



All our information sheets are available to download free of charge because we believe that money should not be a barrier to getting the information you need when you need it.

Please see the end of this information sheet for details of how to support us.

We want to make sure our resources are helpful. Please spend a few minutes giving us some feedback:

[Feedback form](#)

Supporting Family Carers in their Role

Family carers play an important and essential role in ensuring that their relative is appropriately supported, receiving all their entitlements, and having their rights respected. This section of the Family Carer Advocacy Pack provides information about what is available to family carers to support and enable them to remain in their role for as long as they want to, and at a level they want to.



NHSE defines family carers as:

“ Anyone, including children and adults who look after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support. The care they give is unpaid. ”

Even if your relative is no longer living in your home, you can still be a family carer, have the same level of involvement, be advocating on their behalf formally e.g. as their nearest relative or because they have been assessed as lacking capacity for a certain decision at a certain time or informally. However, the level of involvement you, and your relative, decide is entirely your choice. Professionals should never encourage or discourage your involvement, make you feel guilty or force you into taking on anything you don't want or feel able to.

Share the load

Acknowledge the challenges and don't be afraid to ask for help. This does not mean that you are not a good family carer. Think about all the roles you carry out for your relative, for example care and support coordinator, communication facilitator, behaviour support analyst. You will be doing this without formal training and unpaid compared to the professionals involved in your relative's life who have chosen their role as a job.

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For parents... the overriding sense is of their being isolated, excluded and left to get on with a task which is too difficult or beyond the expertise of qualified professionals.

McGill et al, 2005

”

Who can help

- **Other family members.** More than one family carer may be involved in the care and support of your relative e.g. both parents and/or other family members may be taking the lead e.g. siblings, grandparents, aunts and uncles or cousins.
- **Friends.** Maintaining friendships can be a challenge when you are short of time but making time for yourself will benefit your emotional and mental health which in turn will support your physical health. Although it is helpful to have friendships which allow you to share your experience of being a family carer it can be beneficial to have friendships which allow you to be a person independent of this responsibility.
- **Other family carers.** Family carers report that it is often other family carers who are the best source of support and information about local support groups.
- During Covid many charities offered **family support online** using Zoom for example. For some family carers online support continues to be easier to access, e.g. it eliminates the need for travel, they can take advantage of support further afield. The success of this has encouraged many organisations to continue to offer this type of support.



You can find out about [the peer support offered by the CBF](#)

- There are **charities** which offer families support nationally and locally if their relative has a specific diagnosis, e.g. Down's Syndrome Association, Fragile X Society, National Autistic Society.
- Support can be accessed through **social media** including accessing general information by following a particular Facebook page or joining a closed group which allows family carers to ask questions, contribute to discussions.
- Ask **the service your relative uses** what support they provide for family carers.
- Identify one or two **professionals** who you trust, have a good relationship with and understand your relative's and your family's needs. They can act as allies in meetings, when you feel that your voice is not being heard.
- Having to regularly make decisions on behalf of your relative can be stressful. To share this responsibility you could set up a **Circle of Support**.
- Check what **Professional Independent Advocacy** your local authority funds for family carers. In some circumstances you have a statutory right, e.g. if you are having a carers assessment and are finding the process difficult.

You can find out about local groups using [the Carers Trust search facility](#)



What are your rights as a family carer?

Read this guide [‘the Equality Act 2010: What do I need to know as a carer’](#). It explains how the Equality Act offers protection to family carers and includes case studies:



The Care Act 2014

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The Care Bill in many respects marks a quiet revolution in our attitudes towards, and expectations of, carers. At last, carers will be given the same recognition, respect and parity of esteem with those they support. Historically, many carers have felt that their roles and their own well-being have been undervalued and under-supported. Now we have a once in a lifetime opportunity to be truly acknowledged and valued as expert partners in care.

Dame Philippa Russell, Chair, Standing Commission on Carers

The Care Act 2014 puts your rights as a family carer on an equal footing as your relative’s entitling you to an assessment in your own right which considers the impact of your role as a family carer on your wellbeing.

Wellbeing includes:

- Personal dignity
- Physical and emotional and mental health
- Protection from abuse and neglect
- Control over your day-to-day life
- Ability to participate in work, education, training or recreation
- Social and economic wellbeing
- Domestic, family, and personal relationships
- Suitability of living accommodation
- Your contribution to society

Carers UK has a list of [frequently asked questions - and answers - about the Care Act](#)



There is more [information here from Disability Rights UK about the assessment process](#)



Developing your skills and knowledge

- NICE guidelines recommend that family carers should have the opportunity to develop their skills and knowledge through training. They highlight that any training should provide a balance between learning, enjoyment, a chance to meet other family carers and opportunities for peer support.
- Read the self-advocacy guide from Carers UK which has been developed to help family carers to understand their rights, communicate effectively with professionals and recognise how to be heard.



Read more about [the NICE guidelines here](#) (para 1.6.4-1.6.9)



Click here to read [the Carers UK self advocacy guide](#)

- Jointly is a mobile and online app created by family carers for family carers. It is free to download onto most mobile phones and aims to make the administration tasks related to caring a little easier, less stressful and more organised. It combines

group messaging with other useful features including to-do and medication lists, calendar and more.

[Click here to access the Jointly website](#)



Your physical, emotional, and mental health

- Family carers are often guilty of neglecting their own health needs. Read this report from Bringing Us Together which highlights how lack of time and prioritising other commitments e.g. their relative and other family members' needs and work commitments contribute to symptoms including stress, anxiety, depression, and tiredness.
- Register with your GP surgery as a family carer. You are entitled to reasonable adjustments as a family carer, for example the time and length of appointment.
- You will be prioritised for annual flu vaccinations and Covid boosters.
- Read what NICE guidelines say should be in place to support family carers in their role including access to psychological interventions, e.g. counselling to support emotional and mental health and the types of reasonable adjustments they expect to happen.

[Click here to read the report from Bringing us Together](#)



Read [the NICE guidelines on supporting adult carers](#)



Financial support

Being a family carer can result in costs which are not covered by your relative's benefits (e.g. replacing equipment due to behaviour described as challenging, adapting your family home, and having to cover the costs personally) or you may find yourself unable to work part or full time because of a lack of support services, if your relative is in crisis and you are trying to resolve the situation.

- Use this online benefits calculator from the Carers Network to check whether you are receiving all your entitlements

[Click here for the benefits calculator from the Carers Network](#)



This link provides [information about grants and discounts which you can apply for either yourself or your relative](#)



- If your relative is struggling with their finances because of their mental health, they can ask for a referral to the Mental Health Crisis Breathing Space service.

Find out more about the [Mental Health Crisis Breathing Space service](#)



- Be strict about what you take on for free. Family carers are often asked to contribute to consultations, reports, develop training for professionals all in the name of inclusion or co production but this is only the case if you are treated as an equal, e.g. paid for your time.

Further information



Carers Trust <https://carers.org/>

Carers UK - Information about Carers UK local directory, helpline, and online forum which all help connect family carers with others who understand what they are going through – “We’re here to make sure no-one has to care alone”.
<http://www.carersuk.org/help-and-advice/get-support>

Information about being a family carer <http://www.carersuk.org/help-and-advice/guides-and-tools/looking-after-someone-guide/>

Information about flexible working <http://www.carersuk.org/help-and-advice/work-and-career/your-rights-in-work/flexible-working-videos/>

The Challenging Behaviour Foundation

Detailed information sheet about the impact of being a family carer

<http://www.challengingbehaviour.org.uk/wp-content/uploads/2021/02/012-Impact-of-caring-on-families.pdf>

The CBF offer peer support and 1:1 Listening Ear calls hosted by family carers. If your relative has a severe learning disability and behaviour described as challenging, please email support@theCBF.org.uk for further information.

Information about peer support <https://www.challengingbehaviour.org.uk/for-family-carers/peer-support/>

In addition there is the option of joining the CBF’s Family Carers Email Network. The email network allows family carers to ask questions, share experiences, offer practical solutions to everyday problems such as how to fill in a benefits form

<http://www.challengingbehaviour.org.uk/for-family-carers/family-carers-email-network/>

Information about family carer wellbeing and resilience

<http://www.challengingbehaviour.org.uk/information-and-guidance/wellbeing-of-family/family-carer-well-being-and-resilience/>

Information on the Mind website explaining what resilience is

<http://www.mind.org.uk/information-support/types-of-mental-health-problems/stress/managing-stress-and-building-resilience/>

Bringing Us Together (BUT)

BUT regularly offer focused sessions for family carers on topics such as how to manage anxiety and feeling overwhelmed, local authority charging policies and how to claim disability related expenditure. They are also running Peer Advocacy courses for family carers who are in a position to advocate for other family carers. Email katie@bringingusstogether.org.uk for further information.

The Disability Benefits Consortium (DBC)

The Disability Benefits Consortium (DBC) is a national coalition of over 100 different charities and other organisations committed to working towards a fair benefits system. Using their combined knowledge, experience, and direct contact with people with a disability and family carers, they campaign to ensure Government policy reflects and meets the needs of everyone with a disability.

Disability Benefits Consortium website http://disabilitybenefitsconsortium.com/?_ga=2.86669791.63355522.1670251970-376828313.1670251970%2F

National Autistic Society's information on the support available for family carers <http://www.autism.org.uk/advice-and-guidance/topics/social-care/social-care-england-carers/support-available-for-carers>

Sibling Support

Sibs is a charity which provides support to siblings of relatives who have a disability. Sibs website: <http://www.sibs.org.uk/>

Parents often hand over the role of main family carer as they get older. Read a sibling's perspective here: <https://www.challengingbehaviour.org.uk/news/a-siblings-perspective/>

Contact (For families with disabled children)

This page provides links to information about support (1:1 listening ear service) and finance (benefits): <http://contact.org.uk/help-for-families/faqs/>

Mind

Information for family carers about:

- recognising difficult feelings related to being a family carer
- tips on how to look after yourself
- coping with and information about a specific diagnosis
- social care rights of family carers

<http://www.mind.org.uk/information-support/helping-someone-else/carers-friends-family-coping-support/>



We are the charity for people with severe learning disabilities who display challenging behaviour. We make a difference to the lives of children and adults across the UK by:

- Providing information about challenging behaviour
- Organising peer support for family carers and professionals
- Giving information and support by phone or email
- Running workshops which reduce challenging behaviour

To access our information and support, call 01634 838739, email info@thecbf.org.uk, or visit our website: www.challengingbehaviour.org.uk

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www.challengingbehaviour.org.uk Tel. 01634 838739

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