about every clinical trial in the UK. You can find it at www.dmdhub.org/clinical-trial-finder.

It was set up by Duchenne UK to ensure everyone with DMD has the opportunity to access clinical trials.

You should discuss clinical trials in the UK, especially ones that you are considering joining, with your neuromuscular doctor. They will be able to provide information and advice to you.

We recommend you join the DMD Hub mailing list by signing up at www.dmdhub.org/join-the-hub. This will help you to keep up-to-date with the latest clinical trials for DMD in the UK.

5 Find out more about our research

We are constantly developing new research partnerships and projects.

For the latest information, please visit the trials and research page on our website at www.duchenneuk.org/our-research

> Currently, we are funding **more than 50 projects, including three clinical trials.**

We're funding dozens of research projects and clinical trials.

You can find out more on our websites:
www.dmdhub.org
www.duchenneuk.org

Treatments in the pipeline

Medical researchers are working hard to develop treatments that could maintain children and teenagers' long-term muscle function without unacceptable side effects.

In the last 10 years, many potential new treatments have emerged.

Some focus on the underlying cause of DMD (which is a lack of dystrophin). Others aim to reduce the symptoms caused by the lack of dystrophin in the muscles.

Some potential new drugs are now being tested on patients with DMD in clinical trials. Others are about to start trials.

> In the last 10 years, **many potential new treatments have emerged.**

Medical research

is underway to find a treatment.

Great advances

have been made.

Here are four important approaches currently being used to develop new treatments for DMD:

- **Repurposing existing drugs:** Using drugs which were originally developed to treat one condition (e.g. visual impairment) for another condition (e.g. DMD).

  This can be a faster and more cost-effective way to produce treatments than developing new drugs.

  For example, Duchenne UK is supporting a clinical trial looking at the benefits of Tamoxifen (a drug marketed for breast cancer) in DMD.

- **Anti-fibrotic drugs:** Developing drugs which reduce the scar tissue (fibrosis) which replaces muscles when they are injured and cannot repair themselves properly.

  Fibrosis is a stringy, inelastic material which stops muscles from contracting efficiently. By removing it, the remaining muscle can work much better. Duchenne UK is supporting studies into this potentially very useful area of research.

- **Treatments that impact muscle growth and function directly:** Stem cell therapy is one exciting example of this research. We are looking to see if we can use stem cells (capable of growing into functional muscles cells) to replace damaged muscle. It's been shown to work in some animal models.

  Duchenne UK is supporting studies to make this ready for testing in DMD.

- **Gene therapy and gene editing:** These approaches target the cause of DMD, not just the symptoms. Genetic approaches are perhaps the most exciting treatments being developed for DMD currently.

- **Gene therapy:**
  This technique aims to deliver copies of a new (shorter) dystrophin gene to muscle cells.

  Muscle cells can use this functional copy (rather than their own faulty dystrophin gene) to produce a smaller, functional dystrophin protein. Then, muscles will work much better.

- **Gene editing**
  (using CRISPR/Cas9): An exciting technique that has the potential to add, remove or edit genetic material at specific locations in the DNA of
  the cell nucleus itself.

  If we can make this work, then the effects could be much more long-term than gene therapy.

At the moment, researchers are experimenting with exon skipping. It aims to cause the cell to 'skip over' the faulty part of the gene so that a smaller functional dystrophin gene is produced.

In the future, we may be able to repair the gene so that full-length dystrophin gene is produced.

We’re accelerating DMD research

Duchenne UK are determined to speed up the process of developing new treatments for DMD patients.

Currently, developing a new drug is a costly and complicated process that can take many years. This can be very difficult to manage for DMD families, for whom every minute counts.

Accelerating the drug development, clinical trial and approval processes

Duchenne UK are supporting the development of potential new treatments for DMD and the delivery of clinical trials in three ways:

1. **Funding new scientific research and clinical trials into drugs and therapies that could:**
    - Preserve quality of life by minimising damage to patients’ muscles and keeping their hearts and lungs healthy
    - Change the disease itself by replacing dystrophin, increasing utrophin (a natural muscle protein) or repairing damaged muscles
2. **Speeding up clinical trials** – By creating the DMD Hub, dmdhub.org, for DMD clinical trials which supports patients, doctors and industry. It provides details of all trials in the UK and provides doctors with resources to help them run their trials more effectively.

    Already, the DMD Hub has funded more than 30 critically-needed clinical posts and increased the number of hospitals where trials are being run.
3. **Speeding up the approval process for DMD drugs** – Through running Project HERCULES, projecthercules.org, which is a collaboration between a group of leading pharmaceutical companies to fund and develop a single robust evidence base that shows the true economic cost of DMD.

    This evidence base will be used by government regulators when they are considering whether to approve a new drug for use in DMD.

What is a clinical trial?

Clinical trials are research studies that explore whether a medical treatment, drug, procedure or device is safe and effective for humans.

Clinical trials are an important part of the evidence-based process for making new treatments available to patients. They produce the best possible data for healthcare decision-makers.

They are required by the Medicines and Healthcare Products Regulatory Agency (MHRA) which licenses new medicinal products in the UK. Doctors can only use drugs, procedures and devices with this licence to treat their patients.

Doctors, other healthcare professionals and patients also use the results of clinical trials when they are creating their treatment plans. For example, they might look at the results of a clinical trial for steroids to help them decide when a patient should start taking this treatment

Find out more

You can find out more about the different types of trials on Duchenne UK's clinical trial website:

www.dmdhub.org

What are the different types of trials?

Doctors use two different types of clinical trials to study diseases and investigate treatments:

- **Controlled trials** – Doctors give a potential new drug, device or therapy to the patients and measure the effects. This helps them work out if the treatment is safe and effective. (Trials where patients receive treatments are also called interventional studies.)

  For example, doctors might give patients a drug which could be repurposed for DMD. Or they may use different devices for administering steroids on different patients to see which one works best.

- **Observational studies** – Doctors just observe patients and take measurements from them. The patients do not receive any treatments.

For example, the doctor may be interested in comparing the movements of patients who have been taking steroids since they were five years' old and those that have not. So, the doctor will only measure their movement and won't give them any new treatments.

What does this mean for my teenager and our family?

When the time is right, you may like to explore whether your teenager should take part in a clinical trial.

This is a big decision and a very personal one. It depends entirely on what you feel is best for your teenager.

You should talk it through fully with your teenager's doctors. But you should never feel any pressure to take part in a trial.

What are the benefits of taking part in an interventional trial?

Clinical trials are often a family's main hope of accessing potential new treatments that might one day become approved medicines.

If your teenager takes part in an interventional trial, they could receive a potential new drug, device or therapy much earlier than if they don't take part in the trial.

But please bear in mind that some interventional trials use placebo-controls. Placebos are sugar-pills which look the same as the potential new treatment. Doctors give the potential new treatment to one group of patients and the placebos to another. This helps them identify exactly what effect the treatment has on patients.

So, if your teenager takes part in an interventional trial, they may receive the potential new treatment or the placebo.

Clinical trials are often a family's main hope of accessing potential new treatments sooner.

Placebos are sugar-pills which look the same as the potential new treatment.

If your teenager takes part in an interventional trial they may receive a placebo.

If they do receive the potential new treatment, it may help your teenager by making them stronger and healthier. But, of course, the treatment could also have no effect on them. Or it may even harm them.

These are things that you need to think about carefully and discuss with your doctors.

How should my teenager be involved in decisions about clinical trials?

As your son or daughter matures, they should play a bigger part in the decisions about clinical trials.

They'll probably start wanting to know more about clinical trials and research. For most people with DMD, this will be from about 12 years old.

Encourage them to ask questions and express their thoughts and feelings about the different aspects of a clinical trial, including:

- Possible benefits, side-effects and risks
- The experience of taking part in the trial
- Time, travel and energy required
- Disruption to school, hobbies etc.
- Impact on family (support required, time off work)
- Anything else that is important to your teenager and your family

Teenagers with learning difficulties still need to be included in discussions about clinical trials. Parents and doctors cannot assume they will consent.

Ultimately, your son or daughter will only be able to take full responsibility for decisions about clinical trials when they are 18 years old.

What are the benefits of taking part in an observational trial?

If your teenager takes part in an observational study, they will not receive any treatments. They will only be observed and measured.

Your teenager will help doctors to learn more about DMD. Over the long-term, this will help them to develop and use drugs better for many DMD patients.

But they will not benefit directly from the trial themselves.

Your teenager will help doctors to learn more about DMD.

How can I find out about clinical trials for DMD?

You can find all the clinical trials for DMD in the UK on Duchenne UK's clinical trial finder website at **www.dmdhub.org/clinical-trial-finder**

We set up the DMD Hub to ensure that all patients with DMD - children, teenagers and adults - have the opportunity to access clinical research opportunities in the UK.

Your consultant won't always tell you about research. So, you should check the DMD Hub website regularly and sign up to their newsletter so you can stay up-to-date yourself.

The DMD Hub ensures that all patients with DMD in the UK have access to clinical research opportunities.

Fundraising for medical research

We know that the people who are most passionate about raising money to find effective treatments for DMD are the ones who live with it every day.

Many DMD families raise money for Duchenne UK to fund medical research. Together, we have raised millions of pounds which we are investing in research right now to bring treatments to children and teenagers with DMD.

You can find out more about fundraising on the Duchenne UK website at www.duchenneuk.org/support-us

Chapter 15

Chapter 15 - Further Information about DMD

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In a nutshell

1 Causes of DMD

This folder is for parents of teenagers and adults so it doesn't cover the causes of DMD. Many will already know about DMD's causes.

If you need this information, you can find it on Duchenne UK's website, www.duchenneuk.org/what-is-duchenne

2 We're working on treatments for DMD

Medical researchers are working hard to develop effective treatments for DMD.

They are making great advances which are improving the length and quality of life for people with DMD.

You can find out about clinical trials on the DMD Hub website, www.dmdhub.org.

> Medical researchers are working hard to **develop effective treatments for DMD.**

3 Females with DMD

Girls and women very rarely develop DMD because of the way genes are inherited.

Duchenne UK are here to support everyone affected by DMD. Please do contact us if you would like our help.

4 Females who are manifesting carriers

Some girls and women, who are carriers of DMD, have some symptoms. This is because they have reduced amounts of dystrophin.

5 Genetic testing for family members

If your teenager has inherited DMD through their genes, other family members may also be affected.

Genetic counselling can give your teenager and your family the information you need to plan for the future. Your teenager may find genetic counselling helpful if they want to have children of their own.

Causes of DMD

If you would like to learn more about DMD, including its causes and why it affects boys more than girls, please go to the Duchenne UK website, www.duchenneuk.org/what-is-duchenne

In particular, we recommend that you download chapter 1 of the *DMD Family Folder: Support and Guidance for Newly-diagnosed Parents* (www.duchenneuk.org/support-at-diagnosis).

Treatments for DMD

Extensive medical research and clinical trials are underway to find effective treatments.

There are some current treatments which are already improving the quality and length of life for children, teenagers and adults living with DMD.

Great advances have been made in steroid treatments and treatments that protect breathing and the heart. Steroid treatments are now protecting the lungs, hearts and muscles of many people with DMD.

Duchenne UK is investing millions of pounds in medical research and clinical trials. This is bringing us ever closer to effective treatments for DMD.

See Chapter 14: Research and Clinical Trials for more information about potential treatments.

Advice and resources

Duchenne UK can help you to access all the available information and resources so you can make informed choices for your teenager and your family.

Medical research
is underway to find a treatment.

£9 million
committed to all forms of medical research.

Great advances
are being made.

£4.5 million
committed to clinical trials.

*Statistics correct at the date of publishing

Females who have DMD or are manifesting carriers

DMD affects only
1 in 50 million girls
compared to
1 in 3,500 boys.

A girl can only develop DMD if both of
her X chromosomes
have faults in their dystrophin genes.

Girls and women with DMD experience
similar challenges
to boys and men with DMD.

Manifesting carriers

Some female carriers of a faulty dystrophin gene have symptoms of DMD, including fatigue, muscle weakness and cramping.

These girls and women are called ‘manifesting carriers’ because they produce reduced amounts of dystrophin.

Where to get help for your daughter or yourself

If your daughter has DMD or you are a woman who is a manifesting carrier, please contact Duchenne UK at support@duchenneuk.org.

We are here to help everyone affected by DMD – girls, women, transgender and non-binary people, as well as boys and men.

Genetic testing for family members

Genetic advice for men with DMD who want children

Men with DMD have had children of their own. If your son is considering having children, he may find it helpful to get advice from a genetic counsellor or his neuromuscular consultant.

See Chapter 6: Friendships, Relationships and Sex for more information about how genes are inherited by children whose fathers have DMD.

DMD and the wider family

If your teenager has inherited DMD through their genes, other members of your family may also be affected.

Parents who are carriers of DMD

If you are a carrier, you may be at increased risk of heart disease.

We recommend that you ask your teenager's neuromuscular consultant for advice about regular heart check-ups. You should also let your GP know that you need heart check-ups.

Mothers with germline mosaicism

A small number of women who do not test positive as carriers for DMD may still be able to pass a faulty DMD gene to their children. This is called germline mosaicism.

It is caused by a mutation in the DMD gene in the cells of some of the mother's eggs. But the mutation is not in the DMD gene in the rest of the mother's cells.

If one of the affected eggs is fertilised, the resulting baby will have DMD if it's a boy or be a carrier if it's a girl.

Doctors estimate that around 15% of mothers of people with DMD have passed a faulty DMD gene to their children in this way – even though the mothers do not appear to be carriers.

Support from other DMD carriers

If you are a carrier and would like to speak with someone else who is a carrier, please contact us at:

support@duchenneuk.org

Genetic counselling

Genetic counselling can give you and your family the information you need to plan for the future.

It will help you understand how DMD can be passed on through families.

You should ensure you meet with a doctor or researcher for genetic counselling if you have not done so already.

It will help you make informed choices about your health and your family's health.

Genetic counselling also gives your extended family the opportunity to think through whether they should have genetic testing.

You may find you can get the most out of your counselling if you make a list of questions before your appointment. Then, you can make sure you cover everything you want to talk about.

Genetic testing for siblings

Genetic testing is usually only offered to sisters of people with DMD because of the risk they may be a carrier.

The tests are usually offered when the sister is 16 or older. Then, they can have the tests before they begin their own family. The tests can be done earlier if the girl has symptoms.

If you have any concerns about your daughter, you should speak with your neuromuscular consultant.

> You should ensure you meet **with a doctor or researcher for genetic counselling.**

Chapter 16

Chapter 16 - Contacts

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Your contacts

Your teenager and family can get the help you need from healthcare professionals, education professionals, the local authority and the Duchenne community.

But keeping track of all these people can take a bit of effort. So, we've put together these pages with our suggestions for the people who can help you most.

We hope you'll find them useful.

The Duchenne community	
Duchenne UK	**www.duchenneuk.org** We are a charity focused on funding and accelerating treatments and a cure for DMD. We also support families with DMD.
DMD Hub website	**www.dmdhub.org** The DMD Hub website has a clinical trial finder for every existing and pending clinical trial for DMD in the UK. It's run by Duchenne UK. The website has information about clinical trials – including the different types of trials and the things you should think about if you are considering taking part in a clinical trial.
Duchenne UK's Parent Network	Please contact **support@duchenneuk.org.** We can put you in touch with other local families.
Duchenne Family Support Group (DFSG)	**www.dfsg.org.uk** DFSG is a positive national support network of parents, their families and professionals. They run a helpline and newsletter. They signpost families to the relevant organisation and other families in similar situations. And they provide days out and holidays which are tailored for people with DMD.

Support for DMD siblings	**www.facebook.com/DuchenneSiblings** **www.dmdsiblings.com** **www.facebook.com/DMDsiblings** Both these networks were set up by people who have a brother with DMD. They bring together DMD siblings so they can share their experiences and support each other.
Pathfinders Neuromuscular Alliance	**www.pathfindersalliance.org.uk** Pathfinders Neuromuscular Alliance supports teenagers and adults with muscular dystrophy and related conditions with advice, information and advocacy to improve their quality of life.
Decipha	**www.decipha.org** Decipha is a not-for-profit organisation set up by DMD parents who are experts in special education needs. They provide educational advice. They can help you with assessments and Education Health and Care Plans (EHCPs). They also provide reading, maths and social skills programmes for children and teenagers with special needs. And they provide family coaching sessions.
Muscular Dystrophy UK	**www.musculardystrophyuk.org** Muscular Dystrophy UK brings together individuals, families and professionals together to fight muscle-wasting conditions. They support people with 60 rare and very rare progressive muscle-weakening and wasting conditions.

Organisations which can help

Charities which support teenagers with disabilities and their families	• Contact a Family - **www.contact.org.uk** • Caudwell Children - **www.caudwellchildren.com** • SOS!SEN (educational advice) – **www.sossen.org.uk** • Muscular Dystrophy UK - **www.musculardystrophyuk.org** • Scope – **www.scope.org.uk** • See Chapter 8: Financial Support for organisations that provide financial support and advice
Organisations which provide help in your local area	• Citizens' Advice Bureau – **www.citizensadvice.org.uk** • Carers' alliance – search online for the name of your local authority + carers' alliance • Disabled Children's Register – search online for the name of your local authority + disabled children's register • Home improvements agencies (can help with adaptations) – search online for the name of your local authority + home improvement agency

Your personal network

Your local authority	• Social worker • Disabled children team • Occupational therapist – social care • Occupational therapist – healthcare
Healthcare professionals	• GP • Neuromuscular clinic • Consultant neurologist • Physiotherapist • Occupational therapist • Orthotist • Hydrotherapist • Dietician • Counsellor

Education Professionals	• School • Teacher • Special education needs co-ordinator (SENCO) • Speech and language therapist
Research and clinical trials	• Clinic/hospital • Principal investigator

Personal notes and contacts

Your name:

Your teenager's name:

Your address:

Your consultant/s:

Other useful information:

Duchenne UK

WWW.DUCHENNEUK.ORG SUPPORT@DUCHENNEUK.ORG
CHARITY NUMBER 1147094