

Being Heard: a self-advocacy guide for carers

in Scotland



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Introduction

Carers Scotland is part of Carers UK, the national membership charity for unpaid carers. We are here to listen and to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community. We're here to make life better for carers.

This self-advocacy guide

We understand the many challenges that caring brings. This guide has been developed to help anyone with caring responsibilities gain confidence to understand their rights, communicate effectively with professionals and recognise how to be heard.

The guide stems from work carried out by Carers Scotland and the Scottish Government. It has been updated to reflect the situation for carers in Scotland. For accompanying resources, go to: carersuk.org/scotland/training-resources/self-advocacy-toolkit-scotland or call Carers Scotland on 0141 445 3070.

What is self-advocacy?

Caring can be rewarding but also very isolating. You may not know what help to ask for, how to ask, or indeed who to ask. Self-advocacy is about being heard, as well as speaking up for the person you care for.

This guide provides practical guidance on how to get your voice heard when you care for someone in what may be complicated and challenging circumstances.

This guide

Communicating effectively



The first part looks at communication, assertiveness and negotiation skills.

It offers practical advice on getting the best out of interactions with others and how to make a complaint.

Understanding your rights



The second part of this guide has information on the rights that can help you get your voice heard.

How you are feeling



The third part takes a look at other factors that may affect your ability to get your voice heard: difficult emotions, stress and family relationships.

We also explore how new ways of thinking and greater self-awareness may help you to be heard more easily.



Communicating effectively

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Communicating effectively

In this section, we look at how communicating well, and adopting different approaches, can play a key part in achieving what you want with organisations and services. We also offer tips on assertiveness, negotiation skills and how to make a complaint.



Common barriers to communication

It's easy for our message to be misunderstood. It's important not to blame yourself if this happens. Here are a few examples of why this can happen:

- The person you are speaking to may not be fully listening.
- You may not have enough time to get your points across.
- Your tone of voice may make it difficult for you to be heard, eg if it's too soft or too harsh.
- The way you ask for things may be unhelpful:
"I know that you'll say no but..."
- Having distractions – you or the other person may be trying to do something else when you're talking.

TOP TIP

Avoid negative language:

"I know that you'll say no but..."



Ways to communicate well

When you're talking to someone, some things are out of your control: your environment, or how much the other person is really listening. However, there are things you can do to give yourself the best chance of getting your points across:

- **Remain polite, calm and patient** – the person you're dealing with is more likely to go out of their way to help you.
- **Try to keep the discussion objective and non-judgemental**, sticking to the facts. For example, say *"The care workers coming to care for my mother rarely speak to her"* rather than *"The care workers swan in and always ignore my mother, which is cruel."*
- **Avoid sounding too critical**. For example, say *"It makes me anxious when I'm left waiting for you to arrive"* rather than *"You really stress me out when you're late."*
- **Be firm**. Say *"I would like to speak to you about getting a break"* rather than *"I was wondering whether I could get a bit of a break?"*
- **Be specific**. Instead of saying *"I can't cope anymore"*, say *"I'm exhausted and I need a few days off as soon as possible."*
- **Stay focused**. Stick to your point and remember why you're talking to the other person. Write down your points so you have them in front of you.
- **Repeat your request**. If you feel you're being side-tracked, try to keep the conversation on what you want to discuss. Don't be afraid to repeat what you want.
- **Listen to what the other person says**. It is easy to carry on thinking about other things when someone is replying – you can miss important bits of information.
- **Ask for clarification** if you don't understand what the other person is saying.
- **Don't be afraid of silence**: it can give you both a chance to think calmly. It could be a sign that the person is thinking seriously about what you said.
- **Be sensitive to the needs of the person you are speaking to**. For example, if the receptionist at the doctor's surgery looks stressed, say *"I can see you're very busy – please can I just have a minute of your time?"*
- **Expressing gratitude and thanks goes a long way**. Everyone likes to be thanked and it might make things easier for you the next time you need to speak to them.

Syed's story*



Syed is a carer who is not getting the time off he needs. His friend tells him to call the local carers' centre for some advocacy support.

He calls the centre and says: *"Hi. Can you tell me about your services? I'm a bit stressed."*

He doesn't convey how serious the situation is in his message. The staff member thinks he just wants social interaction, rather than one-to-one advocacy support.

She replies, *"Yes of course, we have a weekly café, a massage day on a Thursday and a bridge night every month"*, which doesn't give Syed the information he's really looking for. Instead, Syed could say:

"Hi, can you tell me about your advocacy service as I really need some support to take a break."



"I'm feeling very stressed about this right now."

**The individual's name has been changed*

Body language and tone

Communication isn't just about talking. In fact, research suggests that 55% of our communication is non-verbal. Being aware of your body language and tone of voice is important.

- **Sit square**, with both feet on the ground. This helps you get attention and also helps you listen.
- **Sit with an open posture** with your arms and legs uncrossed. Crossed arms and legs can come across as defensive and unwelcoming.
- **Keep an open facial expression** (ie look as if you're listening) and respond to what they are saying with nods of the head.
- **Establish eye contact**. Try not to stare as this can be off-putting, but meet the other person's eyes every few seconds.
- **Lean towards the person you're talking to** in a way that makes you look interested in what they're saying.
- **Relax as much as you can**. Take some deep breaths, keep your shoulders relaxed and try not to fidget.
- When emotions are running high, we can speak too quickly. **Speaking clearly and slowing down your speech** can help get your message across.



55%

of our communication is non-verbal*

**Albert Mehrabian, a pioneer researcher of body language in the 1950s, found that the total impact of a message is about 7% verbal (words only) and 38% vocal (including tone of voice, inflection and other sounds) and 55% non-verbal.*

Different ways to ask for what you want

If it's easier to discuss your request or a situation face to face or over the phone, it's good practice to follow up and confirm what was agreed by email.

If you wish to make a complaint or have a list of things to say, a letter or an email lets you specify everything and also provides a record of what you've said. Keeping a written record of communications is very important.

Email is fast and efficient and it means you have a copy of your written discussions with professionals. However, it can be easy to give the wrong impression of your tone and meaning.

Make sure you read your email back to yourself: how would you feel if someone wrote this to you? Take your time and reword any strongly-worded phrases to make them more neutral, however much you feel like saying what's on your mind.

TOP TIP

A letter or an email lets you specify everything and also provides a record of what you've said. Keeping a written record of communications is very important.



Assertiveness

Assertiveness is about being direct about what you need, want or feel and standing up for yourself in a way that respects other people. To help you to be assertive, it is important to recognise that you have rights, which we cover in more detail in the next chapter. As a carer, you have a right to:

- an assessment of your needs as a carer (known as an adult carer support plan or ACSP)
- ask for a care needs assessment for the person(s) you look after
- ask for flexible working
- have your views and feelings taken into consideration by social services and healthcare professionals.

Everyone has rights in other areas such as in education, religion, gender, consumer issues, race or class. There is legislation that protects our human rights, and national care standards that aim to respect the dignity and independence of people receiving services.



Why might it be difficult to be assertive as a carer?

It can be difficult to stand up for your rights if you feel like you don't have much time for yourself. Here are some reasons why you may find it difficult to stand up for your rights, especially if your life tends to revolve around someone else:

- You may be too busy to ask or keep on asking for something.
- You may put others before yourself.
- You may feel that you do not deserve help.
- You may not have the energy or strength to say 'no' anymore.

How can you get better at being assertive?

Here are a few suggestions:

Your thoughts

- **Try to have a positive outlook** – it makes it more likely you will have a positive outcome.
- **Remember that you have a right to ask for help** (such as an adult carer support plan or flexible working) if you need it.
- **Be aware of your feelings**, your triggers and your needs. This will give you more clarity of what you need. This is covered in more detail in the section 'How you are feeling'.

TOP TIP

Try to have a positive outlook – it makes it more likely you will have a positive outcome.



Your attitude

- **Be willing to listen to the other person** (the social worker, the GP) and hear what they have to say – and why.
- **Be willing to compromise** on the things that you can live without (see the section on ‘Influencing and negotiating’).
- **Believe in yourself** and treat yourself with the respect that you show others.
- **Know your own needs** (see the section on ‘Reflecting on how you think’) and take some time to appreciate the possible needs of others.

Claim your rights

- **Make sure you’re speaking to the right person.**
- **Start slowly.** Express your assertiveness in low-anxiety situations at first so you can build up your skills – most people don’t learn new skills overnight.
- **Write down what you want** so it’s clear in your head.
- **Choose the right time** to ask, so the person gives your request their full attention.
- **Say ‘I’ not ‘we’** – *“I would like my complaint dealt with within the next seven days.”*
- **Ask for enough time** to make a big decision rather than feeling pressured to decide there and then.
- **Stand your ground on things that you really need.** Repeat your request if necessary in a firm way – this is sometimes referred to as the ‘broken record’ technique.
- **If you’re naturally softly spoken, raise your voice** when you’re speaking – even if it feels unnatural at first.
- **Ask for specific information** if the speaker is being vague or talking in jargon.



TOP TIP

Be willing to compromise on the things that you can live without (see the section on negotiation).



TOP TIPS

Choose the right time to ask so the person gives your request their full attention.

Ask for enough time to make a big decision rather than feeling pressured to decide there and then.



TOP TIP

Stand your ground on things that you really need. Repeat your request if necessary in a firm way.



Influencing and negotiating

This part of the guide looks at how to ask for things in an effective way, including how to negotiate.

Having influence

There are ways in which we can all have influence if we understand what approach to take and are aware of our own abilities to make the right kind of impression at the right time.



Be aware of your own role and ability to affect decisions

- You're an equal partner in care. Your views and opinions should be taken into account when decisions are being made about the person(s) you care for.
- The organisation you're dealing with may have responsibilities to support carers.
- Caring saves health and social care services money. You can use this to amplify your voice.
- You may well be the one that knows the most about the person(s) being cared for.

Capture the attention of the audience with facts

- **Describe the impact on your life.** For example, tell them if:
 - *you haven't had a full night's sleep in two months*
 - *you're on the verge of giving up your job*
 - *the GP has increased your antidepressants*
 - *you often feel frustrated with the person you're caring for.*
- **Health and social care staff have a duty of care to you.** Remember they would rather you carried on caring, so **being specific about how it's affecting you** should make them sit up and listen.
- **Give a worst day scenario.** Clearly explain any difficulties you're experiencing – mentally, physically and emotionally. Don't underplay the impact it's having on you.
- **Say how the situation is making you feel.**

Know what you want to ask for

- **Do some research into what you want,** or ask someone to do it for you. For example, you may want to find out about short breaks in accessible accommodation in the Highlands.
- **Be as specific as you can.** For example, say you want a week-long break with the person you care for in an adapted hotel you have found near Glencoe.

TOP TIP

Give a worst day scenario.



Clearly explain any difficulties you're experiencing – mentally, physically and emotionally. Don't underplay the impact it's having on you.

- **Explain why this will help you** or the person you are caring for. For example, say it will give you some ‘me time’ without housework, cooking and routine and allow you to spend a few days on things you used to enjoy and have missed.

Use language in an assertive way

- **Avoid getting frustrated** by saying things like *“Other people get everything they ask for but we get nothing.”*
- **Slow down your talking speed**, lower the tone of your voice and speak as clearly as you can. You can practise this in day-to-day conversation with people.

Negotiation skills

Negotiation is a way to reach an agreement or compromise while avoiding arguments.

In a caring context, negotiating well could be useful if you want to ask for a specific service or help gain extra support for the care needs of the person you’re looking after. Negotiating is a normal and everyday part of life within families, at work, at home and with professionals.

Effective negotiation skills can help you be heard. It’s a good idea to develop your skills with smaller issues first to give you the confidence to tackle the bigger issues.

If you – like many people – don’t feel ready to negotiate with professionals, contact your local carers’ organisation to see if they can help you or if they offer training in speaking up for yourself. Visit carersuk.org/local-support to find your local carers’ organisation.

You can negotiate formally at meetings or through letters and emails, or informally, such as when you’re speaking to a social worker who is doing a home visit, or during an appointment with a GP. The key thing to remember is that everyone needs to gain something in exchange for any concessions they make, so be prepared to make a compromise.

How to negotiate

- Before you start negotiating, write down what you want to achieve.
- Make your case as briefly, clearly and confidently as you can, trying to stick to the facts.
- Once you have said what you want, pause and give the other person enough time to reflect and consider what you have said.

TOP TIP

Slow down your talking speed, lower the tone of your voice and speak as clearly as you can. You can practise this in day-to-day conversation with people.



DEFINITION

Negotiation is a way to reach an agreement or compromise while avoiding arguments.



- Listen carefully to the other person's response.
- After you've listened to the other person's response, there may be a discussion. Ask them to clarify anything that's unclear or that you don't understand.
- Look for areas where you both agree and think about what you are willing to concede.
- Ask for a break if things become confusing or overwhelming.
- Write things down if you can.
- Ensure you have enough time.
- Keep things objective and focused on a solution that meets everyone's needs as much as possible.
- Don't agree to something that is unacceptable to you.
- Ask for more time to think if faced with a difficult decision.

Be prepared for some give and take in your negotiations:

- Put a value on what you are prepared to give so that it can be matched with allowances from the other side.
- Compromise without losing face. If you have to backtrack on a point you had said was non-negotiable, you could say: *"Since you have changed your position on... I may be able to change mine on..."*
- Make sure the compromise is something you can live with and that your overall position has improved.

Negotiating on the spot

Sometimes you may not get the luxury of having the time to prepare your case. You may be asked to agree to something out of the blue, where you haven't got all the information to hand and you haven't had the chance to work out your priorities, concessions and objectives.

In these cases, ask for more time. If you need support, ask for help from family or friends or your local carers' organisation. Remember, you are an equal partner in care and you should be fully involved in any decisions affecting your caring role.

Jamie's story



Jamie cares for his daughter Clare, who is 21 and has learning disabilities and autism. They live in a former farm cottage in a small village in Scotland and Jamie works locally.

Jamie has managed well, with his family's help, in providing care and support for Clare since his wife died three years ago, but he doesn't have much time for himself now between work and caring. His mum has started to talk about Clare being isolated and frustrated because she has no friends or social activities without her family.

Jamie has also recently been diagnosed with type 2 diabetes and he is worried what will happen to Clare if he becomes ill and his family are not able to help as much.

He arranges for a social worker to come to the house. He hopes they will come with ideas and solutions, but he knows he needs to prepare and think about what he wants to say.

When the social worker arrives, she tells him she doesn't have long and how difficult it is to provide any services in this part of the district. Jamie is frustrated but stays calm, maintaining eye contact and goes over the list of key points he prepared which he hopes will help Clare have the chance to make new friends and try new activities – but will also support Jamie and his mum to care.

He expresses his need for a longer meeting in the next week or two, as the stress of the situation is taking a toll on his health. The social worker acknowledges his points and suggests a meeting in two weeks' time when they can discuss options in more detail.

Making a complaint



Many people find making a complaint very difficult. You may feel frustrated, angry or scared, or the thought of complaining may make you feel like you are moaning.

Both you and the person you care for have a right to receive services that keep you safe and supported. Your complaints or concerns should be treated with respect and courtesy.

You may wish to make a complaint about:

- delays or cancellations to services
- poor quality or overpriced services
- poor behaviour from health or social care staff
- changes or reductions to the care given to the person(s) you look after.

Making a complaint can be a way to get an apology, find out what went wrong, and make sure it doesn't happen again to you or anyone else.

How to make a complaint

Ask the organisation or service for a copy of their complaints procedure. It should be available in different formats, such as in print or online.

You will usually be asked to try and resolve the issue informally with the staff providing the service. If you're not happy with the response, you can make a formal complaint. Read on to find out how to prepare, what to include, and who to contact if you're still not happy with the outcome.

TOP TIP

Ask the organisation or service for a copy of their complaints procedure.



Doing your preparation

Look at the policies of the organisation you're making a complaint about. For example, if you think the person you look after is being charged too much for a service by their council, check the council's guidance and the national guidance about the issue. Is the organisation following its own charging policy and national guidance?

If you're buying services privately, the organisation should include their charges and terms very clearly in your contract.



Do you need help with research or with drafting the complaint?

If you don't have the time or resources to do this research, see if a friend or relative can help.

You can also try contacting your local carers' centre, Citizens Advice Scotland or the Carers UK Helpline (advice@carersuk.org).

Writing the complaint

When you make your complaint:

- Make it as soon as possible after the event. You will usually have a set amount of time in which to make a complaint, often 12 months.
- Make it in writing if possible (or ask a friend, relative or advice worker for help). If you can't, the organisation you're complaining to will need to make reasonable adjustments to allow you to make the complaint over the phone. Find out where to send your complaint by checking the complaints policy or calling the organisation.
- Provide evidence if you can, but keep copies of any documents you send. See the 'Complaints letter template' for more details.
- Include your contact telephone number, address and email address (if you have one).
- Keep a copy of your letter and any response. If someone responds to you by telephone, ask them to put their response in writing. Try to make a note of what they say at the time for your own records.

TOP TIP



Keep a copy of your letter and any response.

If someone responds to you by telephone, ask them to put their response in writing.

Try to make a note of what they say at the time for your own records



Visit carersuk.org/scotland/training-resources/self-advocacy-toolkit-scotland to download 'Complaints letter template'

If you're not happy with the outcome of your complaint

Scottish Public Service Ombudsman (SPSO)

If you have already made a complaint about a service and have not received a satisfactory response after a reasonable amount of time has passed, then you could consider contacting the **Scottish Public Service Ombudsman** [spsso.org.uk](https://www.spsso.org.uk). They have a range of information leaflets on their website, or you could call them on 0800 377 7330.

However, it is important to point out that the SPSO do not deal with complaints about standards of care. These are looked at by the Care Inspectorate (see below).

The SPSO deal with complaints about councils, the NHS, housing associations and most Scottish public bodies. Their website has a complaints form you can fill in. The SPSO deals with complaints that have been made in the last 12 months and they do not deal with complaints that have already been dealt with by or are being looked at in the courts.

The Care Inspectorate

The Care Inspectorate deals with complaints against care services, using the Scottish Government's National Care Standards. They do not have the authority to deal with any complaints about local authority social work departments. However, they do have the authority to investigate complaints against any care services provided by local authorities, voluntary organisations and private care businesses.

Anyone can complain against registered care services and unlike other complaints processes, you are allowed to raise concerns about a service without going through the complaints procedure of the organisation delivering the service.



CONTACT BOOK

Scottish Public Service Ombudsman (SPSO)

T 0800 377 7330

[spsso.org.uk](https://www.spsso.org.uk)

The Care Inspectorate

E concerns@careinspectorate.gov.scot

T 0345 600 9527

[careinspectorate.com](https://www.careinspectorate.com)

Patients Advice and Support Service (PASS)

PASS is part of the Scottish Citizen's Advice Bureau (CAB) Service. The service is independent and provides free, confidential information, advice and support to anyone who uses the NHS in Scotland.

It aims to support patients, their carers and families in their dealings with the NHS and in other matters affecting their health.

The PASS:

- helps clients understand their rights and responsibilities as patients
- provides information, advice and support for those wishing to give feedback or comments, raises concerns and makes complaints about health care delivered by NHS Scotland
- ensures clients feel listened to, supported and respected when raising concerns about difficult experiences
- works with the NHS to use feedback to improve NHS service provision.

You can contact the PASS Service via your local CAB Office. Call the Citizens Advice Scotland on 0800 800 9060 to be put in contact with your local CAB.



You can find further information about challenging a decision at: carersuk.org/scotland/help-and-advice/factsheets/complaints-and-challenging-decisions

Care Opinion

You can also contact Care Opinion which is an independent website that enables you to share your story of using health services with other users and relevant NHS staff: careopinion.org.uk



CONTACT BOOK

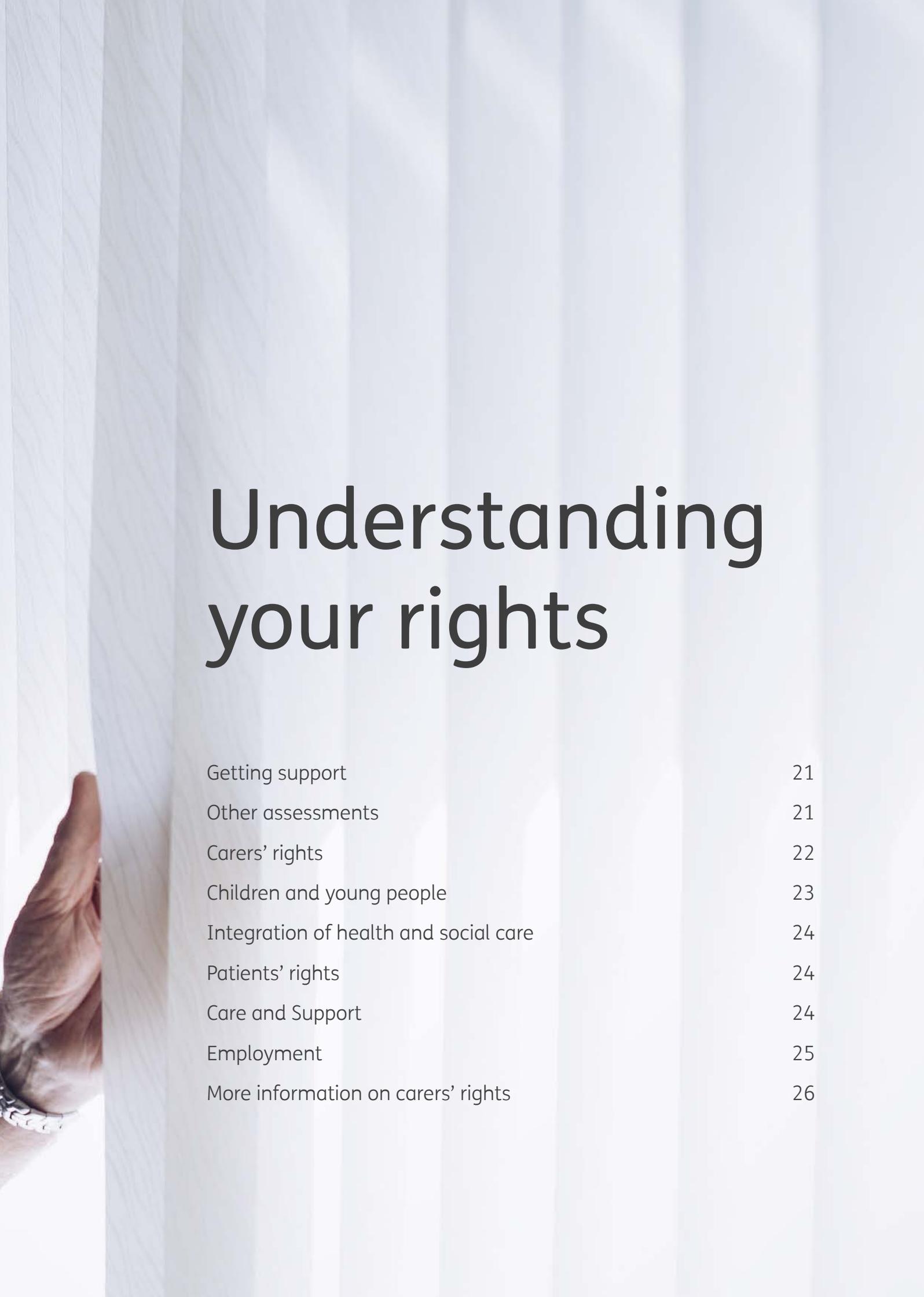
Patients Advice and Support Service (PASS)

T 0800 800 9060
cas.org.uk/pass

Care Opinion

E team@careopinion.org.uk
careopinion.org.uk





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Understanding your rights

The Scottish government has a wide range of responsibilities to carers. They provide the funding to health and social care and set legislation and national strategies. However, local health and social care partnerships develop their own local strategies and make decisions on exactly what services they provide or how they wish to provide support.



The local social work department of your local council can provide various forms of support, such as assessments for carers (now called adult carer support plans and young carer statements) and care needs assessments, meals, care at home, day centres, breaks from caring and residential care. They can also direct you to other services such as supported accommodation, housing services and voluntary services in the area.

Your local council also administers the Council Tax Reduction Scheme, Housing Benefit, the Scottish Welfare Fund (for crisis grants and community care grants) and can also offer help to individuals to make benefits claims.

The Department for Work and Pensions (DWP), which is UK wide, currently delivers the main benefits for carers and disabled people, on behalf of the Scottish Government. However over the coming years, these benefits will be transferred to Social Security Scotland.

Getting support

All carers have the right to an adult carer support plan or young carer statement but what does this mean?

This is an opportunity for you to formally have your needs reviewed, but it is in no respect a test of your abilities as a carer. The assessor will look at your needs and willingness to care, and how caring affects your health, work, free time and relationships.

If you meet the national eligibility criteria, the local authority must meet your assessed needs and provide any necessary support. This will focus on your needs as the carer, not the needs of the person you are caring for, and could range from day care services to help you take a break to a gym membership. Even where you don't meet eligibility criteria, the local authority must provide information and advice and has a power to provide other services to support you.



Other assessments

Care needs assessment

A care needs assessment is an opportunity for the person you care for to have their needs assessed. This could result in extra support, such as meals delivered to the home or the recommendation of a paid care worker providing additional assistance. If the assessment identifies that the person needs more support, they will then also have a financial assessment to see if the council will pay for this. However, the person you care for cannot be charged for any personal care services that are provided.

If you move

If families want to move out of their local area, the new local authority must make sure there is no gap in care. They must carry out an assessment and develop a care plan for the person who requires care and their carer. If they decide to reduce the level of care support, they must provide this decision in writing. If they haven't done the assessment by the time of the move, they must accept the old care plan.



Before a child turns 18

A disabled child is entitled to an assessment by adult social services before they reach 18 years old to help ensure they move smoothly from children's to adult services. If this doesn't happen, adult services have to continue to provide the same support that the child and family received from children's services.



For more information, see
carersuk.org/care-and-support

Other legislation and policy relevant to you as a carer

Carers' rights

Name of Act	Details
Carers (Scotland) Act 2016	<p>This Act became law on 1 April 2018 and increases carers' rights, including (for the first time) providing carers with eligible needs a right to services. This Act also changes carers' assessments to Adult Carer Support Plans and Young Carer Statements.</p> <p>The Act provides rights in a number of areas:</p> <ul style="list-style-type: none">• a duty for local authorities to provide support to carers, based on a carer's identified needs if they meet the local eligibility criteria• a right to an adult carer support plan or young carer statement to identify carers' needs and personal outcomes. (This is available to carers of all ages, no matter how many hours of care they provide and whether or not the person they care for receives care services.)• a requirement for local authorities to have an information and advice service for carers providing advice on, for example: emergency and future care planning, advocacy, maximising income and rights• a duty on the NHS to inform and involve carers if the person they care for is being discharged from hospital.
Community Care and Health (Scotland) Act 2002	<p>This gave carers the right to a carer's assessment in their own right, independent of an assessment taking place for the person they were caring for. It also put a duty on local authorities to tell carers about this right and on health boards to improve the ways in which they inform carers about support available to them. The Act also gave carers under 16 the same right to an assessment as an adult carer.</p>
Carers (Recognition and Services) Act 1995	<p>This was the first piece of legislation that legally recognised carers and gave carers the right to their own separate carer's assessment as part of the assessment process for the service user (the person being cared for). However, there was no requirement to provide services to carers as a result of a carer's assessment. Below is a brief overview of the legislation that provides rights to carers in Scotland.</p>

Children and young people

Children & Young People (Scotland) Act 2014

The Act became law and changes how children and young people in Scotland will be cared for. The Act is wide ranging and includes the creation of new systems to support children and young people and to help identify any problems at an early stage.

The Act allows the Commissioner for Children and Young People to investigate cases affecting individual children and young people for the first time.

The Commissioner can decide whether an individual's rights have not been respected and will be able to make recommendations about what should be done to make things better.

Education (Additional Support for Learning) (Scotland) Act 2004 (amended in 2009)

This introduced the concept of 'additional support' needs in Scotland, which is a wider definition than special educational needs. It also gives local authorities new duties to support children with additional needs and gives the right for parents to request an assessment of needs at any time and to appeal against decisions.



Integration of health and social care

Public Bodies (Joint Working) (Scotland) Act 2015

This Act requires integrated joint boards and partnerships to have representation from carers and carers' organisations. In addition, guidance on the commissioning of services has a requirement to involve carers in the design and delivery of future integrated services.

Patients' rights

Patient Rights (Scotland) Act 2011

The Act details that patients should be treated with dignity and respect and have their views valued. The Act recognises that carers have an important role in supporting patients and that their views should be taken into account when planning and providing care and treatment. The Act also introduced a new independent Patient Advice and Support Service (PASS).

Care and Support

Social Care (Self-Directed Support) (Scotland) Act 2013

Self-Directed Support (SDS) enables service users to have more choice over the care they receive and can enable them to run their own care budget. The Self-Directed Support Act gives a duty to local authorities to offer SDS to carers as well as to the person with the illness or disability. This links to needs identified under the Carers (Scotland) Act 2016. The Act also put duties on local authorities to provide all the options for users, giving users choice and control. Under this legislation, relatives will, in exceptional circumstances, be able to be employed by the person they are caring for as a personal assistant. The Act reinforces the full involvement of carers in the assessment of needs for support and the provision of support for themselves.

Adults with Incapacity (Scotland) Act 2000

This Act set up a framework to enable the finances and welfare of those without mental capacity to be safeguarded. The Act made it possible for an individual to set up a Power of Attorney (POA) before they became unable to make decisions for themselves. It also set up Welfare and Financial Guardians to enable carers to have legal powers to act on behalf of the person they care for if that person had lost capacity or never had capacity, such as a child with a disability. However, even if a carer is not a Guardian or POA, this Act said that carers' views should be taken into account by health and social work services.

Mental Health (Care and Treatment) Act (Scotland) 2003 updated by the Mental Health (Scotland) Act 2015

This Act allows people to have a say in the treatment they receive should they experience an episode of mental ill health in the future. It also sets up a 'named person' who represents the person and helps protect the interests of the service user if they become unwell. The named person can act independently of the service user.

The appointment of a named person (which used to be the person's carer by default unless someone else was named) was updated by the 2015 Act in relation to named persons. This removes the appointment of named persons by default so that adult patients only have a named person if they choose to have one (this does not apply to patients under 16). It also introduces a limited right, for cases where the patient has no named person. Listed persons (the carer, nearest relative, guardian or welfare attorney) can apply or appeal to the Mental Health Tribunal if the patient does not have capacity to do so on their own behalf.



For more information on the Adults with Incapacity Act and the Mental Health Act go to mwcscot.org.uk/law-and-rights



Also find out more at: gov.scot/policies/social-care/adults-with-incapacity

Employment

Work and Families Act (2006)

This Act gives carers the right to ask their employers for flexible working arrangements for regular or one-off needs. Employers have to give good reasons to reject an application and the carer has the right of appeal. One application for flexible working is allowed every year.

Equality Act 2010

This legislation brought a number of equalities-related pieces of legislation under one Act. The Act includes protection for carers (who are looking after someone with a disability) from discrimination in the workplace, and harassment in public places, on the basis of their association with someone with a disability.

More information on carers' rights



See our *Looking after someone* guide for an overview of practical information and benefits you may be able to claim: carersuk.org/scotland/help-and-advice/factsheets/looking-after-someone-scotland



Find out more about Adult Carers Support Plans and Young Carer Statements: carersuk.org/scotland/help-and-advice/factsheets/carer-support-plans-and-statements

For more on having a carer's assessment, visit: carersuk.org/carers-assessment

For more on needs assessments, visit: carersuk.org/needs-assessment

Visit Citizens Advice Scotland for general guidance on your rights: citizensadvice.org.uk/scotland/family/help-for-adults-in-the-community-s

For information about your rights as a carer at work, visit: carersuk.org/help-and-advice/work-and-career/other-rights-at-work

MORE INFORMATION

For more information in general, visit: carersuk.org/help-and-advice

You can also call our Helpline on:

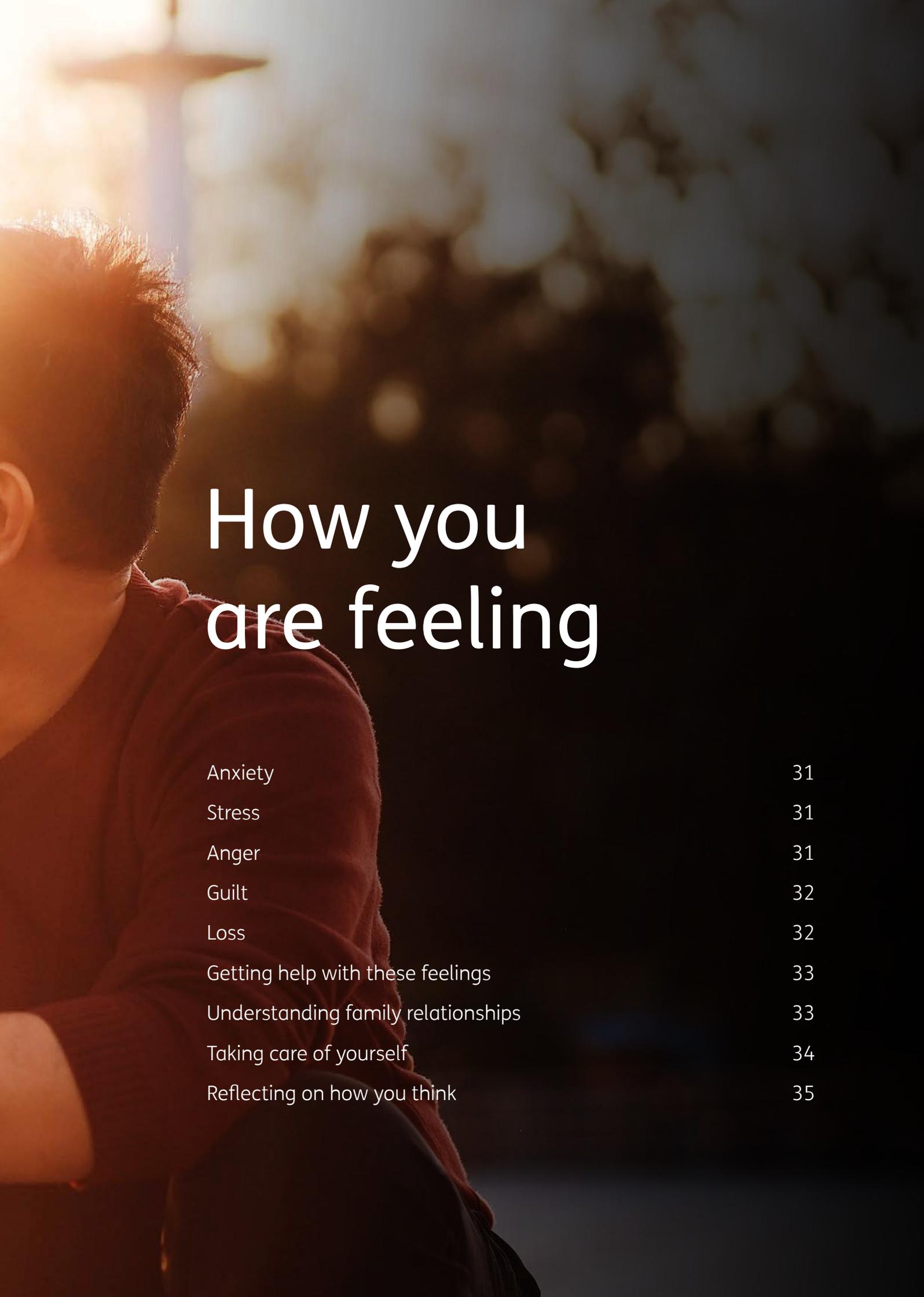
0808 808 7777

Please check: carersuk.org/help-and-advice/talk-to-us for the current Helpline opening times or email:

advice@carersuk.org





A person's profile is shown in silhouette on the left side of the page, looking towards the right. The background is a warm, golden sunset with a blurred street lamp and trees. The overall mood is contemplative and serene.

How you are feeling

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How you are feeling

It's difficult to get your voice heard if you are weighed down with heavy and difficult emotions. Feeling anxious or angry makes it hard to keep things in perspective and stay objective. However by recognising these feelings, you can develop strategies to cope.



Have you ever noticed that it's much easier to ask for something for someone else rather than for yourself?

It's easier to be objective when you're asking for someone else. When you want something for yourself, you may feel that different rules apply or you may tell yourself "*I don't deserve this*". You may attach feelings and judgements to your own needs in a way you don't when considering the needs of others.

As a carer, it's easy to dismiss your own needs and put the person(s) you're caring for first.

As a carer, it's easy to dismiss your own needs and put the person you're caring for first.

Anxiety

Anxiety is what we feel when we're worried or afraid, particularly about things that are about to happen or that we think could happen in the future.

Anxiety can stop you being able to put your views forward or ask for what you or the person you're caring for want. It is often accompanied by unhelpful thoughts such as:

- *"I'm going to look stupid."*
- *"My voice will go."*
- *"I wish I was somewhere else."*
- *"People won't listen to me."*
- *"My mind will go blank."*

Stress

As a carer, it's especially important to look after your own emotional health. You may be juggling paid work or looking after children alongside caring, or you may have had to give up employment to care for a relative. Perhaps you have had to make big and unwelcome changes in your life as a result of illness and disability in the family.

It's natural to feel resentful and/or guilty because of the changes – and these feelings can be very stressful. Having high expectations of yourself can also add to the sense of pressure.

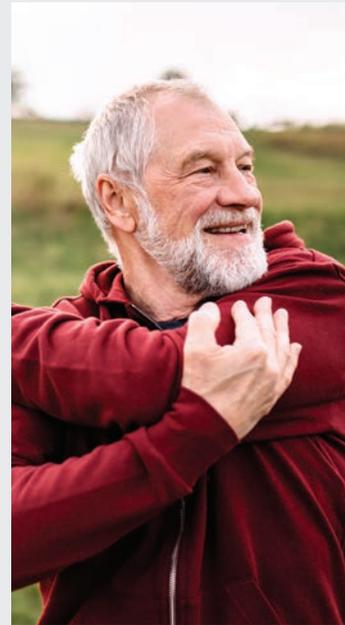
Sometimes stress can spur you on to get things done or get your message across. But if your stress levels become too high, you may feel unable to cope. When this happens, your ability to speak up for yourself – to self-advocate – can be affected.

Anger

Carers often say they feel angry or frustrated. We all express anger differently. You may push these feelings aside if there isn't a safe place to express them. But if your anger comes out as an aggressive outburst, it diminishes your opportunity to be heard.

When you're angry, it can be more difficult to see another person's point of view. It also tends to lead to more hurt and isolation. But anger isn't necessarily a 'bad' feeling. Sometimes it can help us identify things that are hurting us and motivate us to make changes. Channelling your anger in a helpful way can help you and others address your situation.

TIPS FOR COPING WITH STRESS AND ANXIETY



- Try a mindfulness or meditation exercise each day.
- Keep active – exercise like running or yoga will also help you to sleep.
- Eat well-balanced meals and try not to multi-task when eating. Allocate time to relax.
- Identify triggers, such as the news, and consciously limit how much you watch, read or dwell on them.
- Watch a comedy, read an uplifting book or do something to distract you from negative thoughts, such as cooking or art.
- Talk to a close friend or family member about how you are feeling. Sometimes it helps to open up. Also see 'Getting help with these feelings'.

Safe ways of letting out anger

- Walk away from the situation before it becomes a row. Going for a short walk or a run can release tension and give you time to think.
- If you're in a meeting, ask for a five minute break so you can go somewhere quiet to gather your thoughts.
- Try to calm down by breathing slowly, relaxing your body, or using other relaxation techniques such as mindfulness.
- Release your angry feelings in a safe way, for example by tearing up a newspaper or hitting a pillow.
- Find a way to distract yourself such as putting on your favourite music, doing a creative activity, or fixing or making something.

TOP TIP

Find a way to distract yourself such as putting on your favourite music, doing a creative activity, or fixing or making something.



Guilt

Guilt is a common feeling we all experience. It can be a complicated and confusing emotion.

Carers frequently speak about feeling guilty: for asking for help, not doing enough for the person they care for, or because they sometimes resent being a carer, for example. These feelings are normal and understandable. It's perfectly reasonable not to want to care all of the time, or at all. But we can use guilt to stop ourselves from doing perfectly reasonable things. We tell ourselves we're not entitled to things, or we have no right to ask for them.

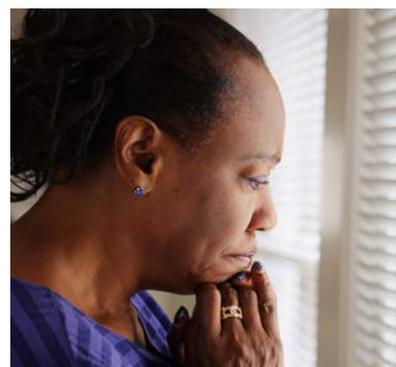
Often guilt stops us admitting our true feelings to ourselves. For example, a carer may feel guilty about their mum moving into residential care to mask the fact that they feel unable to cope. If you feel guilty, it can help to look at your underlying feelings. This can reduce the negative effects of guilt and pinpoint where you may need to ask for help.



Loss

You may experience loss when the person you care for dies or goes into residential care. If this happens, you may miss the person and feel sad that this part of your life is over.

However, loss can be felt in other ways. You may mourn the former identity of the person you care for before they developed dementia. Perhaps you have had to give up work to care for someone or a relative has had to move in with you for practical reasons. Losing your independence and freedom is a less recognised part of being a carer. These changes can knock your confidence and affect your ability to stand up for yourself.



Getting help with these feelings

Recognising you need help is not a sign of weakness. Far from it – it's a positive and courageous step towards feeling better.

Talking to trusted friends and family members can be very helpful. Sometimes just a listening and sympathetic ear can alleviate the burden of these feelings. Alternatively, counselling – also known as 'talking therapy' – involves talking to and sharing difficult feelings with a trained person. It can be easier to talk honestly to someone outside of your family or friendship group. A counsellor won't tell you what to do but can help you come to your own decisions and cope better with how you're feeling. You can also go to family counselling to help resolve relationship problems.

You can refer yourself directly to NHS counselling services or ask your GP for a referral. You may have to wait a while before your first appointment. You may decide to pay for counselling if the waiting list is too long, if you've finished a short course of NHS sessions, or if you want more choice. Your local carers centre may provide counselling at a low charge, or be able to refer you on to other organisations that provide this service for free or at a more affordable rate.

You can also see a private counsellor. Sessions cost anywhere between £10 and £70 depending on where you live. Contact the British Association for Counselling and Psychotherapy (BACP) or the Council of Scottish Counselling Agencies (COSCA) for details of individual qualified private counsellors.

Understanding family relationships

Family relationships can be complicated. When it comes to caring, it's common for one relative to take on the main caring role with others contributing where and when they can. In many cases, other family members may not have any role in caring. As a carer, you often have to work with the circumstances you face.

Most people have the best intentions for the family member needing care, even though their ways of doing things may differ greatly to yours. They may feel guilty if they're unable to offer as much support as you do. Or they may worry it'll look like interfering if they try to do more. They might feel uncomfortable in a caring role, or assume you're happy to carry on providing the amount of care you currently provide.

Using technology to help communicate with other family members is one way to get them more involved in helping you. For example, you could set up a WhatsApp group to keep each other updated. For a more tailored option, Jointly is an app by carers for carers designed to help families coordinate tasks, share responsibilities and communicate more easily.

Find out more at: carersuk.org/jointly

CONTACT BOOK

British Association for Counselling and Psychotherapy

BACP House, 15 St John's
Business Park, Lutterworth,
Leicestershire LE17 4HB

T 01455 883300

bacp.co.uk

COSCA (Counselling & Psychotherapy in Scotland)

16 Melville Terrace,
Stirling FK8 2NE

T 01786 475 140

cosca.org.uk

TOP TIP

The more you understand other family members' needs, the more chance you'll be able to reduce any tension and win over their cooperation.



Taking care of yourself

If you have a hostile or unhelpful relative – including the person you care for – it's important you have a support network around you. Spending time with supportive people will help, along with the stress management and mindfulness techniques offered below.

Try and limit the time spent with those who get you down and make sure you get breaks when you really need them, however short. If the person you care for is creating the bad feeling, explain – if you're able to – that you're doing your best in difficult circumstances and let them know what your needs are.



Visit carersuk.org/scotland/training-resources/self-advocacy-toolkit-scotland to download 'Mindfulness'

TOP TIP



Knowing you have a plan if you are unable to care for someone can provide great peace of mind.

We can help you create one using our Carers UK contingency planning tool, MyBackup: carersdigital.org/mybackup

If you need more support, you could contact Relate. They provide local services that look not just at relationships between couples, but other family relationships too. Find out more at relate.org.uk/relationship-help

The Carers UK Forum is a warm and welcoming online community where you can talk to other carers about what's on your mind and get support from people who understand. Get support from other carers: carersuk.org/forum



Reflecting on how you think

In this part of the guide, we consider how greater self-awareness and new ways of thinking could enable you to get your points across more effectively.

Self-awareness

The way we think, our attitudes and our beliefs are influenced by our culture, genes, upbringing and experience. It can be difficult to shift negative mindsets you've had for many years. Sometimes we're not aware of our unhelpful attitudes and beliefs because they've been part of our lives for so long.

When you're trying to convey your views, you'll be more effective if you know yourself including your own strengths and weaknesses. People with higher self-awareness tend to cope better with stress and anxiety and are better at using practical coping strategies.



Taking time to reflect

When life is busy, it is easy to avoid asking ourselves too many questions about how we feel, our thoughts or our behaviours. But being more self-aware can help you to address your underlying needs and understand how you come across to others.

Our 'Reflecting on events' exercise encourages you to observe the reasons behind your actions and helps you understand your thoughts, feelings and behaviour when something negative happened. You can use this tool with any difficult situation and work out how to communicate differently next time.



Visit carersuk.org/scotland/training-resources/self-advocacy-toolkit-scotland to download 'Reflecting on events'

Negative thoughts

Negative thoughts can stop us from seeing things objectively, and means we don't see positive outcomes when they take place. Sometimes it can be helpful to challenge your negative thoughts or assumptions by looking at events from a fresh perspective with more positive alternatives or explanations.

Tackling negative thoughts

A useful way to challenge unhelpful thoughts is to untangle them and develop a more balanced point of view. One of the simplest ways to challenge negative or unhelpful thoughts is to 'take the thought to court': write down the evidence for and against the thought, and

then come to a more realistic or balanced way of thinking. See the example in the table below.

What's the evidence?

Think of it like a jury in a court case. To know the truth, we need hard facts about what actually happened, not just what we think happened.

For example, a carer who is anxious in a meeting thinks *“There’s no way I’ll be able to speak.”* Looking at the evidence for and against can help them decide whether the thought is actually true.

Evidence for

Refers to the information that you feel backs up your thought. It may be how you feel, or previous experiences.

Evidence against

Is all the information that doesn’t back up the thought – remembering that the carer has been able to speak at a meeting before, so there’s no reason why they won’t be able to speak up this time.

New thinking

This is the thought based on the ‘judgement’ of the evidence. It encourages you to be more realistic in anxious situations.

Original thought	Evidence for	Evidence against	New thinking
I’m going to pass out in this meeting with my mum’s social worker.	I feel dizzy and I nearly passed out when I last felt like this.	I have never passed out before. I’ll feel better if I sit near the door.	I’ve not passed out before so chances are I’ll be ok. I have an escape if I need one.
There is no way I’ll be able to speak at this meeting, it’s too scary.	I’m the only one not to have spoken, my mouth is so dry.	I’ve spoken before at a meeting. I know exactly what I want to say.	I have the proven ability to speak at meetings to get my point across – I could take notes as prompts.

Further information

You can find out about our other resources via our website: carersuk.org/scotland/help-and-advice/factsheets or by calling us for a copy of our current publications list.

References and sources

Mind

mind.org.uk/information-support/types-of-mental-health-problems

NHS

nhs.uk/conditions/stress-anxiety-depression

nhs.uk/conditions/counselling

nhs.uk/conditions/cognitive-behavioural-therapy-cbt

ACUA

Communication in the workplace – self-study pack
Coventry, University of Coventry/ACUA 2012

Archer J

Teach yourself life coach
2nd edition, London, Hodder Headline 2006
Chapter 9

Ellis A and Dryden W

The practice of Rational Emotive Behaviour
Therapy
2nd Edition, Springer Publishing 2007

Hough M

Counselling skills and theory
Hodder Education, 3rd edition, Abington 2011 p41

Marriot H

The selfish pig's guide to caring
Third Edition, London Time Warner Books 2006,
p98-99

Pease A and Pease B

The definitive book of body language: how to read
others' thoughts by their gestures
New edition Orion 2006

Risner N

It's a zoo around here! The new rules for better
communication
2nd Edition London Limitless Publications 2003

About Carers Scotland

Carers Scotland is here for everyone who carers, unpaid, for family and friends who are older, disabled or seriously ill.

Caring is part of life, but without the right support, the personal costs of caring can be high. We work as part of Carers UK to make life better for carers.

We give expert advice, information and support



We connect carers so no one has to care alone



We innovate to find new ways to reach and support carers



We campaign together for lasting change



Visit carersuk.org/scotland to join us, support us or access our online resources.

With your help we can make life better for carers.



Keep in touch

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Carers UK Helpline

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Opening hours may vary. Please check: carersuk.org/help-and-advice/talk-to-us for the current days and times the Helpline is open.



carerscotland.org

Publication code: S9041_1120 | © Carers UK Nov 2020

This guide is designed to provide helpful information and advice. While we work to ensure that our information is accurate and up to date, we would recommend contacting the Carers UK Helpline or visiting our website for more information.

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