

Balancing Work and Caring



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Working Families would like to thank all who contributed to this publication.

Introduction and top tips



At Working Families, we know how challenging it is for parents and carers of disabled children or adults to balance paid work with their caring responsibilities. In our recent survey of parents of disabled children, we found that 76% of those in paid work have refrained from seeking a promotion, declined a promotion, or accepted a demotion because of their caring responsibilities. And nearly two-thirds (65%) have looked for or found a different job because of their caring responsibilities.

We know that as a working carer, you have unique needs for flexibility, specialist childcare, and time off for medical appointments that many parents do not have. We have created this booklet to give you tailored advice and strategies to support you through the challenges you may face as a working carer.

This guide will cover a host of topics – from your legal rights at work, to finding and funding appropriate childcare and care for adults, to tips for self-care. You do not need to read the booklet from start to finish: pick the sections with information relevant to you. There is a list of useful organisations and websites at the end.

We hope the advice and resources in this guide will help you on your journey toward finding a better balance between your responsibilities at work and at home.

Jane van Zyl
CEO, Working Families

Top tips: Succeeding as a working carer

1. Know your **workplace rights**.
2. Remember that it's absolutely fine to open up a dialogue in order to manage your various demands. Ask for the **flexibility you need**.
3. Be prepared to **negotiate** when changing working patterns.
4. Where you can, **share the load** – it's not just you that may be able to work flexibly.
5. Seek help when needed from **friends and family** and look after yourself.
6. Join a **network** for peer-to-peer support (carers network/our closed Facebook group for working carers).
7. Ask clinics and hospitals if they can **schedule appointments to fit with your working hours**, i.e. at the start or end of the day.
8. Get help for your child – they may be eligible for **DLA/PIP**.
9. Use your **local authority** for information and support about childcare, school transport and direct payments.
10. Consider the **long-term benefits of staying in work** where you can, for your own health as well as for family finances, and as a role model for your children.

1

Your rights at work

It's so important that you are aware of what rights you have that can help you arrange your work commitments around your childcare responsibilities.

Your rights at work depend on your employment status. There are three broad categories: employees, workers, and self-employed. This section is mainly relevant to employees.

What's crucial to remember is that your employer may be more generous than the law requires, as is often the case (e.g. with the provision of annual leave). Read your contract to see what room there is for flexible working and leave. For example, you may be entitled to a few days' paid carer's leave. In smaller organisations, it's less likely that there will be specific policies in place for carers, but it's still always worth checking.

This section covers taking time off work to look after someone who depends on you, requesting flexible working, and legal arguments when things go wrong.

“The company I work for operates a system where every six months, you get three days off without loss of pay if your children are unwell. It's good, but no one told me the policy was in operation for ages, so I had been taking holiday off when Emma was ill!”

Susan – health worker and Emma's mum



Taking time off work to look after someone who depends on you (for employees)

One crucial aspect of balancing work and care is being aware of when you have the right to take time off work to look after or spend time with the people who depend on you. This section covers two ways in which you can take that time off without using up your annual leave: time off for dependants and parental leave.

You can, of course, also use your normal paid holiday entitlement to take time off work to care for your child, so this section also reminds you of the main rules on taking annual leave.

We're explaining your *minimum* legal rights. Remember to always check your employer's policies too as they may have more generous provisions.

1 Your rights at work

Time off for dependants

All employees have the right to take a short time off work – unpaid – to deal with an emergency involving their dependant(s). You have this right from day one of employment.

A 'dependant' can be anyone that lives with you as part of your family (partner, child, or parent). Others who rely on you for help in an emergency, such as an elderly neighbour or parent, may also qualify even if they do not live with you.

What is reasonable and necessary?

It must be necessary for you to take time off (think about why it is you, in particular, who needs to be there for your dependant – is there anybody else who can help?) and the time taken off must be reasonable.

Crucially, disruption or inconvenience caused to the employer's business should not be taken into account when determining whether the time off is reasonable or necessary.

How much time can you take off?

There's no straightforward answer to how much time you can take off and no set limit – it depends very much on the circumstances.

For example, if you are part of a couple or the other parent is active in the care of your child, the time off that is reasonable in the circumstances would take that into account. Normally only one parent would be expected to have the time off at once. However, where a child is very ill, has an accident or is having a major operation, it may be reasonable for both parents to have reasonable time off.

To determine what is reasonable, think about the following:

- Is it the first time you're asking for time off for dependants? If not, how often have you taken time off for dependants before and for how long?
- What is/was the incident? How severe is/was it? For how long have you known that it might happen?
- Is there anybody else that can help?
- Is there any other arrangement that is possible?

You can only take sufficient time to deal with the immediate problem.

Remember also that you do not have to take a full day off – you can just take a few hours if that is all you need.

Is it paid?

Legally, time off for dependants is unpaid, although your employer might have a policy that says it is paid. You should always check your contract and staff handbook and inquire what is the usual practice in your workplace.

How to take time off for dependants

You must let your employer know what is happening and get back to work as soon as you can.

- Notify your employer as soon as possible in writing that you need the time off and how long you expect to be off
- Notify your employer as soon as possible if the situation changes
- Keep a record of the conversations you've had with your employer
- If at all possible, try and find alternative arrangements

Taking time off for dependants for a situation you knew about beforehand

Time off for dependants is *usually* reserved for unexpected circumstances. If you knew about a situation beforehand, this would not normally be covered by time off for dependants. You could request unpaid parental leave (page 9) instead. If your child is disabled, you can take parental leave in blocks of a day (as opposed to blocks of a week at a time for parents of children who aren't disabled).

However, knowing in advance that something will happen does not mean that you definitively cannot have the time off for it, so long as you taking time off is necessary. In the case of *Royal Bank of Scotland plc v Harrison 2009*, the Employment Appeal Tribunal found that a mother who had two weeks' notice that her childminder would not be available, and who had tried but was unable to make alternative arrangements for her children, had reasonably taken time off for dependants when she was absent from work.

It all depends on what's **reasonable** and **necessary** in the circumstances. And the longer the notice you have had, the harder it will be for you to justify that no one else could help and that your absence was necessary.



Taking time off for dependants in order to attend a crucial meeting at your child's school

The law on this is not clear. Normally time off for dependants is reserved for emergencies, or a breakdown in care arrangements, which is not the case in a planned meeting. However, our position is that you could still argue that attending a meeting to discuss your child's special needs arrangements counts as time off for dependants if it really can't be attended by anybody but you and the meeting has been arranged at short notice. The law states that you can take the time off ...

- *to make arrangements for the provision of care for a dependant who is 'ill'*. Illness, for this purpose, specifically includes mental illness – so you could argue that it extends to all disabilities.
- *to deal with an incident which occurs unexpectedly while the child is at school*. You could argue that the reason the school has asked to see you is because of a previous unexpected incident.
- *because of the unexpected disruption or termination of arrangements for the care of a dependant*. You could argue that without this meeting, there would be a disruption to the care of your child.

If the meeting was not arranged at short notice, then you could use annual leave to attend the meeting or you may be entitled to take special leave under your contract of employment and it would be worth checking this with your employer. If your child is disabled, you could also make a parental leave request to attend the meeting (remember that parental leave can be taken in blocks of one day if your child is disabled).

1 Your rights at work

Can your employer refuse time off for dependants?

No, your employer cannot refuse the time off, provided the time you take off is reasonable and necessary in the circumstances.

Your employer cannot penalise you for taking time off for dependants

Your employer cannot penalise you for taking, or seeking to take, the time off. You are legally protected from dismissal, detrimental treatment and victimisation for taking time off for dependants. It is automatically unfair to dismiss you if the reason is that you took or sought to take time off, provided your reasons are genuine and it is reasonable.

There is no limit on how many times you can take time off for dependants, but your employer may want to talk to you if they think it is affecting your work.



The difference between time off for dependants and parental leave

The main difference between time off for dependants and parental leave is that time off for dependants is usually used for more short-term leave/emergencies and can be used for anyone that depends on you – it doesn't have to be your child. Parental leave, on the other hand, can be used for longer-term leave or planned appointments and can only be used for children under the age of 18. Both are unpaid. Remember to always check your contract and your employer's parental leave policies, because your employer might give you more than the legal minimum.

“I have flexible hours so that I can adjust my start time if we've had a bad night/morning. There is an inclusive culture enabling constructive conversations about how to manage home and work. I have a carer 'passport' where my current arrangements are communicated to my next manager who then tries to accommodate those needs, and an understanding team able to step in or deputise for me when I have to be away (and this relationship is reciprocal).”



Parental leave

Parental leave gives parents the right to take a period of time off work to look after their child. Parents can use it to spend more time with their children and strike a better balance between their work and family commitments. The leave is unpaid, although in some cases benefits may be claimed, or may increase, when parental leave is taken. Parents of disabled children aren't entitled to any more leave than parents of non-disabled children, but if your child is on Disability Living Allowance (DLA) or Personal Independent Payment (PIP), you can take parental leave in blocks of one day (instead of one week). This makes it a useful tool for parents to take time off work for planned appointments.

Parental leave is not a day-one right; you need to have worked for your employer for one year to be eligible to take it.

To be eligible for parental leave, you must:

- be an employee;
- have, or expect to have, parental responsibility for the child concerned; and
- have worked for your employer for at least one year (regardless of whether you work full- or part-time).

Parental leave is available to parents of all children up to 18 years old, regardless of whether they are adopted or birth children, or whether they are disabled or not.

How much leave can you take?

Each parent can take up to **18 weeks** of parental leave in total for each eligible child as long as they meet the qualifying criteria. So for example, if you have two children, you can take up to **36 weeks** in total. The

statutory default scheme says that you can take **up to four weeks per child per year** but your employer may have a more generous or flexible policy.

Is it paid?

Legally, parental leave is unpaid, but your employer can give you more than the legal minimum and might have a policy that says it is paid – you should always check your contract and staff handbook and inquire what is the usual practice in your workplace.

As your income will change if you take parental leave for a longer period of time, you may also be entitled to some benefits (like Universal Credit) that you are not usually entitled to, during the periods of unpaid parental leave. You might also be entitled to increased amounts of the benefits you are already claiming. You can carry out a benefits calculation using an online benefits calculator to see what you may be eligible for if your income changes: [gov.uk/benefits-calculators](https://www.gov.uk/benefits-calculators).



How to take parental leave

- You are limited to **four weeks'** parental leave per child per year, unless your employer grants you more than this.
- If your child is claiming DLA or PIP, you can take parental leave in blocks of one day. Otherwise, you have to take parental leave in blocks of one week.
- You must give your employer at least **21 days' notice** to take parental leave. The notice letter must state the start and end dates of the leave.

1 Your rights at work

Can your employer refuse parental leave?

Your employer cannot refuse parental leave, but **they can postpone your leave for up to six months** where the business would be particularly disrupted if the leave were taken at the time requested.

There are two exceptions when parental leave cannot be postponed:

- if it's taken immediately after the birth of a child; or
- if postponing the leave means you cannot take it before the child's 18th birthday.

If your employer wants to postpone your leave, they must give you notice in writing no later than seven days after you gave notice to take parental leave. Your employer can't postpone the leave twice or reduce the length of parental leave taken.

Your employer cannot penalise you for taking parental leave

At the end of parental leave, you are guaranteed the right to return to the same job if you take leave of four weeks or less. If you take more than four weeks' leave, you are entitled to return to the same job, or if that is not reasonably practicable, to a similar job which has the same or better terms and conditions as your old job.

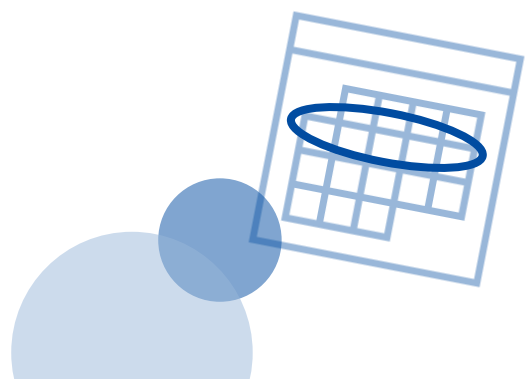
You cannot be treated less favourably by your employer because you have taken or have tried to take parental leave. You are legally protected from dismissal, detrimental treatment and victimisation for taking parental leave.

Annual leave

Full-time workers are entitled to at least 28 days' (5.6 weeks – so five weeks and three days) paid annual leave per year. An employer can include bank holidays as part of annual leave. 5.6 weeks is a minimum: employers can offer more leave (and many do). You should always check your contract and staff handbook and enquire what is the usual practice in your workplace.

It is important to note that it is your employer that ultimately decides when you can (and cannot) take annual leave – unlike time off for dependants as set out above. For instance, it is common to limit the amount of leave employees can take during the school summer holidays when many staff want to go away with their families. Employers can also insist that you give notice of at least twice the period of the intended leave, although many are flexible when emergencies arise.

Part-time workers are entitled to the same annual leave as full-time workers but pro-rata. It is illegal to treat part-time workers worse than full-time workers. There are various ways of calculating pro-rata leave because of the complications of taking into account such things as overtime and the fact that public holidays mainly fall on Mondays. Make sure that your contract is clear about how your annual leave is calculated before any dispute arises. Often, particularly if your part-time work involves working days of different lengths, it is easiest to work out your annual leave in hours (as opposed to days) to make it proportionate to full-time employees based on the hours you work.





Flexible working (for employees)

If you'd like a more long-term change in your work pattern, you might want to consider requesting to work flexibly. This includes changing your hours, compressing them, or changing to part-time or term-time only, or working wholly or partly from home.

It may well be possible to get the hours you want and the time off you need by an informal, friendly agreement. If you negotiate a flexible agreement informally, ensure that both you and your employer are clear about what has been agreed, and that it gets written down (this can be an informal email to your manager confirming the conversation you have just had) so that there is no confusion in the future.

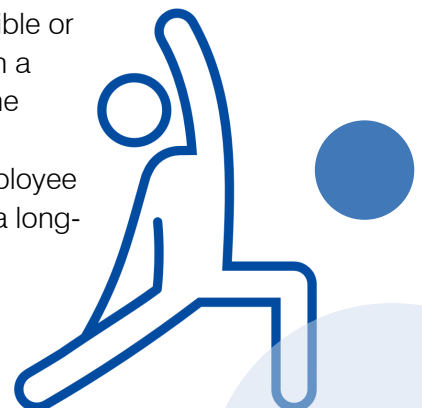
“My department has good flexible guidelines and my manager has been great. I can always take time off for hospital appointments or whatever. They are extremely flexible with me, but then I am careful to meet their business needs. I always try and fit appointments into my annual leave dates. It can be tiring to look after Ellie too, but I always get to work.

“My line manager is brilliant. When I needed to work different hours in the holidays, I explained how I would be able to do extra hours as well. If you show you're willing and able to do a good day's work, your employer appreciates it.”

Claire, manager, and mother of Anna and Ellie (who has cerebral palsy)

“Although not officially sanctioned by my employer, my line manager (who also has caring responsibilities) supports me taking a few hours off during the day for appointments and making the time up. This saves me stress and I don't lose out financially.”

But if that's not possible or you'd like to go down a more official route, the formal, statutory procedure as an employee to go about making a long-term change to your contract is known as *making a request for flexible working*.



1 Your rights at work

Any employee **with 26 weeks of service** with the same employer has the right to make a request to work flexibly. It's a right to *request*, not a right to have: you don't have a right to have what you asked for. Your employer doesn't have to agree to your request, but they must seriously consider it and can only refuse it for one of the permitted business reasons (see page 17). So successful negotiation is key.

“My previous job was advertised as full-time but I rang up and asked if they would be interested in part-time and they said yes.”

“I went for an interview for a job which I knew I could do and I said, ‘Well, how about this as a job share?’ They wouldn't even entertain the idea. They said this was a one-person full-time job.”

The right to request flexible working for parents and carers of disabled children is the same as for parents and carers of non-disabled children. But it is worth mentioning in your application the reason why you are requesting flexible working if it relates to your disabled child. The Equality Act 2010 legally protects people from discrimination in the workplace and in wider society. This includes direct discrimination by association, such as treating a parent or carer less favourably – for instance refusing their flexible working request – just because they have a disabled child (see page 18).

The rules on how applications are dealt with are different in Northern Ireland. The nidirect.gov.uk website contains more information.

Finding a pattern that works for you

It can be difficult for employees to decide what change they would like to their working pattern whilst also remaining realistic about what they can expect. For example, not all jobs can be done from home; and if you want to change the times when you work, this may have an impact on your duties, or how busy you will be. You will need to consider the broader picture of changing your working pattern before making a request for flexible working. Remember you only have the statutory right to make one request per year (although your employer may accept additional, informal requests).

If you are requesting a change to your hours, you will need to weigh up factors such as childcare costs, travel to work, earnings, and any other help you might get, for example, from tax credits, Universal Credit or other benefits.

“My wife and I both work part-time because my son goes to a special school, so there needs to be someone to get him there in the morning and home in the afternoon. When you have a child with a disability, your whole life changes – one minute you're just going to work and you don't have to worry, then you've got all these appointments with hospitals, and because our son has autism, we see psychiatrists as well.”

Wesley, father of three

Impact on your income and benefits

Most of the time, if you reduce your hours your salary will be proportionately reduced. There are online salary calculators like [thesalarycalculator.co.uk](https://www.thesalarycalculator.co.uk) that can help you work out your part-time, pro rata salary.



There are various benefits you may be eligible for as someone who is working who is also a carer of a dependant with a disability, such as Universal Credit or tax credits, Carer's Allowance, and Child Benefit – see the financial support section of this guide (page 23) and the **advice section** on Working Families' website for more details. One key thing to bear in mind is that your eligibility for benefits is likely to change as you adjust your hours and you may be financially better or worse off as a result. As a rule of thumb, the system is designed so that you are usually better off being in (more) paid work, but this isn't always the case so it is worth having a think about which situation is best for you financially.



If you are trying to decide which is the best pattern of work for you, it will help to know how much your income will be after work-related expenses like travel and childcare costs. The table overleaf can help you to compare up to three different patterns of work, factoring in earnings and support from benefits, as well as expenditure. You will have to work out your income from Universal Credit and other benefits – the table will not do this for you. You can use internet-based tools like the benefits calculator on [entitledto.co.uk](https://www.entitledto.co.uk), or any of the other calculators listed on the [gov.uk](https://www.gov.uk) site.



1

Your rights at work

Net income comparison table

	Option 1	Option 2	Option 3
Hours of work			
Notes			

Income			
Take-home pay (after income tax and NI)			
Tax credits			
Universal Credit			
Other benefits like Child Benefit, Housing Benefits, Council Tax Support/Reduction, DLA or PIP (see page 23)			
Childcare vouchers/Tax-Free Childcare			
Other income			
Total income =			

Costs			
Travel costs because of work (e.g. travel to work, travel to and from childcare provider)			
Childcare costs			
Any other costs because of work			
Total costs =			

Comparison			
Total income – Total costs =			

Approaching the request

Once you've decided which pattern will work best for you (personally and financially), have a think about how to approach your employer about the request:

1. **Do the groundwork and start with an informal conversation.** Your employer is likely to prefer an informal approach, especially if you have always got on well and/or known each other for a long time. Even if you are intending to put in a written application, a chat with your employer beforehand could help, so that they do not receive your request unexpectedly. And who knows – your employer might say yes immediately, in which case you can skip all the steps below! But remember to follow up in writing afterwards to avoid confusion in the future.
2. **Gather information** about people who do similar jobs to yours on a flexible basis.
3. **Think carefully about your situation** and try to put forward the best proposal you can for how your new arrangement would work. Think of your red lines – what you are not able to compromise on – and try to come up with different options that can work for you. You multiply your chances of having at least one of your proposals agreed!
4. **Try to plan ahead and be prepared to suggest solutions to any of the problems they might raise.** How can your workload be shared within the team? Will your employer have to recruit someone else – if so, can you help? If working from home, when and how will you check in with your team/manager? How can you minimise any impact your changed pattern will have on the organisation? Is there anything about

this proposal that will be beneficial for your employer's business needs (for example, if you are proposing a job-share, you could argue that two heads are better than one) – make your request as appealing as possible.

5. **Explain why you need the new work pattern** and mention if it is because of childcare and/or disability.
6. **Approach negotiation in an open, positive manner**, but also be careful about how and when you approach your employer in case you cannot reach agreement.
7. **Keep notes** of your meetings, and of anything that is agreed along the way, including trial periods.

Making a statutory request for flexible working

If you decide to make a request via letter or e-mail, it is up to you how formal you make this. If a letter contains everything required by the regulations (checklist overleaf), it will count as a formal request for flexible working. If it doesn't contain all these points, your employer doesn't have to follow the procedure. If you use a form provided by your workplace, you might also want to check whether it contains all the points overleaf.



1 Your rights at work

To be considered a statutory request, your request **must**:

- be in writing;
- be dated;
- explain the change you would like to your working pattern;
- explain when you would like the change to come into force;
- explain what effect the change would have on the business;
- explain how such effects might be dealt with;
- state that it is a statutory request; and
- state if you have made a request previously and if so when.



There is a **template letter to request flexible working** available on our website, and also on page 25 of another of our guides in this series, ***Getting into Work: A guide for parents of disabled children returning to work***.



Negotiations following the request

Your employer may want to have a meeting to discuss your request, and you can request one yourself if your employer is initially hesitant to accept your request. This is an excellent chance for you to make a good argument for why they should accept your proposed working pattern. The ideal

situation is one where the employer can see how the flexible work pattern will benefit *them*, as well as you.



Some ideas about how to negotiate your flexible working request

- Explain your position and your ideas about the changes you are hoping for.
- Present your employer with more than one option and try to explore them together.
- Don't get stuck on one option – instead think about the result you want (being able to pick up your child, etc.). There may be other ideas or options which will come up during the meeting. Think about what is really important to you and what you would be willing to change.
- Suggest a trial period – some employers are very worried about committing for the long-term, and agreeing to just three months is less scary. And if it works for three months, you will be in a really good position to argue that the change should be permanent.
- Even if your employer is being unreasonable, be constructive. Empathise with their concerns and show them how this can work for *them*, not just for you. Try to understand your employer's concerns and present solutions.

What to do if your employer refuses

Once you have made the request, there is not much that an employer must do. The employer has **three months** to give you a decision (although this can be extended by agreement). If the employer turns down your request they must give you one of **the permitted business reasons for refusing**. There is no legal requirement for the rejection to be in writing (although the **Acas Code of Practice** says it is good practice for it to be), and there is no legal requirement for a right to appeal. So the only way an employer can breach the actual procedure is by either not giving permitted reasons, by taking longer than three months to give you a decision, or by giving reasons which are not factually correct.

However, even if your employer doesn't allow appeals, you could write to them anyway explaining why their refusal was incorrect and suggest a meeting to negotiate the request. Use the negotiation tips above – remember, put yourself in your employer's shoes, try and understand their concerns and suggest meeting in the middle where you can. The more constructive you are, the more likely it is your request will be granted.

If you want to appeal a flexible working request refusal, you can use this **template appeal letter** that we've created.

When things don't go as planned – your legal rights as a carer

If you have an issue with your employer, it's always best to talk to them first and try and work through it amicably. But it is also important that you are aware of the rights you have as a carer at work.

Working Families' advice webpages

You can always navigate **Working Families' advice webpages** if you find yourself in a tricky situation with your employer and need more information, fill in our **online contact form** or call our helpline on 0300 012 0312.

Breach of contract

If your employer is trying to change the hours you work, your place of work or something else, you need to think about whether what your employer is asking of you is a change to your contract or whether it is something which the contract allows. Look at your contract to see what it says about your hours/place/way of working. If you do not have a written contract, think about what has been agreed orally between you and your employer. This is still a contract. If there has been no formal agreement but you have worked in a particular way for a long time with the permission of your employer, you may be able to argue that your current arrangements are part of your contract.

1 Your rights at work

If your contract specifies particular hours of work then these arrangements can normally only be changed with your agreement, otherwise it may be a breach of contract and depending on your circumstances may also count as a dismissal or discrimination.

Indirect sex discrimination

It has been successfully argued that, because women tend to shoulder more childcare responsibilities than men, insisting that women work long or inflexible hours can be indirect sex discrimination. The same principles could apply where women employees need flexible work because of other caring situations.

Direct sex discrimination

Men cannot claim indirect sex discrimination for childcare reasons. However, fathers can make a claim for direct sex discrimination if women in their organisation are being given more flexibility than they are. For example, if your employer is making a change to working hours but is making an exception for some female employees because of their childcare responsibilities then, as a man with caring responsibilities, you may have a claim for direct sex discrimination if your employer does not do the same for you.

Direct associative disability discrimination

It is unlawful to directly discriminate against you because you are associated with someone who has a disability – for example,

if the reason you are refused a request for flexible working is because you care for your disabled child. This does not give you a general right to time off to care for your disabled child. You can only complain about direct associative disability discrimination if your employer has treated you less favourably than they treat parents of non-disabled children.

For instance, in *Coleman v Attridge Law* (2008), the employer did not allow Ms Coleman the same flexibility to look after her disabled son as they did her colleagues (who were parents of non-disabled children), and she was described as lazy when she requested time off to look after her son whereas the other parents were not. This amounted to direct associative disability discrimination. But bear in mind that if your employer refuses everyone time off for childcare, whether or not their child is disabled, this would not be direct associative disability discrimination.

The Part-time Workers (Prevention of Less Favourable Treatment) Regulations 2000

If you work part-time, you have the right not to be treated any less favourably than your full-time colleagues, for example in relation to holiday entitlements and pay rates (pro rata, see page 10). Part-time workers should be selected as a full-time worker would be for promotion or redundancy.

Using the Part-time Workers Regulations

by Alison Humphry, partner at Workwise Legal LLP

Historically, cases around part-time workers' equality had to be presented as direct or indirect sex discrimination claims. This can be a complicated way to get to a result, because it requires you to show that women would be more affected than men by a particular policy, criterion or practice in the workplace, which can be time-consuming and expensive.

There are other cases where using the Equality Act is not appropriate or useful. While it is true that the majority of part-time workers are still women, working patterns are changing for many individuals to more flexible ways of working – whether voluntarily or otherwise. Many men are working part-time or zero-hours arrangements in the gig economy, for example. Moreover, more men are taking on childcare responsibility and, most would agree, should have equal levels of protection if they do. One of the unintended consequences of viewing part-timer protection as purely a gender issue is that it

reinforces the idea that men go to work and women look after the children (and the aged).

The Part-time Workers Regulations 2000 ('PTW Regulations') sweep away a lot of the baggage of using sex discrimination law and are a welcome additional tool. If you find yourself being treated less favourably by your employer simply because you are working part-time (for example, being denied promotion or being selected for redundancy), you could use the PTW Regulations. You may also be able to couple this argument with another form of discrimination (for example, on the basis of sex or disability).

For more information on when it may be better to argue sex or disability discrimination and when it may be better to use the PTW Regulations, read the full article on the topic on Working Families' website: [workingfamilies.org.uk/workflex-blog/using-the-part-time-workers-regulations-in-litigation/](https://www.workingfamilies.org.uk/workflex-blog/using-the-part-time-workers-regulations-in-litigation/).



Employment rights for workers and the self-employed

Workers and self-employed people have different employment rights than employees. They cannot take parental leave (page 9) or time off for dependants (page 6), and they don't have the statutory right to make a request for flexible working (page 15) – although they can always ask for flexible working informally. They are however protected from discrimination in the same way as employees (page 18). Working on a self-employed basis can also give you more flexibility on how to balance your time between care and work. See our [Getting into Work guide](#) for more

information if you're interested in working on a self-employed basis. We have more guidance here: [workingfamilies.org.uk/articles/employed-self-employed-or-worker/](https://www.workingfamilies.org.uk/articles/employed-self-employed-or-worker/). And always feel free to contact us if you'd like to find out more about your rights.



"I work freelance, and I'm always very straight up about the fact that I have a disabled child. I embrace it and I want others to as well. I've been told not to mention it as people can see you as less 'reliable', but I don't go along with that. I'm pretty consistent in letting people know that I'm a carer and that my schedule needs to reflect this."

Samuel, father of a disabled child



2 Finding and funding appropriate childcare and care for adults

Finding appropriate care

Finding appropriate care for your dependant(s) can be one of the biggest struggles for parents and carers balancing work and care. Suitable childcare is often of limited availability and unaffordable; this is even more so the case for adults with disabilities.

In order to balance work and care, you need to be assured that your dependants are safe and happy wherever they are being cared for. This section will give you a brief overview of the support available to help you arrange care for your dependant, whether you are at home or working.

Help from your local council



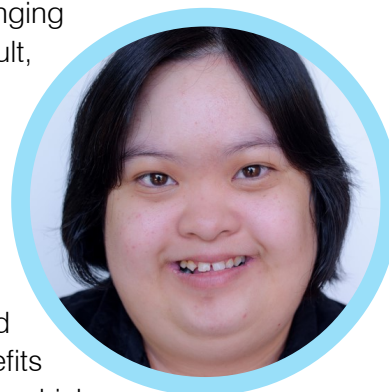
If you haven't already, you should ask the social services team at your local council to carry out a **needs assessment** for the person you care for (available in England and Wales only). You can also ask them about local support groups for carers.

Depending on the outcome of the needs assessment, your local council should provide support for the person you care for, including short break services, holiday play schemes, care at home, aids and

adaptations for your home and financial help (e.g. money towards travel costs for hospital visits). If you are looking after a disabled child, your council has a duty to provide these services under the Children Act 1989 if you are eligible for them. Some are free of charge, others you may have to contribute to financially.

Care for adults

If you are arranging care for an adult, or supporting an adult finding their own care, you should check that they've applied for all the benefits and services to which they are entitled (more information on this is in the next section, 'Financial support for disabled adults' – page 27).



For a young adult, a student wanting part-time work can make a very suitable personal assistant, possibly accompanying the young person as they take part in their chosen outside activities as well as supporting them at home. Contact local colleges – most have systems for advertising jobs to their students. Working Families has a separate guide called ***From Child to Adult: A guide to disability, transition and family finances***, which focuses on the transition period between childhood and adulthood for young adults.



Childcare providers and the Equality Act

The Equality Act covers childcare providers. All childcare providers should welcome and include disabled children. In fact, the law requires them to make reasonable adjustments to the way they provide a service. They must remove the barriers your child faces in relation to their disability so that they can access and participate in education (as far as this is possible) in the same way that their non-disabled peers can. Childcare providers include schools, nurseries and childminders.

“I went through about 20-25 nurseries. As soon as I said my child has additional needs, you should have seen their faces change. They were instantly looking to march me out of the door.”



Obtaining special educational provision for children and young people with special educational needs

If your child has special educational needs and it is affecting their ability to learn, you may wish to ask the school to provide some additional support. If you are concerned that the school is not providing the necessary support, you should talk to your child's teacher and/or the school's special educational needs coordinator (SENCO). Every school will have a special educational needs budget and schools vary widely in how they use this money. If the school feels it is able to meet your child's educational needs within its own budget, an individual education plan (IEP) can be created which sets out what additional support will be provided to your child as well as goals and targets.

If a school is unable to provide the necessary support, a request for an education, health and care (EHC) plan can be made. Unlike an individual education plan, an EHC plan is a legally binding document which sets out any special educational needs a child has and the extra provision a local authority (LA) must put in place to support them.

Obtaining an EHC plan can be a long and frustrating process and there are many misconceptions about what is required to

2 Finding and funding appropriate childcare and care for adults

meet the criteria. The first stage is to request that the LA carry out an EHC needs assessment. This application can be made by a parent, young person or the child/young person's school or college. It is therefore perfectly possible to make the application without the school's support. The test for eligibility for an assessment is actually a very simple one and schools and LAs often misadvise parents about this. The test is:

- whether the child or young person has or may have special educational needs (SEN); and
- whether they may need special educational provision to be made through an EHC plan.

If both of these criteria are met, then the LA is compelled to make an assessment.

“A common misconception is that you need to have a diagnosis in order to get an EHC plan. Whilst a diagnosis can be helpful, it is not a requirement. An EHC plan is about your child's special educational needs and not reliant on a diagnosis.”



The EHC plan process

You or your child's school can contact the local authority's (LA's) special educational needs department to request an assessment. You and/or the school will need to complete an assessment form which the LA will provide; these are often available to complete online. It is a good idea to send any supporting evidence you may have with the application, for example supporting letters from your GP, educational psychologist reports – but this is not a necessity. Once the form is completed and returned to the LA, they must reply to you with a decision within six weeks of receiving your application.

Turned-down application? You must appeal

It is very common for the EHC plan application to be turned down at this point. You should immediately appeal (this is usually done in writing) – the majority of families who appeal are successful, because local authorities often turn down applications for invalid reasons.

Remember all you need to be able to demonstrate is that your child may have special educational needs and that they may need additional support to be provided by the LA.

Once the LA have agreed to assess, they must gather information from you, the school, medical professionals, educational professionals and therapists involved in your child's care. Everyone will have the opportunity to contribute to the plan which will set out exactly what your child's special educational needs are, what support is required, as well as outcomes/targets to be achieved. This process can take some time

and it is important that the document sets out all of your child's needs and that the wording is clear, especially in relation to setting out what support is to be provided.

Once the assessment document has been completed, the LA will decide whether it is necessary for the child or young person to have a plan. If the LA decides not to issue a plan, they must inform you within 16 weeks of the date of the request of the assessment. Again, this decision is appealable. If the LA decides to issue an EHC plan, it will send out a draft plan for you to comment on. The final plan should then be sent to you and the school within 20 weeks from the date the assessment was requested. The additional support as set out in the plan should then be put in place.

An EHC plan must be reviewed at least once a year. This is usually done as part of an annual review at your child's school.

Where to go for further help if you're having issues accessing childcare services

IPSEA: If you require information or advice regarding any educational issue that is connected to a child's special educational needs or disability (SEND), you can get in touch with IPSEA (Independent Provider of Special Education Advice) or use their website for legal advice: ipsea.org.uk/Pages/Category/get-support.

Contact: Contact is a charity for families of disabled children and they have put together three template letters based on the most common barriers to accessing childcare for disabled children and what can or can't be done to overcome them: contact.org.uk/advice-and-support/work-childcare/refused-childcare/.

"The school have an autism coffee morning once a term. We help each other to know what to apply for. There aren't really systems that tell you about EHC plans or DLA, so a lot of parents don't know that they can apply for these things."

Financial support

Financial support for carers

Carer's Allowance

Carer's Allowance is extra money to help you look after someone with substantial caring needs. You can get it if you care for someone who receives the middle- or higher-rate DLA care component, or PIP daily living component. This doesn't have to be a relative or someone who lives with you. To get it, you must:

- care for someone for 35 hours a week or more;
- earn no more than £128* a week (after tax and other deductions); and
- not be in full-time education.

If the person you are caring for is getting other benefits such as Income Support, income-based Jobseeker's Allowance (JSA), income-related Employment and Support Allowance (ESA) or Housing Benefit, you should get advice before claiming Carer's Allowance, as it could reduce the amount the person you're caring for receives.

You could also get **Carer's Credit** so there will not be any gaps in your National Insurance record if you have to take on caring responsibilities.

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Carer's Credit



Carer's Credit is a National Insurance credit towards your State Pension while you're not making any contributions because of your caring role.

You might be able to get Carer's Credit if:

- you are aged 16 or over;
- you aren't yet getting State Pension;
- you don't qualify for Carer's Allowance;
- you spend at least 20 hours a week caring for someone; and
- the person you are looking after receives a benefit because of their illness or disability – for example Attendance Allowance, Disability Living Allowance (DLA) or Personal Independence Payment (PIP).

If the person you're caring for doesn't get one of these benefits then you might still be able to claim by completing a 'Care Certificate'.

Top up on your existing benefits because you are a carer

You might be entitled to an additional carer element or premium if you already get:

- Income Support;
- Universal Credit;
- Housing Benefit;
- Council Tax Support/Reduction;
- income-based Jobseeker's Allowance (JSA); and/or
- income-related Employment and Support Allowance (ESA).

Ask about the 'Carer Premium' at your local Jobcentre Plus or Jobs and Benefits office, or on your journal if you have an online UC (Universal Credit) claim.

Tax credits

New claims for Working Tax Credit and Child Tax Credit have now been closed to most people and replaced by Universal Credit. However, if you get either Working Tax Credit or Child Tax Credit already, you can continue to get them and you can alter your claim if you start working or become responsible for a child. For example, you may already be claiming Child Tax Credit but not Working Tax Credit because you are not working – if you get a job later on, you can then make a new claim for Working Tax Credit because you are already in the tax credits system. The number of hours you need to work to add Working Tax Credit to a Child Tax Credit claim will depend on your circumstances.

In very limited circumstances, if you are a disabled person yourself and are on one of the older benefits, you may be able to make a new tax credit claim (even if you are not yet claiming any tax credits). You can find more information on the Working Families website article on **Working Tax Credit**. You can continue getting Child Tax Credit even if you leave work, but your Working Tax Credit might stop.



Universal Credit

Depending on your financial circumstances, you may be eligible to claim some Universal Credit (UC). UC includes help with childcare costs, housing costs and can include a carer element. You can't get UC at the same time as tax credits or Tax-Free Childcare. Beware that if you make a claim for Universal Credit, this will stop your claim for any of the **benefits that UC is replacing**. Any Income Support, income-related Employment and Support Allowance (ESA), income-based Jobseeker's Allowance (JSA) and tax credits will stop, and Housing Benefit is also likely to stop. You should get advice from a benefits expert before deciding to make the switch. You may be better or worse off financially as a result of claiming UC.



You can get the carer element of UC if you have 'regular and substantial caring responsibilities' for a 'severely disabled person'.

- You have 'regular and substantial caring responsibilities' if you satisfy the eligibility conditions for Carer's Allowance (see above), or you would do so but for the fact that your earnings are too high.
- A person is 'severely disabled' if they receive the middle- or higher-rate care component of Disability Living Allowance (DLA), the daily living component of Personal Independence Payment (PIP), Attendance Allowance, Armed Forces Independence Payment (AFIP) or Constant Attendance Allowance.

The carer element is currently £162.92 a month*, but the actual amount may be reduced depending on your household income.

The person you are caring for may also be eligible for Universal Credit in their own right. However, if the person is a disabled child for whom you are responsible, make sure you also get any disabled child element you're entitled to in your UC (this will apply if the child gets DLA or PIP – see below).

You could also claim back up to 85% of your childcare costs, with registered childcare, if you're eligible for UC and you or your partner are in work (or have a job offer). The most you can get back is £646 a month for one child, and £1,108 a month for two or more children.*

Direct payments – for disabled children and adults

To get direct payments, you should contact the social services team at your local council to carry out a **needs assessment** for the person you care for (available in England and Wales only). If your local authority assesses the person you care for as being in need of services, such as a nursery place or short breaks (respite care), you can ask for a direct payment and arrange services yourself instead of getting them from your council.



“My daughter is at an age where she doesn't want a parent with her. She wants to be independent, but we need her to be safe. Direct payments allow her to be more independent, but we have found carers have frequent changeover – we've had four in the past four years and they can be unreliable.”

2 Finding and funding appropriate childcare and care for adults

Direct payments mean that you have much more flexibility over how and when you receive the help to care for your dependant. For example, direct payments can allow you to arrange childcare at a time when you're at work, helping you balance your work and caring responsibilities. If you want more choice in the services and support you receive, and you don't mind the extra responsibility that comes with organising the care yourself, direct payments could be a useful option for you. You should be aware that if you hire care workers directly, it's likely that in doing so you take on the legal role of an employer. This means registering with HMRC as an employer, setting up a system to pay wages, deduct tax and national insurance, among other things. Your local authority should provide support for you in your role as an employer.

If you hire care workers through an agency, then you won't normally be classed as an employer. The agency will handle all payments, taxes and insurance, as well as doing police checks and following up references. However, you might not always have the same person visiting your home. And it costs more – allow an extra £5 to £10 per hour, depending on your care needs and where you live.

If you're not comfortable with the additional responsibilities that come with employing care workers yourself, such as managing money and keeping a record of important documents, then you can of course continue to use the care and support services provided by your local authority. To find a home care agency, visit the **UK Homecare Association (UKHCA) website**.



You need to have been assessed by your local council authority before applying for direct payments. If you already receive care services and haven't been informed about direct payments, ask your local council for more information.

“We have carers that come for four hours each Saturday and take the boys out. It's nice for my daughters not to have the boys at home for a few hours each Saturday. So they're free to sit at home and watch TV, or we can go somewhere that I know the boys would not want to go. Or if they want to have their friends over, they can have that time to do so. I don't know what I would do without those four hours of care. I really had to fight for this care, and tell the council I'd hit rock bottom before they gave us the carers, but it helps so much.”

Sarah, mother of four and care worker



Financial support for disabled adults

If a disabled person is not able to claim benefits in their own right, you or another appropriate person can become an appointee. This means you are responsible for claiming and keeping the claim up to date with any changes.

Personal Independence Payment (PIP)

PIP is the main disability benefit for people aged 16 or over who have not reached State Pension age. PIP is a points-based benefit. You get points depending on how difficult you find it to do everyday activities and to move around. There are two components:

- **The daily living component** looks at how you cope with activities like washing, going to the toilet, dressing, eating and communicating. You can also get points if you have difficulty with activities such as engaging with people and budgeting.
- **The mobility component** looks at how you manage with planning and following journeys and moving around.

Note: in **Scotland**, changes to disability benefits are planned which mean DLA (in Scotland, this will eventually be called Child Disability Payment) will continue until 18. See page 29 for more information.

Attendance Allowance

Attendance Allowance is for people who have reached pension age and who have a disability that is severe enough that they need someone to help look after them. It's paid at a lower and higher rate, depending on the level of care needed.

Employment and Support Allowance (ESA)

You might be able to get Employment and Support Allowance (ESA) for your dependant if they cannot work because of illness or disability, and they have been paying National Insurance contributions or National Insurance credits in the last two to three years (so for example, if they were previously in work but have had to suddenly stop working because of their disability). The DWP (Department for Work and Pensions) calls this 'New Style' ESA.

Universal Credit

Unless they are already on benefits, the benefit disabled adults may have to claim is Universal Credit (UC). However, if a disabled person is already on any of the benefits replaced by UC, it's important to get advice first as claiming UC may make them worse off and can cause other difficulties.

When a disabled person first claims UC, it is important to make it clear they are disabled and, if they want their disability to be recognised in the calculation, provide fit notes from a medical practitioner. That should lead to a Work Capability Assessment (WCA) which looks at whether the young person can work. Depending on the result, the young person may get extra money.

If a disabled young person works when they have 'limited capability for work' status, they can work as much as they wish on UC. Their earnings will reduce their UC, but some of their earnings will be ignored because of their limited capability for work status, making them better off.

2 Finding and funding appropriate childcare and care for adults

Housing Benefit

If a disabled young person lives independently, rent will usually be part of any Universal Credit they claim. However, there are circumstances in which they can get Housing Benefit (even though new claims aren't usually possible). This would apply if they are in certain types of supported accommodation.

Other benefits

It's not usually possible to make new claims for Income Support, income-related Employment and Support Allowance (ESA) or tax credits. However, some disabled people may be entitled to make new claims in very specific circumstances where they live independently, get disability benefits and are also on one of these older benefits already (Housing Benefit, Income Support, income-related ESA or income-based Jobseeker's Allowance). The circumstances where this is possible are very limited and it's best to get advice before anyone who is already on benefits makes a new claim.

Benefits and studying

If a disabled person claims benefits when they are in full-time education, there are special rules. It's important to get advice about these as some benefits can only be paid to students in certain circumstances.



“If your child has a learning disability, to get the high rate of DLA, you have to know what the rules are, which nobody tells you (I found out because I’m a support group junkie and get all my information from other parents). Very often, when there’s not a physical issue with your child, they turn you down – but if you go to appeal, something like 75% of cases get accepted. I’ve now helped other parents get the high-rate mobility component. What support groups can give you is the detail – I belong to about 10. I believe in networking so much.”

Susan, health worker and Emma's mum

Financial support for disabled children

Disability Living Allowance (DLA)

You can get DLA for children under 16 if your child needs more care, supervision or guidance than other children of the same age. DLA has two components:

- **The mobility component** can be paid if your child has problems with getting around.
- **The care component** may be paid if they have care needs which are more than most children of their age.

If your child is 16 or over and on DLA, they will be invited to claim Personal Independence Payment (PIP) instead of DLA,



unless they are terminally ill (when they stay on DLA until their award expires). Have a look at our [From Child to Adult guide](#) for more information about the transition-to-adulthood period and its impact on benefits.

Note: in **Scotland**, DLA for children is going to be replaced by Child Disability Payment, which will continue until children are 18. Applications for the new Child Disability Payment will start in the summer of 2021 under a pilot scheme, with a full roll-out planned for autumn 2021. Children with existing DLA awards will gradually be moved to the new benefit in stages and this process is expected to be completed by 2025.

Universal Credit

If you get Universal Credit, it can include an additional amount for disabled children or young people who get DLA or PIP. However, if you are already on benefits, you should get advice before any claim for UC, as it could mean your existing benefits stop. More information on UC for carers is under 'Top up your existing benefits if you are a carer' (see page 24).

Tax credits

New claims for Working Tax Credit and Child Tax Credit have now been closed to most people and replaced by Universal Credit (see above). If you are already claiming tax credits, you can claim back up to 70% of your eligible childcare costs (up to a cap) for children under 16, or under 17 for your disabled children. Depending on your income, you could get up to £175 per week for one child or £300 for two or more children.* You can't get tax credits at the same time as Universal Credit or Tax-Free Childcare. If you're already getting one tax credit, you can start getting the other. For

example, if you get Child Tax Credit and start working enough hours, you can receive Working Tax Credit, depending on your income.

Tax-Free Childcare

Tax-Free Childcare is an alternative to claiming childcare costs through UC or tax credits. If you aren't eligible to claim childcare costs through UC or tax credits, you could look at opening a **Tax-Free Childcare account online** instead. Tax-Free Childcare is a government scheme that pays 20% of childcare costs up to a maximum of £4,000 for disabled children* (£2,000 for non-disabled children) per year. The scheme is open to all parents of children under 12 (or under 17 if disabled). Working Families has a **useful webpage on Tax-Free Childcare** where you can find out more information.



Bursaries and grants

A few local authorities have their own schemes in place to help parents of disabled children with the extra costs of childcare for their disabled children. You can contact your local council for more information.

Free nursery education

All three- and four-year-olds in the UK are entitled to 15 or 30 hours per week of free early education or childcare. You could also get 15 hours' free childcare for your two-year-old if you are on benefits or your child has a special educational needs (SEN) statement, or an Education, Health and Care (EHC) plan. How much you can get depends on which country you live in. We have more information on the available schemes, and how they differ between UK countries, on our website [here](#).



2 Finding and funding appropriate childcare and care for adults

Local Offer and Family Information Services

Your local council should have a 'Local Offer', which outlines the services available for children and young people with special educational needs and disabilities. It should include childcare services available in your area. Search 'local offer [your local council]' online or contact your local council for more information.

Your local council's Family Information Service will also be able to provide information on childcare in your area. Your local council may be able to provide holiday play schemes or financial help towards travel costs. You can contact your local council for more information.

What to do if you disagree with a benefits decision

If you disagree with a decision about benefits, you can ask for the decision to be looked at again – this is known as a 'mandatory reconsideration'. You'll need to ask for this within one month of the date the decision was made. If you disagree with the outcome of the mandatory reconsideration, you can appeal the decision to the Social Security Tribunal. The majority of disability benefits decisions are overturned at appeal stage, and we strongly encourage you to appeal if the assessment has been done incorrectly or the assessors haven't taken into account all of the factors surrounding your dependant's disability. The same advice applies to decisions made about disability within Universal Credit (for example, whether your disabled dependant, claiming UC in their own right, has limited capability for work).

"I have overturned a benefits decision twice. My oldest daughter tiptoes so she can't walk long distances. But for one of her assessments, they gave her the lower component of mobility in her DLA claim. So I took them to Tribunal. They asked me a few questions and immediately overturned the decision."

Ines, mother of four and care worker



*Note to reader

These are the rates for April 2020-2021. The rates are likely to change slightly from year to year, so make sure to check [GOV.UK](https://www.gov.uk) or contact our helpline for the most up-to-date figures.



3 Who cares for the carers?

Break the myths and get your energy back

The majority of this guide has covered your rights at work and your eligibility for help with childcare costs. While knowing your rights is incredibly important, what can sometimes be forgotten if you are often battling childcare providers and employers, is that to balance work and care long-term, you need to be able to look after *yourself* as well as your dependants.

Through our extensive work with carers who are working or trying to get into work, Working Families recognises that when it comes to help, support and self-care, one size doesn't fit all. We know that every carer and their family's circumstances are different; what's possible and practical and helpful for one, may not be for another. For example, a parent of a child who finds unfamiliar/noisy settings over-stimulating may consider in-person support groups with their child unworkable for their family. And a forces family living overseas, or a very rural family, or a family living far from close relatives and friends, will likely not have the same childcare or support options as someone living in a big UK city with loved ones nearby.

Talking to the parents we work with has highlighted how incredibly helpful the internet is for today's carers, both as a source of information from specialist organisations, and a means of accessing peer support – a virtual 'coffee morning' with other carers with similar experiences and who have tips and coping strategies to share. A 'support network' can be virtual – and at least as effective.

The following section has been contributed for you as parents, as carers, to give you some ideas that might help you navigate your competing responsibilities, and gently remind you that you need care sometimes, too – with some suggestions to try. We hope at least one or two of these ideas will connect with you and help you and your family.



3 Who cares for the carers? Break the myths and get your energy back

The remainder of this section has been contributed by Silba Staffler, transformational coach, speaker and facilitator

Carers are modern-day heroes. Our systems would collapse without their committed and selfless support. Whether you look after your child, your partner or another family member, your work is of incredible value. But being a carer is not always easy. You may dedicate most of your time to your dependant or need to juggle the caring with other commitments, such as a job or a wider family; caregiving requires energy, organisation and ongoing support. Yet many carers feel like they must do it all alone. They push themselves to their limits and sacrifice their own wellbeing and vitality. The cost of caring can lead to mood swings, exhaustion, irritability and cynicism, as well as feelings of anxiety, emptiness and overwhelm.



How did we get to this? It looks like somewhere along the line we were told that it's more important to care for others than it is to care for ourselves. We were told that if someone is in difficulty, they become the

priority. Who are we to demand anything, when we are healthy and able? But you cannot serve from an empty vessel – what you empty out has to be filled again. Taking care of yourself is not selfish or indulgent. Caregivers not only deserve to look after themselves; self-care also helps them to be able to continue looking after their dependant.

Don't struggle alone

The most important skill to learn as a carer is to ask for, and accept, help. Unlike nurses and doctors, who can go home after their working hours, a family carer is always on call. Speaking about disability can be difficult and many carers isolate themselves from their communities to escape judgement and to avoid being a burden on others. Working Families understands why carers sometimes choose to do this. But even if you prefer to take a step back from your community or to be private, you don't need to do this all on your own.

1. Build your own support network

As a carer, you spend countless hours searching for the best medical team for your dependant. Apply that same approach to your network. List all the friends, relatives, neighbours, colleagues and other people that you can reach out to when you are encountering challenges. This could be looking after your child while you go to the shop or to simply listen to you on the phone when you've had a tough day. If you don't

have, or want, in-person support options, consider going online – there are lots of specialist, knowledgeable and supportive forums (see 4. below).

2. Don't be too proud or scared to reach out

People don't always know how to help, but humans are wired to support each other. Share your experience, if you feel comfortable. Even when everything is going dandy, knowing that there is a bunch of people you can count on will make you feel stronger. And whoever you are caring for will feel it too.

3. Learn to accept help

If someone offers you their hand, don't assume that it is out of courtesy. Think about how they may support you and let them know. Whether that is a stranger on the bus, or a friend who isn't that close. Focus on small tasks – could they go to the shop for you occasionally? Or pick up that parcel that has been sitting at the post office? Well-meaning friends who don't fully 'get' your situation can still give you practical help with errands, for example.

4. Connect with people who understand

Find groups for caregivers. We live in an age where you can connect to people through the click of a mouse. Look for online groups that may provide useful information and support. If you prefer face-to-face interaction, look for groups in your neighbourhood or district. If

there isn't one in your community and you'd like there to be one, build one! Who better than you knows what carers need to hear?

5. Consider external support

It might not always be a quick process, but there are countless public counselling services around the country that can support you with topical help. You might be surprised by how comforting even one session with a counsellor can be. Speak about it to your GP. If there are private counsellors or therapists that you think may be more targeted and easier to reach but you cannot afford their prices, message them anyway. Practitioners often offer reduced prices for clients that can invest less.

“After my second child was diagnosed as having a learning difficulty, I hit rock bottom and I went for counselling. I needed someone who really understands. It's good to have friends and family, but it's also nice to have someone to talk to who will really listen. The counsellor helped me think in a different way about my situation. I knew that every Tuesday evening was a set period that I had for myself where I would see her. It really helped me get through that rough patch, and I was quite sad when it finished.”

Sarah, mother of four and care worker

3 Who cares for the carers? Break the myths and get your energy back

Be your own caregiver

When time is scarce and your energy limited, you will have the tendency to put your dependant first. This works in the short-term but will soon start eating into your own reserves of energy, until there is so little left, that your giving suffers. This is the paradox of giving: the quality of your giving depends on the quality of your receiving.



1. Self-care is a necessity

Looking after yourself is not a luxury or something to be added at the bottom of your to-do list. It's a requirement to be able to cope in the face of stress and pick yourself up when times are hard. When you fly on an airplane, the flight attendant instructs you to put your oxygen mask on first, before helping others. Life is no different; if you run out of steam, both you and your dependant may suffer.

2. Self-care can be short and sweet

Most people associate self-care with long bubble baths, getting your nails done, going for a walk with a friend or managing to make your weekly football training session. While these activities are valuable, the time and money investment they can require can make them look out of place in your daily life. But



looking after yourself can be much easier than that; it can be a 10-minute break without distractions, drinking your tea while reading your favourite magazine or going for a brisk walk around the block. Self-care is every activity that is focused on you and that makes you feel at ease in your body and mind. What are the small things in life that bring you joy?

3. Self-care is about being present

More and more research is showing the impact of mindfulness: a set of tools that help people be present with what they're experiencing. It lowers stress, enhances ability to deal with challenges and improves overall health. Mindfulness can be as simple as setting a timer for two minutes and just focusing on your breath. Or you could eat a piece of chocolate giving your full attention to its taste and texture. And you don't need to do it alone! There's a great range of apps that have basic free versions to get started (e.g. Calm, Insight Timer, Headspace, and Stop, Breathe & Think). Alternatively, you could look for mindfulness groups in your area if this would suit you.

4. Self-care is about feeling alive

Remember that hobby that you abandoned when you started taking care of your dependant? Hobbies may seem superficial compared to the difficult demands of your household. But whether it is dancing, painting, baking or martial arts, your activity of choice will be the outlet that will allow you to release stress and come back home/to caring recharged. What activities make you feel alive?

5. Self-care is about consistency

For any self-care practice, the key is routine. Don't let it exist only in a dreamed corner of the mind or on exception days where your diary is free. Self-care is medicine for the soul, so carve out time for it if you can. Test different options and once you've found one or two practices that work for you, add them to your schedule and make them non-negotiable. Find someone who can take care of your dependant every Thursday evening and go to that Zumba class! Or set a reminder to get into bed five minutes early to do a breathing exercise before falling asleep. You will feel happier and so will the people around you.

Be your friend

The harshest comments we receive come from the critic inside our head. This is the loud voice that reminds you of all the things you've done wrong. It tells you off for double-booking that doctor's appointment and says

"Don't give up. Be kind to yourself. You are doing a good job."

Lisa, parent of a disabled child

you are not good enough when you break down in front of your child after a difficult day. It criticises your words, your appearance, your worthiness and your potential.

1. The inner critic is wrong

The inner critic sees everything in terms of doom, and bosses you around with threats of catastrophe. Should-haves and could-haves are its favourite utterings. In hard times, the inner critic only pushes you harder. It perceives your pain as weakness and makes you believe that the only way forward is to clench your teeth and "just keep going".

2. Self-compassion is the answer

Science suggests that what we need in hard times is to be kinder to ourselves. Self-compassion involves treating yourself with the same kindness, caring and concern as you would a good friend. If a friend told you they were having a difficult day, would you tell them they deserve it and list all the things they should have done differently? Of course not! You would see their pain as legitimate, you would show them your concern and allow them to rely on you. Why is it so different when you're the one in pain? Being kinder to yourself has incredible benefits: it increases motivation, boosts happiness, enhances self-worth, builds resilience to adversity and decreases anxiety.

3 Who cares for the carers? Break the myths and get your energy back

3. Self-compassion is a daily practice

Self-compassion should be practised daily. Here is a little guide to tame the critic and bring more kindness to your internal dialogue:

- Notice when the critic flares up and gets louder. Usually you will find it hiding where there is conflict, struggle or doubt. Listen to what it says as if it was someone outside of you speaking to you. Giving it a name and garments may help you distance yourself from it.
- Ask yourself whether you would say those words to a friend who was struggling in a similar situation.
- If the answer is no, what would you tell that friend instead? Find an alternative way of speaking to yourself in those moments of challenge. If a friend were in your shoes, how would you respond to them? What advice would you give them?

Allocate your time and energy wisely

Multi-tasking should be a synonym of caregiving. As a carer it can often feel like there isn't enough time or energy to get to all the things on your to-do list. Let's take a step back to reconsider your priorities and implement some tools that may help you feel more in control.

Energy boosters versus energy gobblers

It's important to recognise the activities that bring you energy and those that drain you. The aim is to make more room for your energy boosters, and fire some of your energy gobblers. The consequences are straightforward: if you do more of what nourishes you, you will have more to give back to those around you and it will be easier to do those tasks that drain you but must be done.

Take a pen and paper and write down the activities, people and environments that fit under each of the two categories:



Energy boosters	Energy gobblers
These are the activities, people and environments that make you feel nourished. You walk out of them feeling energised and hopeful.	These are the activities, people and environments that seem to eat up your energy. You walk out of them feeling tired and depleted.
<i>E.g. exercise, walk in the park with a dear friend, quality time with my child/partner/parent</i>	<i>E.g. coffee with a friend I don't really like, looking at my phone first thing in the morning, baking cake for class party</i>

Energy boosters

Energy boosters are activities, people and environments that make you feel nourished. You walk out of them feeling energised and hopeful. Examples may be that hobby that you really like, exercising, a walk in the park with a dear friend or quality time with your family or partner. What are your energy boosters? You may realise that a lot of these you don't do often. They may seem frivolous or unimportant. But think of them in terms of food for your energy. The more you consume from this pot, the more you will be able to give back to others. You will also feel more ready to tackle those energy gobblers you can't avoid.



Energy gobblers

Energy gobblers are activities, people and environments that eat up your energy. You walk out of these moments feeling confused, tired or depleted. Examples may be having coffee with that friend you don't really like, last-minute baking for your child's class party or grabbing your phone first thing in the morning. It may also include things you cannot easily get out of, such as washing up, calling up the doctor or paying bills. Include everything that you think fits this category and aim to minimise these as much as possible. The more you consume from this pot, the lower your energy will be. Which of these are not important to you? Which of them can you delay, delegate or not do?

Implementation

Set up clear boundaries. Caregivers may identify with their role of giving, expecting themselves to always be available for support, help and to requests from others. You may accept invitations even when you don't want to and end up filling your cup to the brim. However, when you do things out of duty rather than out of joy, your energy suffers. So, what can you do? The key is to set clear boundaries. Say no to any requests that you feel will drain you rather than fill you. At first this will feel hard and may surprise others. But the more you stick to it the more empowered you will feel, and others will respect you for standing up for yourself.

“It can be hard to take a step back during difficult times. When I have respite during school hours, I meditate and practise yoga – I find this helps a lot. I have also recently been introduced to mindfulness. Deep breathing works.”

Chantelle, freelancer and mother

3 Who cares for the carers? Break the myths and get your energy back



Dealing with overwhelm

Some days you may feel like everything is going wrong. You feel on edge, your mind is running in all directions and the inner critic is louder than ever. Something cracks and you can't hold it in anymore; the world seems to be crashing down and you don't know how to pick yourself up again. Feeling overwhelmed is common for carers. Here is a framework that can help you in these moments.

RAIN for overwhelm

This practice was established by Michele McDonald, a nurse and mindfulness practitioner, to overcome moments of strong emotional reactivity. Each letter stands for a step. It can be done in just a few minutes and is a great tool you can bring with you anywhere you go. It has a proven track record and will help you break the negative spiral of overwhelm.

When you feel overwhelmed, take a pen and paper and write down your answers to each of the four steps:

R – Recognise what you are feeling in the moment

When strong discomfort takes over, we tend to react in one of three ways: ignore it, numb it or be paralysed by it. Yet when you don't let your feelings come out, they will come back later, stronger. The first step to breaking the

spiral of negativity is to recognise that you are stuck and give your full attention to what is going on in your body and mind. What are your thoughts saying? What sensations are showing up in your body? What emotions are you feeling, and how strong are they?

A – Allow the experience to be here, just as it is

The second step is about acceptance. Let the thoughts, sensations and emotions that you have recognised simply be there. By accepting what is going on you are creating a pause, a distance that will allow you to gain perspective and exit the tunnel vision of overwhelm. It may be helpful to support this step with a phrase like, "It's going to be OK."

I – Investigate with kindness

Now, it's time to understand where the overwhelm is coming from. As you may with a friend in distress, be inquisitive and supportive. What triggered the feeling of overwhelm? What situation were you in? What is calling for your attention? What do you need right now? How can you honour these needs?

N – Nurture

You have stopped the spiral and recognised what is going on inside you. You have then taken a step back and allowed the experience to be as it is. You have understood where it is coming from and identified your needs. Now it's time to nurture your needs and act. Is there something about the initial triggering situation that you can adjust? Does your reaction to the situation need updating? Recognise what isn't working for you. Is there anything that you can change?

Example of RAIN

Mara is the main carer for her son, Oliver, who has a chronic pain condition and needs assistance for most of his movements. Mara hasn't seen her friends for more than a month and has decided to go for coffee with Jo and Nicky, her two closest friends. She planned the afternoon two weeks early, to make sure that everything would be taken care of. Her brother John, who is a nurse and knows Oliver well, agreed to look after her son. However, as Mara is getting ready to go see her friends, John calls up to say he has the flu and can no longer look after Oliver. Mara puts the phone down and feels tears swelling up in her eyes. Her son Oliver asks her if she's OK. She feels overwhelmed and angry so she ignores Oliver and runs upstairs. Then she remembers the R.A.I.N. technique. She feels so low, but she decides to give it a go. She takes a pen and paper and follows the steps.

R – Recognise what you are feeling in the moment. *I'm feeling sad and angry. My chest is tight and it's hard to breathe. My mind is racing; I keep on thinking I've failed, I'm a bad mum. I'm angry at my brother John and angry at all the parents that can count on their partner or who don't have to look after their son 24/7. I'm angry at myself for ignoring Oliver.*

"I now have friends at the school that also have disabled children. You tend to gravitate towards them because they understand. I had a last-minute surgery that I knew about only the night before, so I called up one of the other mums and asked if she could pick up my two boys (both have learning difficulties) from school. It's really helpful and reassuring because I know I can trust the other parents, and I'd do the same for them if they needed me."

Sarah, mother of four and care worker

A – Allow the experience to be here, just as it is. *I'm finding it very hard to connect to what I'm feeling. It all feels too much and I'm scared that if I let it in, I will break. I feel a lot of resistance towards this exercise and my emotions. At the same time, I'm already starting to feel a little better, because I'm not wallowing in my thoughts. I know that keeping this in will not help me, and I don't want to let this eat me up and impact Oliver.*

I – Investigate with kindness. *I think the main thing that triggered me was the thought of not being able to see my friends. I haven't seen them in so long and I can't remember the last time I had fun. I spend so much time focusing on Oliver that I forget about myself and end up resenting him for it. It's been going on for a while and now there's all this frustration that's built up.*

N – Nurture and act. *I now understand where my feelings are coming from. I am not a bad mother, on the contrary, maybe I am trying too hard to be a good mother and forgetting to be a good friend to myself. Maybe I should take more time for me so that I don't break if the one time I have something planned doesn't work out. For today, I'm going to call Jo and Nicky and see if they can come to the house instead. It won't be the same but at least I will not be punishing myself. And before they leave, we can schedule our next meet-up to make sure I soon get another dose of fun and connection. Yes, that's a good plan. And before that, I'm going to apologise to Oliver and give him a big hug. Ah, I feel a lot better.*

"It's not through choice that we are in this situation [having a disabled child]. We try our best every day to do what we can and provide for our families and have as normal a life as possible. [We just want] employers to see that – that we are trying your best. We are entitled to work, and we are entitled to have a life."

4 Useful contacts

Working Families

Working Families uniquely works with parents, carers and their employers to help parents and carers balance their work commitments and home responsibilities.

- Helpline phone: **0300 012 0312**
- Online advice contact form: workingfamilies.org.uk/contact-us-for-advice/
- Website: workingfamilies.org.uk



working families

Our support project for parents of disabled children who work or wish to work was set up in 1996. The project produces a free newsletter three times a year which goes to a network of over 2,000 families and some 500 interested professionals. The special helpline, 0300 012 0312, answers parents' questions about childcare for their disabled children and about their rights to parental leave, flexible working and other workplace issues. The project also has a closed Facebook support group. You can **sign up to the Facebook group and the newsletters** on our website.



Over the years the project has run conferences and meetings, produced publications for parents and professionals, and campaigned with some success for changes in the law to help parents balance their paid work and caring for their disabled children.

Working Families' parliamentary work and campaigning, and the advice we give employers on becoming more family- and carer-friendly, are informed by our project for parents of disabled children who work or wish to work, as well as by the calls taken by our legal advisers from a whole range of parents and carers seeking advice about their rights in the workplace.

There is also a range of factsheets available on our website, and there are two other guides in this series for parents and carers of disabled dependants: ***From Child to Adult: A guide to disability, transition and family finances***, and ***Getting into Work: A guide for parents of disabled children returning to work***.





Other useful organisations

Adoption UK	adoptionuk.org
Advisory Conciliation and Arbitration Service (Acas) – for workplace issues	acas.org.uk
Carers UK	carersuk.org
Citizens Advice	citizensadvice.org.uk
Contact – charity supporting families of disabled children	contact.org.uk
Disability Rights UK	disabilityrightsuk.org
Equality Advisory Support Service (EASS)	equalityadvisoryservice.com
Family Fund	familyfund.org.uk
Family Lives	familylives.org.uk
Gingerbread – charity for single-parent families	gingerbread.org.uk
Independent Living Funds (ILF)	ilf.org.uk
Independent Provider of Special Education Advice (IPSEA)	ipsea.org.uk
Jobcentre Plus – find your local branch	GOV.UK/contact-jobcentre-plus
Money Advice Service	moneyadviceservice.org.uk
National Careers Service	nationalcareersservice.direct.gov.uk
Office for Standards in Education (OFSTED)	GOV.UK/government/organisations/ofsted
Scope – disability charity	scope.org.uk
Timewise – flexible jobs database	timewise.co.uk
UK Home Care Association	ukhca.co.uk





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