

Being Heard

A self-advocacy guide for carers

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.

For accompanying resources, go to: carersuk.org/self-advocacy or call Carers Scotland on 0141 378 1065.

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.

Recognising your feelings



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.



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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 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 communicate his need by saying:

"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. Being aware of your body language and tone of voice is also 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 you are discussing a request or a situation face to face or over the phone, always 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:

- a carer's assessment
- 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 or race. 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 a carer's assessment or flexible working) if you need it.
- **Recognise your feelings** and understand your triggers and your needs. This will give you more clarity of what you need. This is covered in more detail in the section 'Recognising your feelings'.

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 to receive an update on my complaint within the next 14 days, as indicated in your complaints policy.”*
- **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 in plain English** 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 people's attention with facts and the realities of your caring role

- **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 help you. For example, if you want a break away in the Highlands with the person you care for, look for places that can accommodate the person you care for, eg specially adapted hotels.

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.

- **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 in Glencoe.

Use language in an assertive way

- **Avoid getting frustrated and overly negative** 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 and directly as you can. You can practise this in day-to-day conversation with people.
- **Build common ground and maintain rapport** by balancing anything negative you have to say with something positive.

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.



Negotiation skills

Negotiation is a way to reach an agreement or compromise while avoiding arguments. Effective negotiation skills can help you be heard.

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.

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 also contact the Scottish Independent Advocacy Alliance (SIAA) who may be able to put you in touch with a local advocacy service. Visit siaa.org.uk, call 0131 510 9410 or email enquiry@siaa.org.uk

How to negotiate

- Before you start negotiating, write down what you want to achieve and list your priorities.
- 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.
- Listen carefully to the other person’s response.
- After you’ve listened to the other person’s response, 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.

DEFINITION

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



- 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:

- 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.

David's story*



David cares for his wife, Claire. He can't leave Claire alone for too long and she now needs more help with personal care. David is starting to get tired and sometimes feels unable to cope.

David contacts adult social services and arranges for a social worker to come to the house. He hopes they will come with ideas and solutions, but knows he also needs to prepare and think about what he wants to say. He also contacts his local carers centre to find out more about support they offer and his rights as a carer.

A social worker comes to the house a week later but tells him this is just to meet David and Claire and that she doesn't have long. David is frustrated but stays calm, maintaining eye contact and goes over the key points he prepared. He wants Claire to go to a day centre twice a week so he can have a break and he also requests an Adult Carer Support Plan.

David expresses his need for a longer meeting over the coming weeks to discuss options for Claire and to get his ACSP as the stress of the situation is taking a toll on his health.

**Names have been changed.*

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. You will usually have a set amount of time to make your complaint, often 12 months.
- Complain in writing if possible (or ask a friend, relative or advice worker for help).
- Be clear what you are unhappy with. It may help to write down dates, explaining what has happened and what you feel has gone wrong.
- Try to stay calm when making your complaint. You could run the complaint by a friend to check that the tone is reasonable and measured.
- Consider what you want the outcome to be. For example, would you like another review of your case, or simply an apology?
- Try to support what you say with facts and/or evidence. You could also refer to legislation to back up your points (see 'Understanding your rights' for more details).
- Keep a copy of your letter and any response.

TOP TIP

Keep a copy of your letter and any response. If someone responds to you by phone, you might find it helpful to make a note of any key points or ask them to follow up in writing.



Visit [carersuk.org/self-advocacy](https://www.carersuk.org/self-advocacy) to download 'Complaints letter template'

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

Scottish Public Service Ombudsman (SPSO)

The SPSO is the final stage for complaints about public service organisations in Scotland. If you are not happy with the outcome of your complaint to an organisation, you can bring the complaint to the SPSO. They have a complaints guide and further information on their website: spsso.org.uk

The Care Inspectorate

The Care Inspectorate deals with complaints against care services, using the Scottish Government's National Care Standards. These can be 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

The Care Inspectorate

E concerns@careinspectorate.gov.scot

T 0345 600 9527

careinspectorate.com



Getting help with making a complaint

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.

PASS can help you make complaints about the NHS and ensure you understand your rights and feel supported and listened to when raising concerns.

You can contact the PASS Service via your local CAB Office.



You can find further information about challenging a decision at: carersuk.org/scotland/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

If you want support with making a complaint, contact your local carers' support service. Find your local service on our website at carersuk.org/localsupport

CONTACT BOOK

Patients Advice and Support Service (PASS)

T 0800 917 2127

cas.org.uk/pass

Care Opinion

E team@careopinion.org.uk

careopinion.org.uk





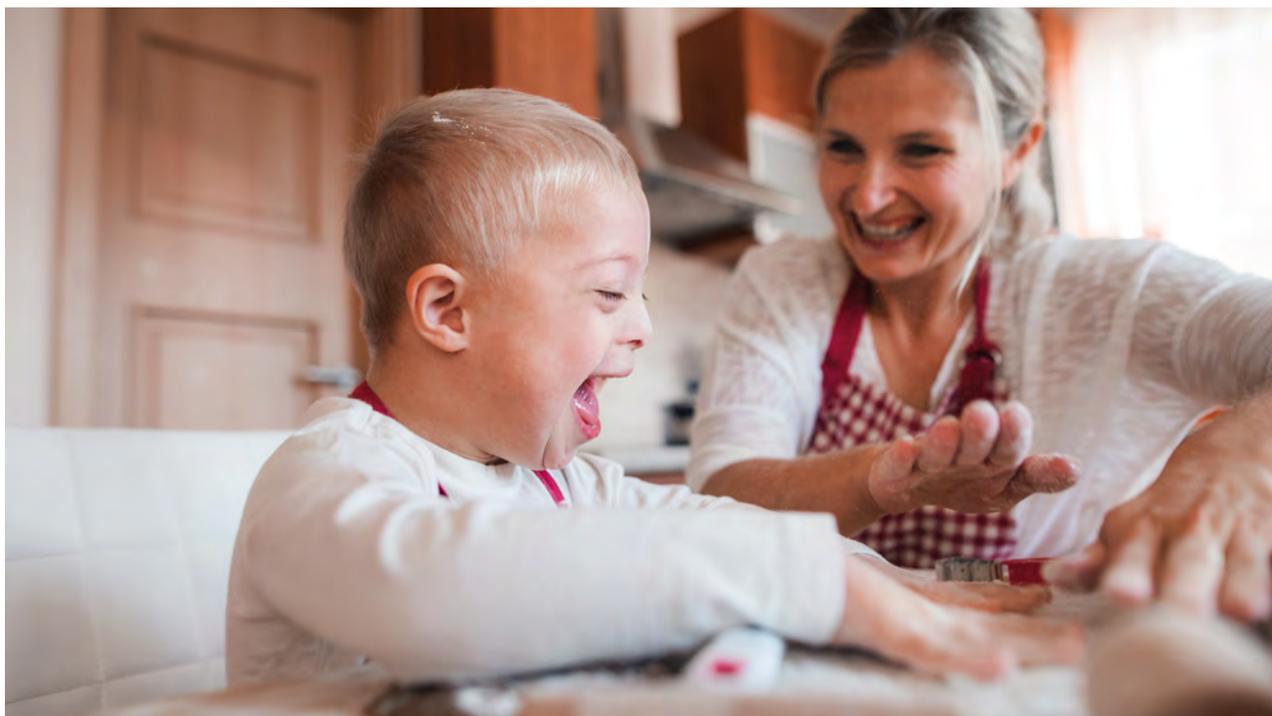


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Understanding your rights

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/health and social care partnership can provide various forms of support, such as assessments for carers (called adult carer support plans and young carer statements) and care needs assessments, meals, care at home, day centres, community alarms, breaks from caring and residential care. They can also refer you to other services like housing or voluntary services in your area.

Your local council also administers the Council Tax Reduction Scheme, Housing Benefit, the Scottish Welfare Fund (for crisis grants and community care grants), Discretionary Housing Payments and other schemes such as free school meals and help to make benefits claims.

The UK wide Department for Work and Pensions (DWP) currently delivers most of the main benefits for carers and disabled people, on behalf of the Scottish Government. However some new Scottish benefits are now available for new claims and, over the coming years, the remaining benefits will be transferred to Social Security Scotland.

Find out more about benefits in Scotland, including those delivered by the DWP, at www.mygov.scot/browse/benefits

Getting support

Adult Carers Support Plan (ACSP)

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, your willingness to care, emergency planning 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. You can request an update to your support plan if circumstances change.

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, especially when you are unable to provide care due to your own needs.

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 drawn up by the previous local authority.

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.



We have a detailed factsheet about carers' assessments which you can download for free at:
carersuk.org/carersassessment

Other legislation and policy relevant to you as a carer

Carers' rights

Carers (Scotland) Act 2016

This Act became law on 1 April 2018 and increases carers' rights.

The Act provides rights in a number of areas:

- 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.





Children and young people

Children & Young People (Scotland) Act 2014

The Act includes 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. 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. 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. This includes the ability for an individual to set up Power of Attorney (POA) before they become unable to make decisions for themselves. As Welfare and Financial Guardians, carers also have legal powers to act on behalf of the person they care for if that person has lost capacity or never had capacity, such as a disabled child. However, even if a carer is not a Guardian or POA, this Act says 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.

In addition, the Act 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.

WHAT IS MENTAL CAPACITY?

Having mental capacity is having the ability to make everyday and important decisions for yourself independently without assistance.



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



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

Employment

Your rights in work come from two sources:

- the law gives you ‘statutory rights’ which everyone has
- your employment contract gives you ‘contractual rights’ which can be more generous than statutory rights.

Statutory rights

The right to request flexible working (Work and Families Act 2006)

All employees have a right to request flexible working after they have worked for the same employer for 26 weeks (six months).

Requests should be made in writing and include details of the revised working pattern you are seeking and how you think this can be dealt with. Only one request is allowed in a year. Employers have to give good reasons to reject an application and the carer has the right of appeal.

The right to time off in emergencies

All employees have the right to take a ‘reasonable’ amount of time off work to deal with an emergency or unforeseen matter involving a dependant. This may be your partner, child or parent, or someone living with you as part of your family – others who rely on you for help in an emergency may also qualify. The time off is unpaid unless your employer is willing to give paid time off as a contractual right.

Protection from discrimination (Equality Act 2010)

This protects carers (who are looking after someone with a disability) from discrimination in (and out) the workplace, or harassment on the basis of their association with someone with a disability.

The right to parental leave

If you have worked for the same employer for 12 months and are responsible for a child aged under 18, you are entitled to 18 weeks' leave per child, which must be taken by the child's 18th birthday. This time off is unpaid unless paid time off is a contractual right.

Contractual rights

Check your contract of employment, staff handbook, HR policies or letter of appointment to see if you have any contractual rights on top of your statutory rights. These might include paid carers leave and other benefits.



More information on carers' rights



See our *Looking after someone* guide for an overview of useful practical information and benefits you may be able to claim: carersuk.org/las



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

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

Care Information Scotland – a phone, webchat and website service providing information about care services for people living in Scotland: careinfoscotland.scot/

Carers Trust also offer a lot of services for young carers: carers.org/about-caring/about-young-carers

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 contact our Helpline by emailing:

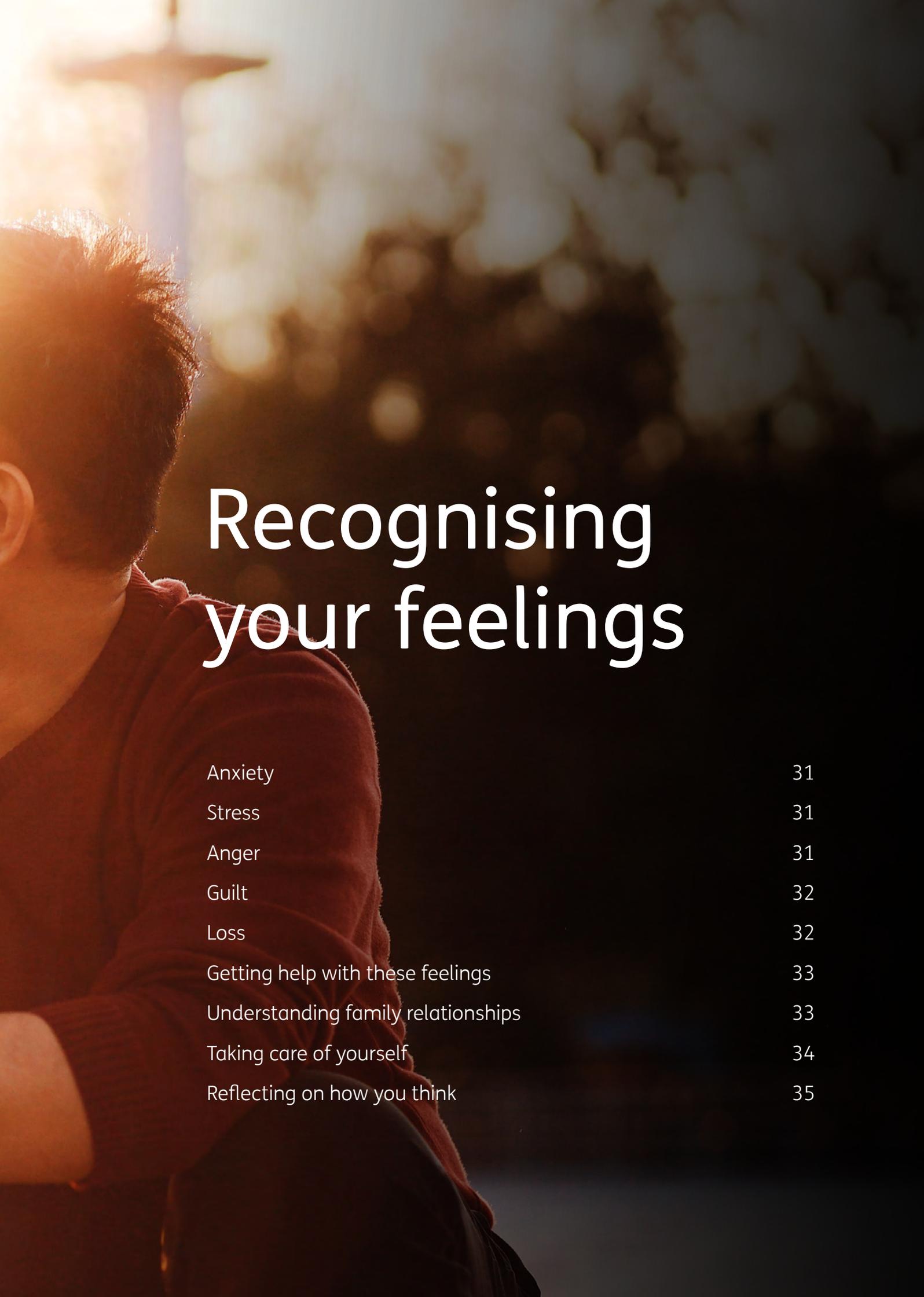
advice@carersuk.org

Or you can phone:

0808 808 7777

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



A person's profile is shown in silhouette on the left side of the page, looking towards the right. The background is a bright sunset or sunrise, with the sun low on the horizon, creating a warm, golden glow. The sky is filled with soft, out-of-focus light, and the overall mood is contemplative and serene.

Recognising your feelings

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Recognising your feelings

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.

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 from putting your views forward or asking 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 important to look after your own emotional and physical health. You may be juggling paid work or looking after children alongside caring or perhaps you have had to make big 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.

If your stress levels become too high, you may feel unable to cope and your ability to speak up for yourself can be affected.

Anger

Carers often say they feel angry or frustrated. We all express anger differently 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 and can lead to hurt and isolation. Channelling your anger in a helpful way can help you and others address your situation.

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.

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'.

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

Guilt

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. But we can use guilt to stop ourselves from asking for help or 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.

However, loss can be felt in other ways. You may mourn the former identity of the person you care for before they developed dementia or perhaps you have had to give up work. These changes can knock your confidence and affect your ability to stand up for yourself.

TOP TIP

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



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, you may prefer to talk honestly and share difficult feelings with a counsellor. They won't tell you what to do, but can help you make your own decisions and cope better with how you're feeling.

You can refer yourself directly to NHS counselling services or ask your GP for a referral. Your local carers centres may also provide counselling at a low charge, or be able to refer you on to other organisations.

You can also pay for a private counsellor. 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.

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

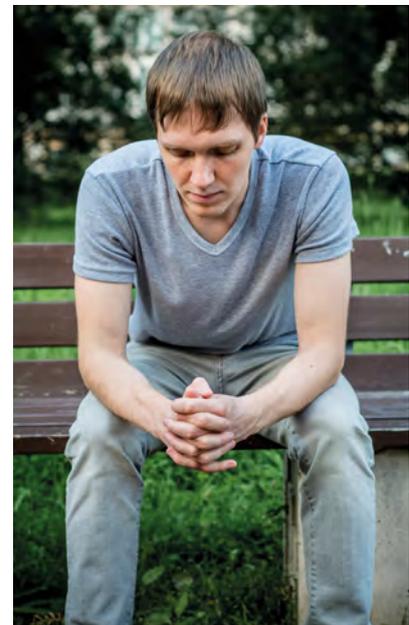
bacp.co.uk

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/self-advocacy to download 'Mindfulness'

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



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

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. Negative mindsets and unhelpful attitudes can be difficult to change if 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 better including your own strengths and weaknesses.



Take time to reflect

Being more self aware and asking ourselves about how we feel, our thoughts or our behaviours can help address our underlying needs and understand how we come across to others.

Our 'Reflecting on events' encourages you to unpick 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/self-advocacy to download 'Reflecting on events'

Negative thoughts and tackling them

Negative thoughts can stop us from seeing things objectively, and means we don't see positive outcomes when they take place.

A useful way to challenge your negative thoughts or assumptions is to develop a more balanced point of view by looking at events from a fresh perspective. Try writing down the evidence for and against a thought to help you come to a more realistic or balanced way of thinking.

Evidence is based on facts and not assumptions. See the example in the table on the next page.

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.

Original thought

There is no way I'll be able to speak at this meeting; it's too scary.

Evidence for

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

I'm the only one not to have spoken; my mouth is so dry.

Evidence against

This 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.

I've spoken before at a meeting and I have prepared for this one and know exactly what I want to say.

New thinking

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

I have the proven ability to speak at meetings to get my point across. The key priorities I prepared will help me and keep me on track.

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

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About Carers Scotland

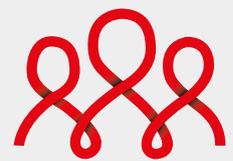
Carers Scotland is here for everyone who carers, unpaid, for family and friends who are older, disabled or seriously ill.

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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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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