



Support for Parent Carers

Version 1.0

Contents

| | |
|--|----|
| Contents..... | 2 |
| Introduction | 3 |
| Parent Carer’s Assessment | 4 |
| Respite | 5 |
| Financial Support | 6 |
| Carer’s Allowance (CA) | 6 |
| Carer’s Credits..... | 7 |
| Additional funding for parent carers | 8 |
| Your Rights in the Workplace | 9 |
| Flexible working | 9 |
| Dependants Leave | 9 |
| Unpaid Carer’s Leave | 9 |
| Parental leave | 9 |
| Mental Health Support | 10 |
| Version Control | 11 |

Introduction

Caring for a child with trisomy 13 or 18 might feel exhausting at times. You may be struggling with the physical or emotional challenges of managing your child's additional needs, or you may be worried about the extra financial costs of running medical equipment or reducing your work hours to provide care.

This guide has been put together to provide an overview about what support is available to parent carers, and to provide information about how to access it. Hopefully, by pooling this information together in one guide, it will make it easier for you to find what you need. We encourage you to speak to your local Citizen's Advice Bureau for accurate and bespoke advice.

If you have any feedback, please let me know through the following link:

<https://forms.gle/hao77rzG4Qp5MjpA6>

Parent Carer's Assessment

You may find it useful to request an assessment from your local council or health and social care trust. This will highlight the types of support that you need. All parent carers in the UK have a right to ask for an assessment under the Children and Families Act 2014.

If you live in **England, Wales** or **Scotland**, you can request an assessment by contacting the children's services department at your local council directly to explain that your child is a child in need and that you would like an assessment of their needs and your family's needs. You can find contact details for your local council through the following link: <https://www.gov.uk/find-local-council>. If you live in **Northern Ireland**, you will need to contact your health and social care trust: <https://www.nidirect.gov.uk/contacts/health-and-social-care-trusts>. Alternatively, you can ask your GP, health visitor or voluntary organisation to contact your council for you. It is good practice to follow up requests in writing.

In preparation for your assessment, gather relevant medical letters and notes as well as statements from people who know your situation. Think about what you want to say and what risks you or your child might have if support is not provided. Your local council's or trust's website might have a 'Carer's Assessment Checklist' which gives details about what will be discussed during the assessment. This might be helpful to look at in advance to help you prepare. You will be asked about how caring affects your wellbeing, mental and physical health, relationships, work or education and leisure or interests. Some things you might want to consider are:

- Whether you get enough sleep
- How caring affects your health
- Can you leave your child unattended?
- Are you worried about having to give up work?
- Do you get time for yourself?

Following your assessment, your local authority or trust should issue a plan letting you know whether any services will be provided, how long for, what different people are expected to do, and when the plan will be reviewed. You may need to pay something towards the cost of the support offered. This will be determined by a financial assessment from your local authority if you live in **England** or **Wales**. In **Northern Ireland** you may be charged for services, but this is not common.

If you are unhappy with the outcome of your assessment, you can complain to your local council or trust. If you are unhappy with how this complaint is dealt with, you can contact the local government and social care ombudsman.

Carer's assessments should be reviewed every year, and you can request a re-assessment if your circumstances or your child's circumstances change. If your child is transitioning to adult health care, you can request a child carer's assessment 'in transition' under the Care Act 2014 in the same way as carer assessments for younger children.

In **Scotland**, carer's assessments may be referred to as an Adult Carer Support Plans. You should not be charged for services provided to you as part of this plan.

Sources:

<https://www.scope.org.uk/advice-and-support/preparing-for-carers-assessment/>

https://www.carersuk.org/media/obyppgdbx/assessments-england_april-2023-24.pdf

<https://contact.org.uk/help-for-families/information-advice-services/social-care/carers-assessments/>

<https://www.nidirect.gov.uk/articles/assessments-carers>

<https://www.carersuk.org/media/rsngy1ac/assessments-ni-april-2023-24.pdf>

<https://www.mariecurie.org.uk/help/support/being-there/support-carers/assessments>

<https://www.carersuk.org/scotland/help-and-advice/practical-support/adult-carer-support-plans/>

Respite

Local Authorities have an obligation to provide respite care (short breaks) for parents of children with additional needs, if they are eligible. Local authorities in **England, Scotland** and **Wales** should publish a “short breaks statement” (this may also be called a “short break service statement”) which you can search for online.

These breaks can include universal services (which are available to all children), targeted services and specialist services. You do not need an assessment for your child to access universal or targeted services, but you do to access specialist services.

Specialist services can include:

- Caring at home
- Day care away from home (day centres, support from a personal assistant)
- Overnight short breaks
- Residential breaks
- Family link schemes

If you live in **Scotland**, you can search for short break services here:

<http://www.sharedcarescotland.org.uk/> In **England**, you may wish to consider joining your local parent carer forum to receive more information about short breaks services in your area. There is more information about parent carer forums here: <https://contact.org.uk/help-for-families/parent-carer-participation/>

In **Northern Ireland**, you can find out about respite breaks from your child’s medical team, or from your health and social care trust.

Sources:

<https://www.nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/carers-breaks-and-respite-care/>

<https://www.homecare.co.uk/advice/respice-care-for-parents-of-disabled-children>

<https://contact.org.uk/help-for-families/information-advice-services/social-care/short-breaks/>

<https://www.specialneedsjungle.com/how-the-respice-of-a-short-break-can-keep-a-family-together/>

<https://www.dewis.wales/short-breaks-for-carers>

Financial Support

Carer's Allowance (CA)

You can claim this allowance if you provide care for at least 35 hours a week, and your child is receiving certain disability benefits:

- Personal Care component of Disability Living Allowance (DLA) at middle or high rate; or if they are 16+ the daily living component of Personal Independence Payment at any rate (in **England, Wales or Northern Ireland**)
- OR Child Disability Payment at middle or high rate for personal care or daily living component of Adult Disability Payment (in **Scotland**)

If you share the childcare with someone else and you each provide 35 hours a week of care to the same child, only one of you can claim Carer's Allowance. You can only claim if your earnings are up to certain limit (£139/week after deductions {this is anticipated to rise to £151/week from April 2024}) but this only applies to your own earnings, not your partner's. Savings and other income are not counted. When calculating earnings, some childcare costs are ignored. These include:

- costs which allow you to work e.g. childcare providers for any children up to 16, so long as the providers are not close relatives (totalling up to half earnings)
- half of your contributions to works or personal pension schemes
- work expenses which are necessary for carrying out your job, such as equipment and travel (other than travel between work and home)

Your earnings do not include any personal or occupational pensions you receive. You cannot claim if you are in fulltime education (i.e. a course which is described as full time by the course provider) or part-time education if it involves 21 hours or more of supervised study, including non-contact hours. It is also dependent on immigration status and the amount of time you have been in the UK. You may be able to increase childcare costs or pension contributions to qualify for CA if your earnings are above the limit (this may be preferable to reducing work hours if you are receiving a work-hour-dependent benefit such as Work Tax Credit).

Carer's allowance is £76.75 per week (£81.90/week from April 2024). You can only get one award, regardless of whether you are looking after more than one person. If you get any of the following, you may not receive CA, or you may receive a lower amount of CA:

- Incapacity Benefit
- Contributory Employment and Support Allowance
- Maternity Allowance

- Bereavement benefits
- Contribution-based Jobseekers Allowance
- State Retirement Pension

If the above benefit is the same as or more than the CA, you will receive the other benefit. If it is less, you will receive that benefit with the balance of CA on top. In these cases, it may still be worth trying to claim CA, as you may have an underlying entitlement to it. Please speak to your local Citizen's Advice Bureau to get advice for your individual situation.

If you receive CA or have an underlying entitlement to it, you will qualify for the 'Carer's Premium' for any of the following benefits you receive:

- Income Support
- Income-related Employment and Support Allowance
- Income-based Jobseekers Allowance
- Housing Benefit
- Council Tax Reduction/Rate Relief
- Pension Credit

If you get Universal Credit, you can get an additional amount (the 'carer element') if you are eligible for CA, even if you do not apply for it.

You will receive class 1 National Insurance credits for the time you are on CA, which means that it can help protect your right to a state pension and maternity allowance. It can also help you to meet the conditions for new-style Jobseeker's Allowance, new-style Employment and Support Allowance, Maternity Allowance, some bereavement benefits and the State Pension. CA should be backdated to the start of the DLA/PIP award as long as you claim within three months of receiving the decision about the award.

In **Scotland**, the Carer Support Payment will replace Carer's Allowance from Spring 2024. The earning threshold and weekly rate are the same as for CA. CA claimants in **Scotland** receive supplementary payments, called the Carer's Allowance Supplement from the Scottish Government twice a year (£288.60 in June and December).

In **England, Wales and Scotland**, you can claim CA through the gov.uk website (<https://www.gov.uk/carers-allowance/how-to-claim>) or by post. If you live in **Northern Ireland**, you can apply online (<https://www.nidirect.gov.uk/services/apply-carers-allowance-online>), over the phone or by post. You need to request a DS700 form in each case.

This document has some helpful tips if you are applying for the first time:

https://www.carersuk.org/media/e3sh3zhx/carers_allowance_-_tips_for_applying_for_the_first_time.pdf

Carer's Credits

If you are not eligible for CA, you may be able to claim Carer's Credit in order to protect your National Insurance record. To qualify for carer's credit, you will need to provide more than 20 hours of care per week and be under the state pension age. The child you are caring for must claim one of the following (although you may be able to Carer's Credit even if they do not get any of these):

- Personal Care component of Disability Living Allowance (DLA) at middle or high rate; or if they are 16+ the daily living component of Personal Independence Payment at any rate (in **England, Wales or Northern Ireland**).
- OR Child Disability Payment at middle or high rate for personal care or daily living component of Adult Disability Payment at the standard or enhanced rate (in **Scotland**)

Carer's Credit is not a monetary benefit. Instead, it is a class 3 National Insurance credit, which can help protect your record and can be used to help you meet the conditions for State Pension and some bereavement benefits.

Sources:

<https://www.nidirect.gov.uk/articles/carers-allowance>

<https://www.citizensadvice.org.uk/benefits/sick-or-disabled-people-and-carers/carers-allowance/>

<https://contact.org.uk/wp-content/uploads/2021/03/Carers-Allowance.pdf>

<https://contact.org.uk/help-for-families/information-advice-services/benefits-financial-help/carers-allowance/>

<https://www.nidirect.gov.uk/articles/carers-allowance>

<https://www.gov.uk/carers-credit/eligibility>

<https://www.homecare.co.uk/advice/carers-allowance-in-202021-amounts-and-how-to-claim>

<https://www.independentliving.co.uk/advice/carers-allowance-threshold/>

Additional funding for parent carers

- **Carer's Wellbeing Fund** – Available in parts of **England, Wales and Scotland**, this is a discretionary payment of up to £300 which you might be able to apply for through your carer's support service or nominated organisation. The fund is intended to benefit your needs and promote your health and wellbeing.
If you live in the Highlands, you may find this flyer helpful:
<https://www.nhshighland.scot.nhs.uk/media/smxn3qyg/carers-wellbeing-fund-leaflet-2023.pdf>
- **Carer's Trust Grant Fund** – Grant of up to £300 for carers over 16 years old, to be used towards an item or activity which will make the caring role easier. For more information, please contact your local Carer's Trust Network Partner: <https://www.carers.org/carers-services/find-your-local-service>
- **Turn2us** – You may find other grants which you are eligible for on the Turn2us website: <https://grants-search.turn2us.org.uk/>
- There is also a list of organisations which provide funding for respite breaks and holidays on the Grants and Funding page here: <https://www.soft.org.uk/grants-and-funding>

Your Rights in the Workplace

Flexible working

If you have been working for your employer for 26 weeks (6 months) or more, you have the right to request flexible working, as long as you have not made a request for flexible working within the last year. You need to make this request in writing and set out what flexibility you require, how this may affect the business and how that can be dealt with, and whether you have made a previous request. Flexible working may not be available to those working for agencies or the armed forces. There is more information about the application process in **Northern Ireland** here:

<https://www.nidirect.gov.uk/articles/flexible-working-and-work-life-balance#toc-2>

From April 2024, you can request flexible working from your first day, and you are allowed to make two requests within a year.

Dependants Leave

You also have the right to take a reasonable amount of time off for emergencies or unforeseen issues involving dependants. This is unpaid unless your contract specifies otherwise, and you can apply from the first day of employment. There is no set limit for the amount of time you take off for dependants leave, but it must be reasonable for the circumstances.

Unpaid Carer's Leave

From April 2024, carers in **England, Wales and Scotland** can take up to 1 work week unpaid leave (either in a block, or as individual days or half days) per year. You can take this from the first day of work. There is more information here: <https://www.gov.uk/carers-leave>

Parental leave

If you have worked for the same employer for 12 months, you are entitled to at least 18 weeks' leave if you are responsible for a child under 18. This must be taken before your child turns 18 and is unpaid unless your contract specifies otherwise. You must give at least 21 days' notice, and it is available to both parents. This leave usually has to be taken in blocks of 1 week or more, but if your child receives DLA or PIP, you can use it a day at a time. You can use up to 4 weeks per year and you are guaranteed to return to the same job. At your employer's discretion, you can take longer. In this case, if it is not reasonably possible for you to be allowed to return to the same job, you are entitled to a similar job. You can carry over unused parental leave between different jobs.

Sources:

<https://www.carersuk.org/media/uarbiuje/your-rights-in-work-september-2022.pdf>

<https://contact.org.uk/help-for-families/information-advice-services/your-child-your-family/work/flexible-working-and-time-off/>

Mental Health Support

It is important to look after your mental and emotional health, especially when you are finding life challenging or overwhelming. Unique have produced two leaflets full of resources to help you manage how you are feeling. Some of the links within these guides are now out-of-date, but many are still active.

Mental health and wellbeing:

<https://rarechromo.org/media/familyguides/English/Mental%20Health%20and%20Wellbeing%20FTNW.pdf>

Carers' Wellbeing:

<https://rarechromo.org/media/familyguides/English/Carers%20wellbeing%20FTNW.pdf>

At SOFT UK, we aim to support all families affected by trisomies 13 and 18. To help us understand your mental health needs and how we can support you, we would be grateful if you would consider completing the following survey. This survey is anonymous and should take about 5-10 minutes to complete: <https://wkf.ms/4arueDN>

Version Control

| Version | Author | Date | Changes |
|---------|--------------|------------|-------------|
| 1.0 | Sarah Bowell | 29/03/2024 | First draft |