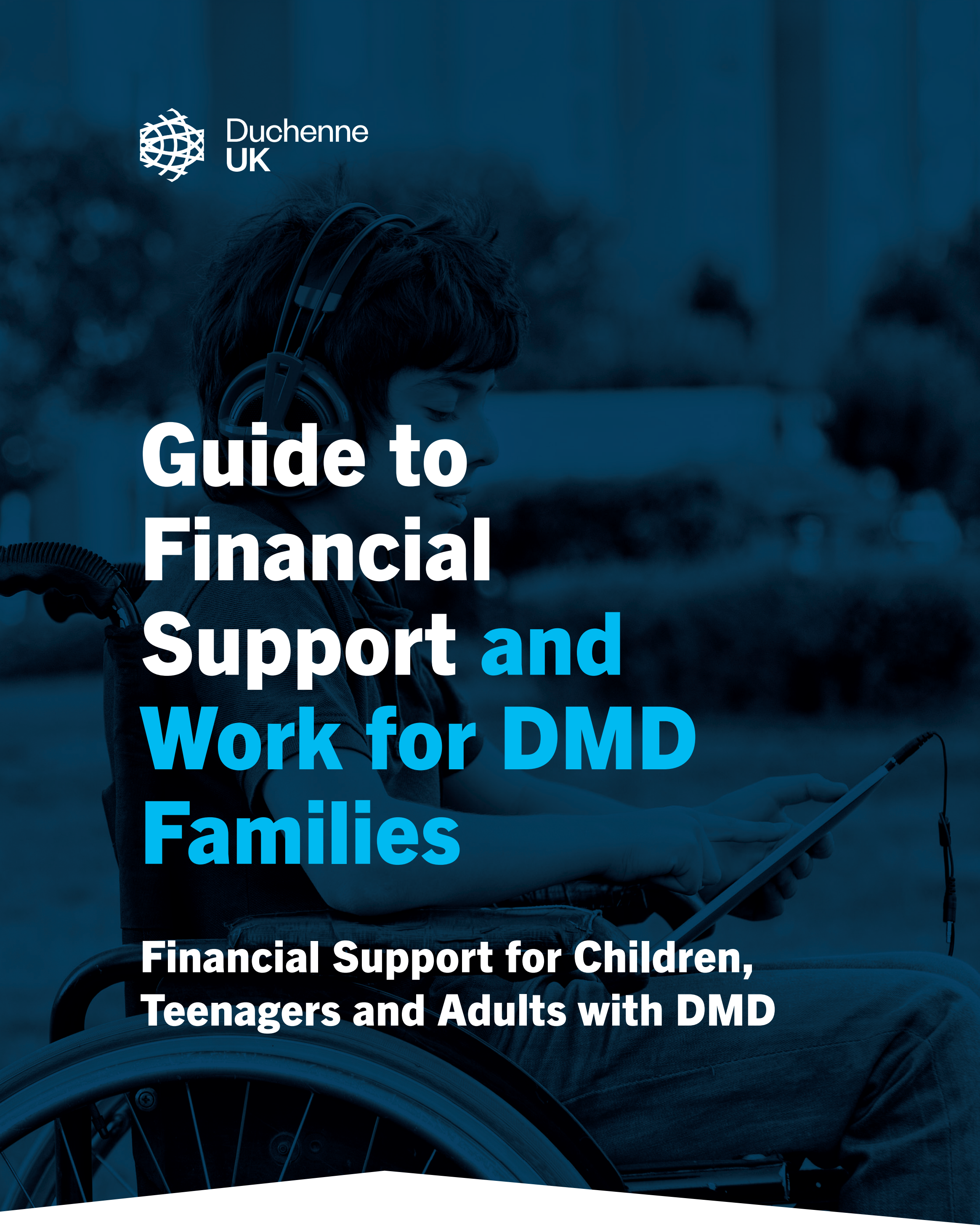

Duchenne
UK

Guide to Financial Support and Work for DMD Families

Financial Support for Children, Teenagers and Adults with DMD

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CHARITY NUMBER 1147094

Guide to Financial Support and Work for DMD Families

Part 1 — Financial support

Part 2 – Your work

Note about the wording in this guide

This guide has been produced for parents by parents.

In most cases, we have used ‘your child’ to refer to the person with DMD. However, we recognise that they may be a child, teenager or young adult. We have done this to keep the wording in the guide as simple as possible.

In a nutshell – Financial support and your work

1

You’re entitled to support from the Government

Until your child is 16, the Government will pay you a Disability Living Allowance (DLA) because you are looking after a child with a disability. When they turn 16, they’ll receive a Personal Independence Payment (PIP) instead.

You may also receive Carer’s Allowance, Universal Credit or other benefits.

If you are not working or on a low income, you may also be eligible for a motability car 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 child needs new equipment.

3

You can access new support as your teenager grows up

The benefits and support available will change to meet your child’s changing needs.

They may receive personal budgets for health, social care or education.

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.

They may be able to get a wheelchair from the NHS or receive a contribution towards one. And they may be eligible for grants for adapting your home.

As your child grows up, they'll 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 child'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 children, teenagers and young adults with DMD continue to work.

We can put you in touch with other DMD parents so you can talk about combining work and care with them. Please email us at support@duchenneuk.org.

Important note

The information in this guide was correct at the time of writing in 2020. But benefits change frequently. So, we recommend that you look up the most up-to-date information on the internet.

You're entitled to financial and care support

As a parent who is bringing up a child with a disability, you are entitled to support from the Government and your local authority.

If you are on a low income,you'll get more support.

Part 1 – Financial support

Government

You will have to apply for benefits (except for child benefit). You can find information about eligibility and application processes for each benefit on the internet.

Disability Living Allowance (DLA)

www.gov.uk/disability-living-allowance-children

Disability Living Allowance (DLA) is given to people who are looking after a child under 16 who has difficulty walking or needs much more looking after than a child of the same age who doesn't have a disability.

You can claim DLA for a child as long as you look after them as if your their parent. So, you could be their step-parent, guardian, grandparent, foster parent or older sibling.

DLA is not means-tested so your income and savings will not be assessed. It can be claimed even if both parents are working. It is usually paid every four weeks into your bank, building society or credit union account.

Many DMD families

receive DLA payments from diagnosis

Two types of DLA

Two types of DLA – care and mobility.

Care DLA has three levels, depending on your child's needs:

- **Low (£23.70/week)** – for children who need help for some of the day or night
- **Medium (£60.00/week)** – for children who need frequent help or constant supervision during the day and supervision at night
- **High (£89.60/week)** – for children who need help or supervision throughout both the day and night

Mobility DLA has two levels, depending on how much help your child needs getting about:

- **Low (£23.70/week)** – for children who can walk but need help and/or supervision when they are outdoors
- **High (£62.55/week)** – for children who can't walk, can only walk a short distance without severe discomfort, or could become very ill if they tried to walk

Eligibility

The rate of DLA that your child receives depends entirely on their present day-to-day care needs. Their diagnosis and their future needs will not be taken into account.

Many DMD families do receive DLA payments from the time of diagnosis because their child's needs are already significantly different to the needs of most children of the same age. So, people who are caring for babies and toddlers are eligible too.

In order to get DLA payments, you need to prove that your child needs more help than children of the same age who do not have disabilities.

You do that by filling in a DLA Claim Form. There are no tests. You can download a form from www.gov.uk/government/publications/disability-living-allowance-for-children claim-form.

You need to describe their needs in as much detail as possible so that the DLA Assessors can understand all of their requirements. So, don't describe one of their best days.

You'll also need to include details of the medical professionals who look after your child. We recommend that you include the doctors at their neuromuscular clinic. They'll have the best understanding of the impact of DMD on your child.

It's a long form so take your time to fill it in.

The DLA assessment is not a one-off process. You will probably have to get your child's needs assessed a few times as they grow up.

When you have your child re-assessed, you may find that your DLA payment is increased. But please be aware that it can stay the same or even be reduced.

Help applying for the DLA and PIP

You can get help filling in the DLA and PIP Claim Forms if you need it.

Cerebra, a charity which supports children with brain conditions and their families, has created a guide to filling in the DLA form and a video with additional hints and tips. You can find them at **www.cerebra.org.uk/help-and-information/guides-for-parents/dla-guide/.**

You can also get individual help from:

- the Welfare Officer at the DLA Helpline on 0800 121 4600
- your local authority
- your local independent living centre (use Google to find your local centre)
- the Citizens Advice Bureau (www.citizensadvice.org.uk)
- The Welfare Officer at the PIP Helpline on 0800 121 4433

Appealing the DLA Assessment

If you think the DLA assessment of your child is wrong, you can appeal. (Please don't worry too much about this. Families with a child who has DMD rarely have to go to tribunal.)

The assessors must re-consider their decision. Then, if you are still not happy with the second decision, you can go to a tribunal, with a judge and doctors. If you do, we recommend that you seek support from a third party, such as the Citizen's Advice Bureau, the Welfare Officer at your local authority or your local independent living centre.
Find out more: www.gov.uk/disability-living-allowance- children

Personal Independence Payments (PIP)
www.gov.uk/pip

Personal Independence Payments (PIP) are for people who are between 16 and 64-years-old and have long-term ill health or a disability.

It is a cash payment which aims to cover the extra cost of having a disability. It is not means-tested. It is payable even if an individual is working.

You must have a health condition or disability which causes difficulties with daily living or getting around or both to be eligible for PIP.

PIP has two parts. Both parts have standard and enhanced rates -

- **Daily Living PIP** – this is for support in daily living and care:
  Standard - £60.00
  Enhanced - £89.60
- **Mobility PIP** – this is for support in getting around:
  Standard - £23.70
  Enhanced - £62.55

The amount you receive depends on how DMD affects you. Your rate will be regularly reviewed to make sure you receive the right support.

Moving from DLA to PIP

Shortly after your child’s 16th birthday, the Department for Work and Pensions (DWP) will invite them to apply for PIP.

They need to apply by the deadline before their DLA payments stop. As their parent, you will be able to help them with their application.

> They need to apply by the deadline before their DLA payments stop. **As their parent, you will be able to help them with their application.**

Application process

They need to request a PIP claim form from the DWP. They can call them or write to them using the contact details on the PIP web pages.

Once they have completed and returned their PIP claim form, they’ll be invited to a meeting by the DWP. The meeting can be either at their home or an assessment centre. The interviewer will ask them about how DMD affects their ability to carry out activities and impacts on their daily life.

Assessors want to know about:

- their specific needs at school, in the home or when out
- the extra help they need with dressing, washing, eating, communicating and moving about
- any personal budget or Education, Health and Care Plan (EHCP)

You may find it helpful to keep a diary recording how your child’s condition affects their daily life. You should also ask for supporting evidence from health professionals, your child’s school or social worker.

Preparing for the interview

The assessor will interview your teenager. You will be able to accompany them to the assessment.

You'll be able to clarify what your teenager says. You can refer to your claim form when you answer questions.

You can request a paper-based review if you feel your teenager cannot cope with the interview. You can request this by speaking to the DWP.

These guides on PIP can help you prepare:

- **Citizen's Advice's guidance** - www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/pip/help-with-your-claim/your-assessment
- **Scope** - www.scope.org.uk/advice-and-support/personal-independence-payment-pip

Appealing the PIP Assessment

You can appeal the decision from your PIP assessment. This is called a mandatory reconsideration. The assessors must re-consider their decision.

You need to request a mandatory reconsideration within one month of the decision date. You do this by contacting the benefits office that gave you the decision.

You will need to show why the original decision was wrong. You can provide new medical evidence, new reports or care plans from specialists, therapists or nurses and bank statements or payslips.

Advice Now has guidance about how to win an appeal – www.advicenow.org.uk/guides/how-win-pip-appeal

(Please don't worry too much about appealing the decision. People with DMD rarely have to go to tribunal.)

Universal Credit
www.gov.uk/universal-credit

Universal Credit is a single monthly payment which consists of a number of elements:

- **Standard allowance** – the basic rate which is given to everyone who receives Universal Credit
- **Child element** – for children under 16 and qualifying young people under 20 (only if you are responsible for them)
- **Disabled child addition** – for children who receive DLA or PIP
- **Limited capability for work or work-related activity element** – may not apply to new claimants
- **Carer element** – for carers
- **Housing element** – to help meet the cost of housing
- **Childcare costs element** – to help meet the cost of childcare

Universal Credit eligibility

You are eligible to claim Universal Credit if you are caring for a disabled child or young person. (Usually, it is only given to people who are actively looking for work.)

It is means-tested, so your income will be taken into account. Your savings will also be taken into account if they are more than about £16,000. Disability Living Allowance (DLA) is not taken into account. If you own the home that you live in, its value is not taken into account.

Use the Government's eligibility Checker
to see which benefits are available to you

If you receive Universal Credit, you may also be eligible for free school meals, dental work, prescriptions and reimbursement on transport to and from hospital.

The rules for receiving Universal Credit depend on where you live. You can use the Government's Eligibility Checker to see which benefits are available to you: www.citizensadvice.org.uk/benefits/universal-credit/before-you-apply/check-if-you-can-get-Universal-Credit.

If you don't have a postcode you can use, check if you can apply for Homelessness Help at www.citizensadvice.org.uk/housing/homelessness/applying-for-homeless-help/check-if-you-can-apply-for-homeless-help

Carer’s Allowance
www.gov.uk/carers-allowance

You are eligible for the Carer’s Allowance of £67.60 if your child receives the middle or high level of DLA Care Allowance and you care for them for 35 hours or more per week.

There are no age restrictions on the child who is being cared for. So, people who are caring for babies and toddlers are eligible too.

But the Carer’s Allowance is means-tested. People who earn more than £128/week (£6,656/year) after tax and expenses are not eligible. Your expenses can include 50% of your pension contributions and some of the costs of caring for your children while you’re at work. Your savings are not taken into account. Also, you cannot be in full-time education.

The Carer’s Allowance is paid to the parent or caregiver who is personally caring for the child. So, it is not affected by your partner or spouse’s income.

It is paid weekly in advance or every four weeks into your bank, building society or credit union account.

Additional benefits for people who receive Carer’s Allowance

Each week that you get Carer’s Allowance, you’ll automatically get National Insurance credits too.

You may also be able to apply for:

- support from your local authority
- reduced Council Tax
- Pension Credit if you’re over working age

You are eligible for the Carer’s Allowance if your child receives the middle or high level of DLA Care Allowance and you care for them for 35 hours or more per week.

There are no age restrictions on the child who is being cared for.

The Carer’s Allowance is means-tested but your savings are not taken into account.

Local Housing Allowance (LHA)

www.gov.uk/guidance/local-housing-allowance

Local Housing Allowance (LHA) helps tenants renting from private landlords. LHA rates are based on private market rents being paid by tenants in the broad rental market area. This is the area within which a person might reasonably be expected to live.

You will be eligible for a set number of bedrooms depending on the number of people in your household. You can check the LHA rates for your area and the number of bedrooms that you are eligible for on the LHA web pages.

Pension Credit

www.gov.uk/pension-credit

If you have reached the Government's retirement age, you may be eligible for higher amounts of pension credit because you have caring responsibilities.

Pension credit provides extra retirement income if you are on a low income.

Motability Scheme

www.gov.uk/help-for-disabled-child/motabilty-scheme

www.motability.co.uk

The Motability Scheme leases cars, scooters and powered wheelchairs to disabled people in exchange for their mobility allowance component of their Disability Living Allowance (DLA).

You'll be eligible for a motability vehicle if your child receives the high rate of the mobility component of their Disability Living Allowance (DLA).

Through the scheme, you'll be able to lease a brand new car that's suitable for your child. If they are regularly using a wheelchair, you'll be able to get a wheelchair accessible car.

You may need to make an upfront payment to cover part of the costs, especially for larger vehicles. You will need to pay for petrol. Insurance, tyres and servicing are included in the scheme.

Road Tax Exemption

www.gov.uk/financial-help-disabled/vehicles-and-transport

If you own your car and your child receives the high rate of the mobility Disability Living Allowance (DLA), you can apply for an exemption on road tax through the DVLA. Also, motabilty vehicles are not taxed.

Benefits calculator

www.gov.uk/benefits-calculators and **www.gov.uk/financial-help-disabled**

You can use a benefits calculator to see if you are eligible for any other support.

You can also get advice from one of the national charities who advise people about benefits, such as Turn to Us, Entitled To and Policy in Practice.

You can find their details later in this guide.

Child Benefit
www.gov.uk/child-benefit

You should already be receiving child benefit.

Everyone who is responsible for one or more children under 16 in the UK should receive child benefit. (Although, only one per person can get child benefit for each individual child.)

But if you or your partner's individual income is over £50,000, you will have to pay back some or all of your child benefit.

Child benefit is paid every four weeks and the current rates are:

- eldest or only child - £21.15/week
- additional children - £14.00/week

Child benefit also gives you National Insurance Credits which will count towards your state pension. So, it's worth having even if you have to pay it back.

VAT exemptions
www.gov.uk/financial-help-disabled/vat-relief

Wheelchairs, adapted beds, hoists, ramps, stair lifts, and adaptations for your car and medical appliances are all exempt from VAT.

This is worth knowing as VAT adds 20% to the cost of most goods.

Cold weather payments
www.gov.uk/cold-weather-payment

If you receive Universal Credit, you can also get cold weather payments.

Then, you can claim £25 for each day where the weather in your area is zero degrees celsius or below for seven consecutive days.

Support from your local authority

By law, your local authority must provide services and support to your child and you.

The Local Offer in your area – Google 'local offer' + [the name of your local authority]

The local offer is a list of all the services provided by your local authority for children and young people (0 - 25-years-old) who have a disability.

Your local authority has a statutory duty to provide a local offer to residents. It must cover health, education and social services. This includes special education provision, short break services, leisure activities and childcare for disabled children.

Personal Budgets www.nhs.uk/conditions/social-care-and-support-guide/money-work-and-benefits/personal-budgets/

A personal budget is the money available to an individual or family from the Local Authority to meet their health, social or educational needs.

Personal budgets give people more choice and control over their health, care and parts of their education. You can decide what type of support works best for you and then use your personal budget to buy that support.

Your teenager will need to have a social care assessment as part of their application for a personal budget. You can find out more by talking to your local authority and the healthcare professionals in your area.

Personal budgets can be run in three ways:

- **A managed account** – your local authority manages your personal budget according to your wishes as set out in your care plan
- **A third party account** – a broker or service provider manages your funds (these are sometimes called 'individual service funds')
- **Direct payments** – you are given the money to spend yourself on meeting your needs in line with your care plan

The three types of personal budgets are:

- **Personal health budgets** –for services that help people stay healthy physically and mentally, e.g. hydrotherapy, counselling or wheelchairs.

  If your child's needs increase significantly, they may get more support from a personal health budget than other forms of financial support. Their GP or social worker should be able to advise you. They are managed by your local clinical commissioning group (CCG), not your local authority.

- **Personal social care budgets** – for services that provide practical or emotional help, e.g. help in the home, short breaks, social work and other things that help people live well.
- **Personal education budgets** – for services that support education and learning, e.g. special equipment or school transport

> You can have three types of personal budgets - **health, social and education.**

Direct payments to parents – www.gov.uk/apply-direct-payments

Direct payments are payments that parents receive to buy social care,health or education services themselves, rather than using the local authority’s services.

You can also use direct payments for equipment.

For example, parents might use direct payments to pay for a short break which they arrange themselves rather than using the short break services which their local authority provides.

They are part of your local authority’s care package for your child. They are not a benefit (like the Disability Living Allowance or the Carer’s Allowance).

Direct payments

are part of your local authority’s care package

Your local authority will assess your child’s needs and agree an outcome for your child with you (such as accessing leisure activities or seeing friends and family).

Then, they’ll pay for a service that achieves this outcome (such as paying for swimming lessons or paying for a personal assistant to play sport with your child). But the direct payment cannot be used to pay for something that achieves a different outcome (such as buying a new washing machine).

You can choose to take a mix of direct payments and local authority services. Or you can choose to take only your local authority’s services.

Some families prefer the greater choice and independence of direct payments. Other families don’t want to manage payments themselves so just use the local authority’s services.

How do you apply for direct payments?

Different local authorities use different assessments to work out what a child needs and if their family is able to meet their needs.

Most local authorities have a Children with Disabilities team who will do a Children and Family Assessment. This should include assessing the impact on you as your child's carer.

Your child's needs and your family's situation should be reassessed every year if they are changing quickly.

How to use direct payments to employ your own personal assistants?

You can use your direct payments to employ your own personal assistants.

Personal assistants can provide a wide range of personal care, including preparing meals or help with getting dressed, taking medication or traveling to school. While your child is young, they could be a registered child minder.

The Direct Payment team at your local authority will help you find personal assistants and employ them properly. Your direct payments will cover their pay, national insurance, holiday pay and sick pay.

You cannot use direct payments to employ a close relative or someone who lives in the same house as you.

Can direct payments be used to pay for childcare while you work?

Unfortunately, childcare for parents to work is usually not eligible for direct payments.

But you may be able to arrange to use your direct payments for short breaks to pay for after-school or holiday care so you can work. If that's something you want to do, you should talk it through with the team at your local authority.

Short breaks
www.gov.uk/government/publications/short-breaks-for-carers-of-disabled-children

Short break services provide care for children by someone other than their family or school.

By law, local authorities must offer short break services for children with disabilities. It is a statutory requirement under the Children's Act Sections 17 and 20.

Your child's and your family's needs for short breaks over the year should be assessed by the local authority.

Local authorities offer different types of short break services, including:

- **few hours** – such as play provision or 1-2-1 support
- **overnight for 1, 2 or up to 7 nights** – from a specialist family carer, which tends to be for older children
- **befriending services** – run by volunteers, holiday or summer camps and approved foster care.

Parents can also arrange their own short break services using their direct payments.

Disabled Facilities Grant for making adaptations to your home

www.gov.uk/disabled-facilities-grants

If you need to adapt your home to make it suitable for your child, your local authority may give you a disabled facilities grant to pay for the building work.

For example, you may need to install a lift or a downstairs bathroom in your house. (You can find more information about adaptations in the ‘Your Home’ chapter of the *Guide for Newly -Diagnosed Parents*).

The maximum amount you can apply for varies depending where you live:

- **England** – up to £30,000
- **Wales** – up to £36,000
- **Northern Ireland** – up to £25,000
- **Scotland** – not available not available (see alternatives at www.gov.scot/Topics/Health/Support-Social-Care/Independent-Living/Equipment-Adaptations)

Your grant must be approved before you begin any building works, and before asking an architect to design the adaptations to your house or applying for planning permission from your local authority. Grants cannot be awarded after you have begun work.

The Social Care Occupational Therapist (OT) at your local authority will assess your home and work out what adaptations you need to make your house accessible for your child.

Your benefits will not be affected if you receive a Disabled Facilities Grant.

Applying for a Disabled Facilities Grant

You need to contact the Social Care Occupational Therapist (OT) at your local authority. You can contact the OT yourself or through your child’s social worker.

Local authorities cannot refuse a request for an OT assessment. The OT will assess your home and work out what adaptations you need to make to your house so that you can care for your child properly.

Find out more: www.gov.uk/disabled-facilities-grants

Council housing

Your child’s OT can also give you a medical referral for priority council housing if your home cannot be adapted to meet their long-term needs.

Find out more: www.gov.uk/council-housing

Council Tax Reduction

You may be eligible for reduced council tax if you have a low income, claim benefits or have particular adaptations to your home.

Your bill could be reduced by up to 100%. It doesn’t matter if you own your home or rent it privately. Your eligibility depends on where you live and your circumstances. Find out more: www.gov.uk/apply-council-tax-reduction

Northern Ireland has a different scheme: www.nidirect.gov.uk/rates-help

Wheelchairs

When your child’s needs are changing significantly, ask their OT to refer them to the NHS wheelchair services.

Electric wheelchairs are provided by the NHS wheelchair services, not your local authority.

You can get a personal wheelchair budget to spend either within the NHS or outside the NHS.

(See: www.england.nhs.uk/personal-health-budgets/personal-wheelchair-budgets)

You may also want to speak to Whizz-Kidz (www.whizz-kidz.org.uk), a charity which helps young disabled people. They provide a range of mobility equipment to give children and young people with a physical disability independence at home, at school and at play.

Social care assessments

All children with disabilities are entitled to an assessment of their social care needs by their local authority.

This is because they are considered to be in need. They do not have to be at risk of abuse or neglect.

Your child's assessment will be used to work out which social services they need from the local authority.

Your
Child
Is entitled to
an assessment

For most children, their social care assessment should be done as part of their Education, Health and Care Plan (EHCP).

Their EHCP will bring together all the information about them into one document. This includes the assessment of their needs (sections B, C and D) and the provision of support (sections F, G and H). The support could include direct payments and funding for short breaks.

The EHCP will be created and used by teachers, health care professionals and social workers. (See the education chapter of the *DMD Family Folder for Newly-Diagnosed Parents* for more information about EHCPs.)

If you have never had a social worker or had any social care provision, then you will need to request a social care assessment. You can do this through the Children and Disabilities Team in your local authority.

The Special Educational Needs Co-Ordinator (SENCO) at your child's school should arrange the EHCP. However, social care will not be automatically included unless your child has had a social care assessment.

What happens during an assessment?

Different local authorities use different assessment processes. Many use the Common Assessment Framework (CAF), the Early Help Assessment (EHA) or social care assessments.

The social worker or other agreed professional will use the assessment to build up a picture of your child's current needs and the family's current ability to meet their needs. They will not predict their future needs.

The
Social Worker
will assess their
current needs

During the assessment, the social worker will gather information from your child and you and your partner. They will probably want to meet at your family home so they can observe your child's social skills and social environment.

They may also wish to see your child at school and talk to their teacher, GP, school nurse and/or neuromuscular consultant. Your child won't have to do any tests.

The social worker may wish to see your child at school **and talk to their teacher, GP, school nurse and/or neuromuscular consultant.**

How do I get an assessment for my child?

Most local authorities have a specialist social worker or team for children with disabilities.

You can request an assessment for your child yourself by telephoning the social care department at your local authority. You can also be referred by your child's GP or their teacher.

Your child will be entitled to new assessments as their needs change. Social care services understand that DMD is a progressive illness.

How soon should I get a referral?

Social care exists to prevent problems for people, as well as solve them. You need to have a defined need to access Social Services. But you don't need to be in crisis.

So, contact Social Services when your child's needs are beginning to change and your family is finding it increasingly difficult to meet them. Don't wait until you feel overwhelmed.

Some Social Services teams are very busy. This can cause delays so it's always better to contact them sooner rather than later.

Occupational therapy

Occupational therapists (OTs) are the people who will assess your family home to see if it's suitable for your child for the long-term. And they will help you apply for a Disabled Facilities Grant.

If your home cannot be adapted to meet your child's needs, your child's OT can give you a medical referral for priority social housing.

Confusingly, there are two different services which are both called 'occupational therapy':

- **Social care occupational therapy** – For aids, equipment and adaptations in the home (including referrals to wheelchair services)
- **Healthcare occupational therapy** – For bodily functionality (such as help with walking or using pencils)

Your child's OT can give you a medical referral for priority social housing

Some local authorities have combined the two functions into one service. Some haven't.

Applying for a Disabled Facilities Grant

The process is the same for people who live in their own homes, rented homes and social housing.

They will assess your home and recommend the adaptations that you need to make so it's suitable for your child's current and future needs. They can also advise you if you need to move home so that you can choose a new place that it is suitable (or could be adapted so it's suitable).

They will help you:

- **If you own your home** – Apply for a disabled facilities grant for making adaptations
- **If you rent your home** – Apply for a disabled facilities grant for making adaptations if your landlord is willing for the changes to be made

  – Provide a medical referral for priority social housing if you can't stay in rented accommodation
- **If you live in social housing** – Provide a medical referral for a bungalow or other suitable housing; or help you apply for a disabled facilities grant for your current home.

Get a referral sooner rather than later

We encourage you to get a referral to an occupational therapist as soon as you can – even if you think your child won’t need adaptations to your home for a few years.

The process for applying for grants and making adaptations or being moved to a suitable council house can take one or two years – or even longer.

You can refer yourself to the occupational therapist team at your local authority.

Or you can ask your child’s social worker to refer you.

> The process for applying for grants and making adaptations or being moved to a suitable council house **can take one or two years– or even longer.**

Help accessing financial support

You can get advice about benefits from your local authority and from charities which support disabled people and those on low incomes.

Your local authority

We recommend that you contact your local authority soon after your child is diagnosed with DMD.

Local authorities vary. Some are more helpful and organised than others. So, don't wait until you are struggling. Contact them early so you have time to get everything set up properly.

Your child's social worker

Your child's social worker is the best person to contact first. They can help you to navigate the benefits system.

They can help you to access financial support by assessing your eligibility. And they can arrange direct payments and other types of support.

Your child's medical care team

You may also find other people in your child's care team who can help you with benefits – such as their occupational therapist, their physiotherapist or a specialist nurse.

Look out for people who are helpful and seem to know how the system works. Then, ask them if they will give you advice.

Don't wait
until you are struggling, contact the authorities early.

Some authorities
are more helpful and organised than others

Look out for people
who are helpful and know the system

SENDIASS

(Special Educational Needs and Disability Information Advice and Support Service)

Every local authority has a SENDIASS service for the 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 offers free, confidential and impartial advice and support. It is run at arms-length from the local authority itself. They will work with you, your child 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

You can find your local SENDIASS service through your local authority or on Google.

Advice from charities

These charities can give you personalised advice about the benefits which you can receive from the Government and your local authority.

Turn to Us (www.turn2us.org.uk)

Turn to Us is a national charity which provides practical support to people who are struggling financially.

They can give you information about income-related benefits, tax credits, Council Tax Reduction, Carer’s Allowance and Universal Credit. They can also give you advice about how your benefits will be affected if you start work or change your working hours.

They also award grants of their own.

They provide their services through their website, email helpline and in person, using local advisers in partner organisations.

You can get quick information about your personal entitlements using their:

- online benefits calculator – tells you which means-tested benefits you may be eligible for
- online grants search – helps you find grants and other types of help

Carers UK (www.carersuk.org)

> Carers UK is support network and campaigning movement for the **6.5 million people in the UK who are carers.**

They have excellent fact sheets and guides about financial support, benefits, pensions, finances, work and careers, as well as many different aspects of caring.

Their UPFRONT Guide to Caring (www.carersuk.org/upfront) is an online tool which helps you to identify which type of benefits you could claim. They also run a telephone helpline, online form and a support service.

EntitledTo (www.entitledto.co.uk)

EntitledTo provide online benefit calculators on their website and to local authorities, housing associations, charities and other websites, like moneysavingexpert.com.

Their benefits calculators are free and confidential.

You can use their benefits calculator to work out if you are eligible for income-related benefits, tax credits, contribution-based benefits, Council Tax Reduction, Carer’s Allowance, and Universal Credit.

Their benefits calculators can also show you how your benefits will be affected if you start work.

Citizens’ Advice Bureau (www.citizensadvice.org.uk)

Citizens’ Advice Bureau is a national charity which supports people facing all types of problems, including health, financial, legal and consumer problems.

You can get advice from the Citizens Advice Network on their website, by phone and in person from an office local to you.

Policy in Practice (www.policyinpractice.co.uk)

Policy in Practice are a charity which helps people towards financial independence.

You can use it to find out if you are eligible for income-related benefits, tax credits, contribution-based benefits, Council Tax Reduction, Carer’s Allowance and Universal Credit.

Their calculator will also show you how your benefits will be affected if you start work or change your working hours.

> They have an award-winning benefits calculator which is used **by over 10,000 people every day.**

Contact a Family (www.contact.org.uk)

Contact A Family is a national charity which supports families who have children with disabilities.

They provide the best possible guidance and information. And they bring families together so they can support each other.

You can access their advice and services through their:

- website www.contact.org.uk
- helpline 0808 808 3555
- workshops and information sessions
- parent support groups
- SENDirect service – helps you find local services and activities for your family

Local independent living centres

Local independent living centres are organisations which are run and controlled by disabled people. They provide advice and services to other disabled people.

They vary by local authority because they are small charities. So, they are not run in one standard way.

Your local independent living centre may be able to help you with benefits, housing and managing your relationship with social services. Many centres also campaign on behalf of disabled people in their local area.

Find out more:
Google 'local independent living centre in [name of your local authority]'

Financial support from charities

You may also be able to get financial support from charities – especially if you need a grant for equipment for your child.

Local charities can be a good source of financial support. We encourage you to google them and contact them.

Family Fund
www.familyfund.org.uk

Family Fund provides grants to families with disabled or seriously ill children and young people.

Their grants can be used for a wide range of items, such as washing machines, sensory toys, family breaks, bedding, tablets, furniture, outdoor play equipment, clothing and computers.

The Patrick Trust
www.thepatricktrust.org.uk

The Patrick Trust provides financial assistance to young people who are experiencing problems. They have a particular interest in supporting people who have muscular dystrophy.

Turn2Us Funds
www.turn2us.org.uk/Get-Support/Turn2us-Funds

Turn2Us Funds support people who are in financial need. They run a number of funds, including one in Edinburgh.

Promise Dreams
www.promisedreams.co.uk

Promise Dreams is a national charity that aims to make a real difference to seriously-ill children (0 - 18-years-old) by making “their dreams come true”.

As well as organising special events, they also provide equipment, such as adapted trikes, or resources for the home.

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 or family members.

So, even if you manage their money for them because they are young or have a learning difficulty, we still encourage you to set up a separate account for them.

Part 2 – Your work

Living with a condition such as DMD has an impact on parents' work and careers.

Different families manage work and caring for children and teenagers differently. There is no single right or wrong answer. The key thing is to make sure your employer understands your needs and you can access support.

In the first year, try to carry on with your work as much as you can. It may help by giving you a break from the diagnosis. You don't need to make any big decisions about your current work or your career immediately.

Your reactions to your child's diagnosis

People respond to their child's diagnosis in different ways.

One parent may want a break from work. The other parent may want to get back to work as quickly as possible.

This is perfectly normal. There is no one right way of reacting to the diagnosis or managing your work.

Both parents need space and support while they are processing the diagnosis in their own way.

We encourage you to give yourself six to twelve months to come to terms with your child's diagnosis. **This will give you time to think about what's best for your family.**

Talking about DMD with the people you work for

You'll need to talk with the people you work for, whether you're an employee, an agency worker or self-employed.

Employees should talk to their line manager and their HR manager (if they are available). Agency workers will need to talk with their account managers. Self-employed people will need to talk with their clients.

We encourage you to share the diagnosis with them. You'll need to explain DMD and its impact on your child. Tell them that DMD is a progressive disease so your child's condition will change slowly over many years – but nothing is going to change overnight.

The diagnosis is very difficult. So, it's best to ask the people you work with for their understanding in the first few months.

A Guide to DMD for Employers

We've produced 'A Guide to DMD for Employers' to help you have positive and constructive conversations with the people you work for.

You can find it at

www.duchenneuk.org/support-at-diagnosis

As parents of children with DMD, we encourage you to ask them for:

1

Understanding and support

You'll need to be able to express your feelings about the diagnosis

2

Time and space to come to terms with the diagnosis

You might need a few days off or have to take a break during the day at work. You may find that the diagnosis affects your concentration and performance in the short term. But this will get better with time.

We encourage you to consider talking about this with your employer to help them understand this.

3

Flexibility with your working arrangements

You'll probably need some time off to take your child to medical appointments.

4

Control over the way the diagnosis is communicated to other people at work

You could ask your manager to tell the other people in your team that you are dealing with a serious family matter, that you'll need some time off work and understanding from others, but that you're not ready to talk about it yet.

Do talk to your colleagues when you are ready. There's no need to keep this a secret.

5

Time before making long-term decisions

Ideally, you should wait six to twelve months before you make long-term decisions about your career.

Your employment rights

Your employment rights are protected by law if you are an employee or work on a zero-hours contract.

If you are an employee

You have statutory employment rights as an employee.

You may also have contractual rights from your contract of employment with your employer. So, it's worth reading through the contract you signed when you joined the organisation.

Your statutory rights are:

- the right to take time off in emergencies, including breakdown in care arrangements
- the right to be protected from discrimination because you are a carer
- the right to request flexible working which can include home-working, part-time working and term-time working (if you have worked for the organisation for 26 weeks' or more and you haven't already made a flexible working request in the last 12 months)
- the right to 18 weeks' unpaid parental leave (if you have worked for the organisation for at least one year)

Find out more from Carers UK: www.carersuk.org/help-and-advice/work-and-career

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If you work on a zero-hours contract

If you work on a zero-hours contract, you have the same statutory rights as an employed person.

Find out more: www.gov.uk/government/publications/zero-hours-contracts-guidance-for-employers

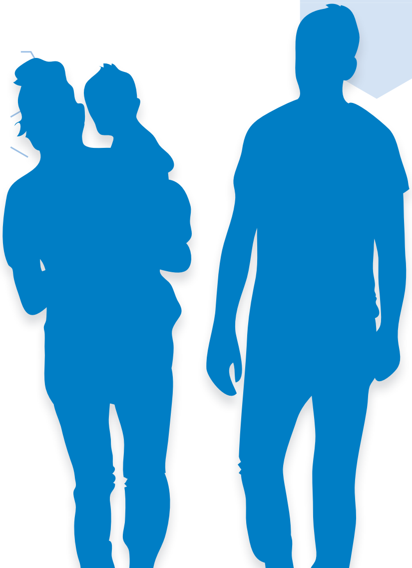
If you are self-employed

If you are self-employed, you'll probably need to talk to your clients about your child's diagnosis.

Initially, just tell them what you can do for them over the next few weeks.

Give yourself time to work out what to do for the next few weeks, then the next few months.

Try to manage their expectations so you don't wear yourself out by over-working.



Long-term decisions about work

DMD families arrange their work and childcare responsibilities in many different ways.

Duchenne UK knows families where:

- both parents work full-time
- both parents work part-time
- one parent works full-time and the other parent works part-time
- one parent works and the other parent stays home
- single parents who work full-time
- single parents who work part-time
- single parents who don't 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.

Difficulties of continuing to work

Combining working with bringing up children is difficult for everyone. But working while you are bringing up a child with a disability is more difficult.

We have to juggle our work with our child's school holidays and medical appointments, as well as arranging their care and education.

Benefits of continuing to work

Working has many benefits in addition to earning money.

Work gives you time off from thinking about DMD. You'll have to think about and do other things.

It will help you keep your own identity as a person in your own right, not just a carer. You'll have the social benefits of being with other adults, so you'll be less likely to suffer from social isolation.

Work can help keep life as normal as possible for you, your child and your family.

Help with childcare costs

You may be able to get help with childcare costs from the Government or your local authority.

Help with childcare costs from the Government

You should be able to get help with the cost of childcare from the Government if you are using a registered child minder or childcare provided by your children's school.

There are different types of help with childcare costs:

- Free education and childcare for 2-year-olds
- 15-30 hours free childcare for 3 and 4-year-olds
- Tax-free childcare
- Tax credits
- Universal credit (additional payments for childcare)
- Childcare vouchers and other employer schemes
- Help while you study

Help with childcare from your local authority

Your local authority must also provide you with information about short break services and childcare for disabled children.

Short breaks can work for holiday childcare (in some local authorities). You may also be able to come to a special arrangement with your local authority where you take direct payments for after-school and holiday childcare instead of short breaks.

You are not alone

Duchenne UK supports a lot of families. You can get help while you are figuring out how to access financial support and manage your work.

You can speak to a member of our Patient Advisory Board. Or we can put you in touch with other families who have already navigated through finance and work support.

> Please email us at support@duchenneuk.org.
> **We will connect you with someone who can help.**

Personal notes

Thank you!

Thank you for taking the time to read our advice.

If you like to find out more about DMD, please visit our website www.duchenneuk.org or get in touch with us at support@duchenneuk.org

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This guide was part of a set of resources originally created for newly-diagnosed parents produced by Duchenne UK with the support of DMD families. It includes the *Folder for Newly-Diagnosed Parents* and five guides.

It was expanded in 2021 to cover support for teenagers and adults with DMD and their families.

You can find all these resources at www.duchenneuk.org/resourcesforparents.

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