

Being Heard

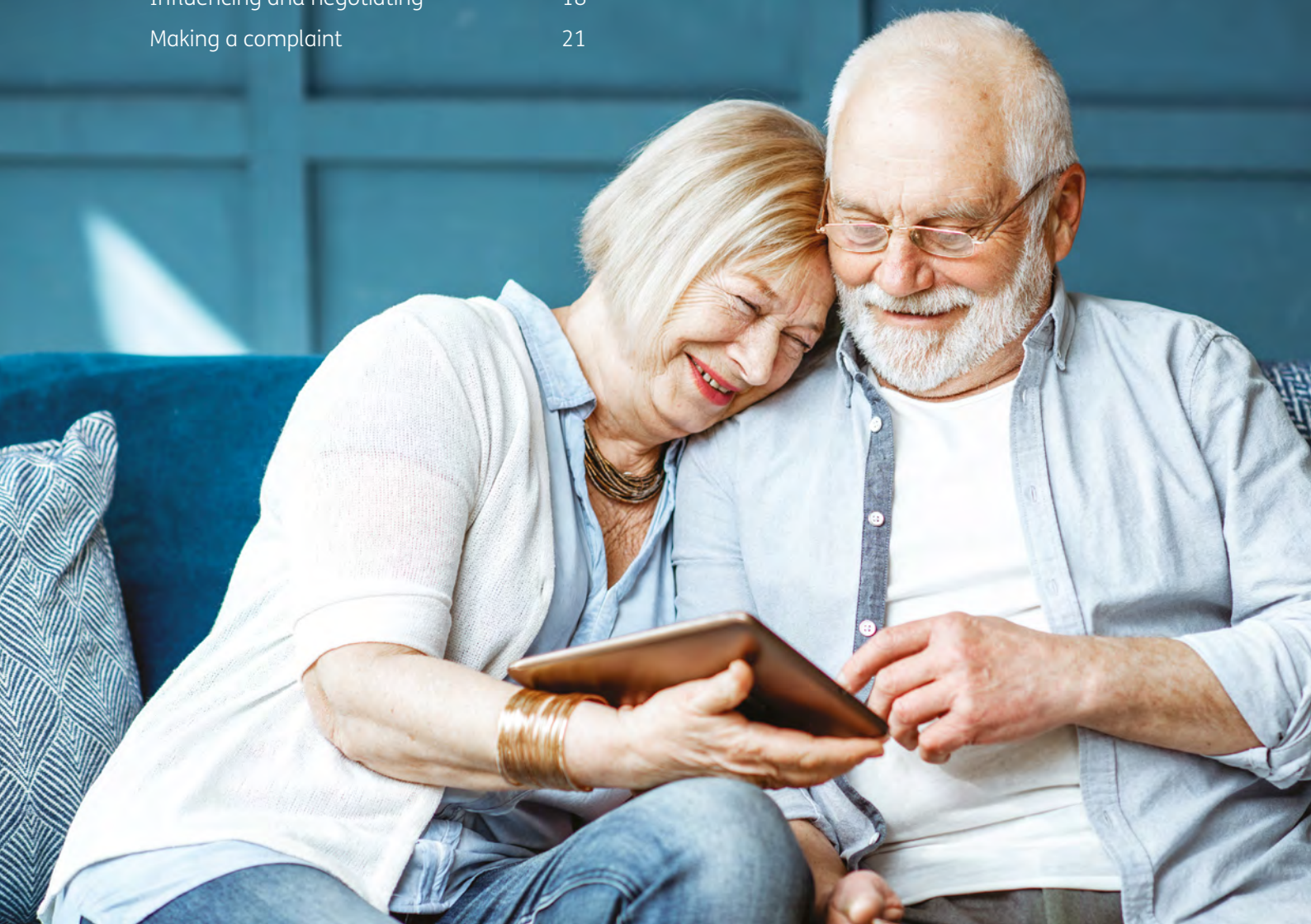
A self-advocacy guide for carers

England



Contents

INTRODUCTION	03	RECOGNISING YOUR FEELINGS	25
UNDERSTANDING YOUR RIGHTS	05	Anxiety	27
Your rights when getting help and support in England	06	Stress	27
Having a carer's assessment	06	Anger	27
Other assessments	07	Guilt	28
Other legislation relevant to you as a carer	08	Loss	28
More information on carers' rights	09	Getting help with these feelings	29
COMMUNICATING EFFECTIVELY	11	Understanding family relationships	29
Common barriers to communication	12	Taking care of yourself	30
Ways to communicate well	13	Reflecting on how you think	31
Body language and tone	15	Final thoughts	32
Different ways to ask for what you want	15	ABOUT CARERS UK	33
Assertiveness	16	FURTHER INFORMATION	34
Influencing and negotiating	18		
Making a complaint	21		



Introduction

Who we are

Carers UK is 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. If you have caring responsibilities, this guide can help you gain confidence to:

- understand your rights
- communicate effectively with professionals
- manage your emotions.

For accompanying resources, go to:
carersuk.org/self-advocacy

What is self-advocacy?

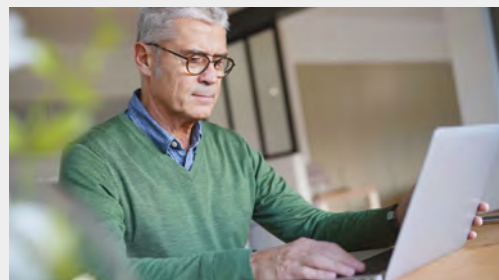
Caring can be rewarding but also very isolating. You may not know what help to ask for, how to ask, or indeed who to ask. Self-advocacy is about being heard as well as speaking up for the person you care for.

While there may be people or organisations available to help, it's important to feel confident standing up for yourself in meetings, understanding your rights as a carer and the rights of the person you're caring for, and that is where self-advocacy becomes really empowering.

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

Understanding your rights 05



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

Communicating effectively 11



The second 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.

Recognising your feelings 25



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.



Understanding your rights

Your rights when getting help and support in England	06
Having a carer's assessment	06
Other assessments	07
Other legislation relevant to you as a carer	08
More information on carers' rights	09



Understanding your rights



Your rights when getting help and support in England

The UK government has a range of responsibilities to unpaid carers. They are responsible for welfare benefits and set the laws around what local government should provide to unpaid carers and disabled people. They also set the funding and general strategies for health and social care services, although many local areas decide exactly how to provide support. The UK government website gives you an overview of all the government services: [gov.uk](https://www.gov.uk)

Having a carer's assessment

The Care Act 2014 brought together many of the old laws around carers and introduced important new rights. One of these is the right to have a carer's assessment.

Carers have the right to request a carer's assessment but what does this mean?

Having a carer's assessment 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 ability and willingness to care, and how caring affects your health, work, free time, relationships and more.



If you meet the national eligibility criteria, the local authority must meet your assessed needs and provide any necessary support (in some cases subject to a financial assessment). 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. Many local authorities do not currently charge carers for these services.

Examples of services

A carer's assessment could lead to various forms of support being put in place, depending on your circumstances. This might include:

- respite services so you can have a break
- support with keeping healthy such as a gym membership
- help with housework.

Other assessments

Needs assessment

A 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 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.

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. See our [transition guide](#) for more guidance.



For more information, our factsheet which can be downloaded from carersuk.org/needs-assessment

THE CARE ACT

In 2015, The Care Act 2014 was introduced as the primary legislation for adult social care in England. It replaced most previous law regarding carers and people being cared for.

What does it outline?

The Care Act 2014 outlines:

- How local authorities should carry out assessments for carers and needs assessments for those they care for
- How they determine who is eligible for support
- How they should charge (if applicable) for residential or community care
- That they have a duty to prevent care needs from escalating.

Who is the Care Act for?

Adults in need of care and support, and their adult carers. There is also some guidance about the transition of children receiving support as adults.

What about children in need of care and support, parent carers of children and young carers?

If you are under 18 and have caring responsibilities, you would have a right to a young carer's assessment under the Children's Act 1989 and the Children and Families Act 2014. Parent carers can also request a 'parent carer needs assessment'. Read more in our assessments factsheet - see link below.

Other legislation relevant to you as a carer

Children and Families Act 2014

This law introduced Education, Health and Care plans for some disabled children. It includes new laws affecting young carers and parent carers.

The Children Act 1989 has been amended to include a duty to carry out a young carer or parent carer's assessment where there may be a need for support.



Useful legislation for quick reference

Name of Act	Details
The Care Act 2014	For adults caring for adults and adults needing care. carersuk.org/carers-assessment and carersuk.org/needs-assessment
The Carer's Leave Act 2023	This means that, as an employee, you can apply for unpaid carer's leave for up to five working days if you are arranging or providing care for someone with a long-term need. This applies within a 12-month period. carersuk.org/help-and-advice/work-and-career/the-carers-leave-act-2023
Employment Relations (Flexible Working) Act 2023	Any employee can now request flexible working from day one of employment. Two requests per 12-month period can be made. carersuk.org/help-and-advice/work-and-career/the-flexible-working-act-2023
The Health and Care Act 2022	As a primary carer, you have a right to be consulted about decisions and plans for the discharge of the person you care for from hospital. Read more on page 9.
Carers (Recognition and Services) Act 1995	This Act is for adults who are not parents of disabled children but have a right to an assessment. This could be a grandparent or an older sibling caring for a disabled child, for example.
Equality Act 2010	This includes protection for carers (who look after someone with a disability) from discrimination and harassment in the workplace and in services.
Mental Capacity Act 2005	This Act covers people who are unable to make some or all decisions by themselves. The ability to understand and make a decision is called mental capacity. It gives carers some rights to be consulted in some situations where decisions are being made. More information on the Mental Capacity Act can be found at: carersuk.org/mental-capacity-act
Mental Health Act 1983	This Act covers people who are experiencing mental health issues and sets out their rights. It also includes rights for the nearest relative, who is not necessarily the next of kin or the carer. For more details see: rethink.org/advice-and-information/carers-hub/rights-for-loved-ones-and-carers

More information on carers' rights



The Health and Care Act 2022 and caring for someone who's coming out of hospital

This legislation reinforces carers' rights when it comes to hospital discharge. If someone is likely to need ongoing care and support after they leave hospital, NHS trusts and foundation trusts have a duty, where appropriate, to involve patients and carers (including young carers) at the earliest opportunity in decisions and plans around their ongoing care needs. You can read more about this and find a useful checklist on our website: carersuk.org/help-and-advice/practical-support/coming-out-of-hospital



LOOKING AFTER SOMEONE GUIDE

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

Other sources of information

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

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

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

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

Visit Citizens Advice for general guidance on your rights: citizensadvice.org.uk/family/looking-after-people/carers-help-and-support

For more information about the rights of young carers, visit the NHS website: nhs.uk/conditions/social-care-and-support-guide/support-and-benefits-for-carers/being-a-young-carer-your-rights

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



CARERS UK HELPLINE

You can also contact our Helpline by emailing: advice@carersuk.org

Or you can phone:

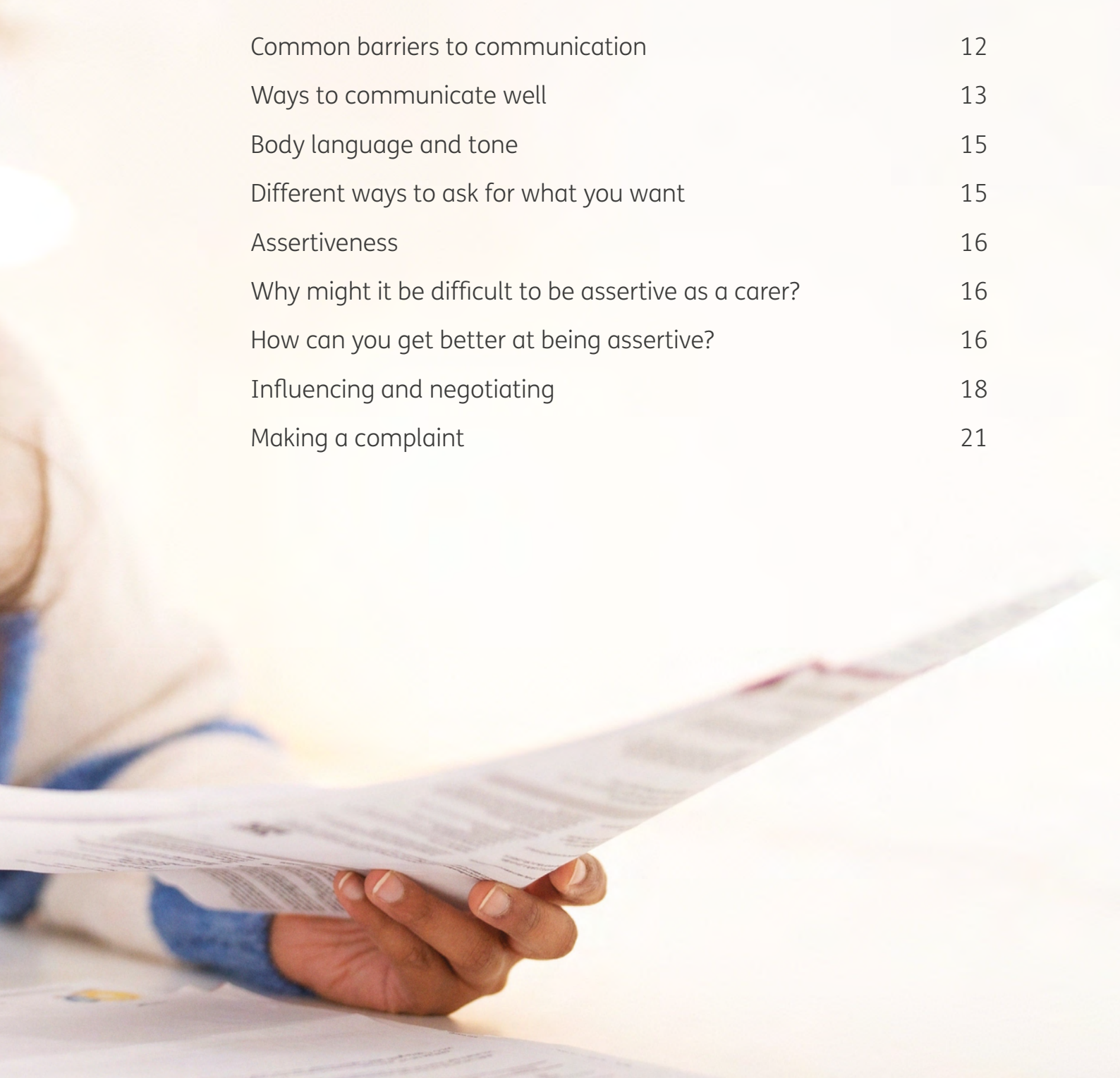
0808 808 7777

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



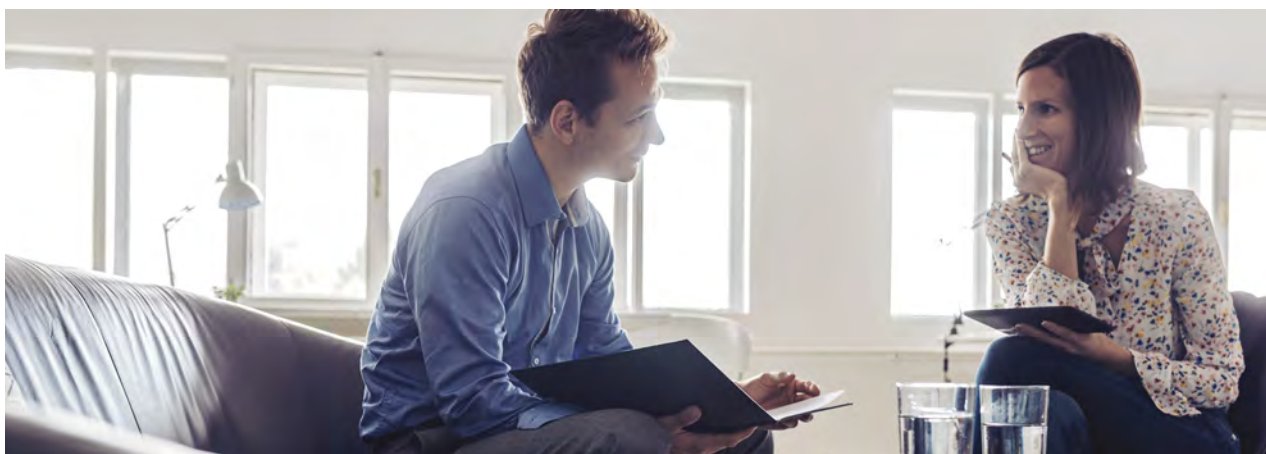
Communicating effectively

Common barriers to communication	12
Ways to communicate well	13
Body language and tone	15
Different ways to ask for what you want	15
Assertiveness	16
Why might it be difficult to be assertive as a carer?	16
How can you get better at being assertive?	16
Influencing and negotiating	18
Making a complaint	21



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.



We've looked at what your rights are as a carer and what should happen when you seek help. But what if the system doesn't work as it should? What if the way things should happen, isn't what is actually happening? This is where you may need to stand up for your rights and the rights of the person you are caring for.

We're very aware that this can feel daunting and that you may not feel able to speak up when things are not going the way they should. That is why we've developed this guide – to give you the tools, knowledge and support to be strong, speak up and get your voice heard! And we'll be here to support you every step of the way.

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.

Instead of saying:

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

Try:

"A way to meet that need is..."



Ways to communicate well

When you're talking to someone, some things are out of your control such as 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:

Meeting communication tips

Before meeting: prepare, prepare, prepare!

- **Make sure you are fully informed of your needs as a carer and the needs of the person you are caring for**, so you can accurately share this information. Our 'toolkit for support' could help.
 - **Make notes of what you want to discuss** and leave space so you can write notes during the meeting related to each point.
 - **Clarify what the meeting will be about** so you're not blindsided and neither are they.
 - If you have trouble with taking in information all in one go, **you could ask permission to record the meeting**.
-



During the meeting

- **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. Perhaps 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.



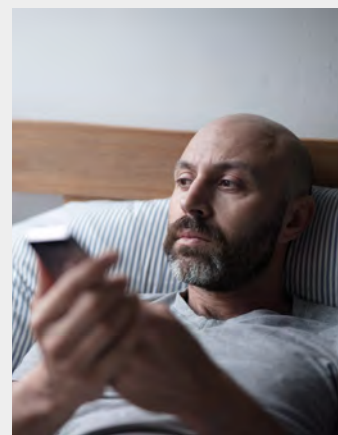
- **Don't be afraid of silence;** it can give you both a chance to think calmly. It could be a sign that the person is thinking seriously about what you said.
- **Be sensitive to the needs of the person you are speaking to.** For example, if the receptionist at the doctor's surgery looks stressed, say *"I can see you're very busy – please can I just have a minute of your time?"*
- **Ask for a minute if you need to make notes/get overwhelmed/upset.** Have some stock phrases written on your notes that you can say eg: *"I'm going to need a minute to process my thoughts, please bear with me."* or *"I need to finish making notes on what we've just discussed – thank you for your patience."*
- **If you don't get the answer you want, ask for clarification as to why:** eg. *"What are the reasons this request is being refused?"*, *"Can you please note in our records that I made this request and it was refused and why?"* or *"Can I please have details of your manager so I can make a complaint about this refusal?"*

Ending the meeting

- **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.
- **If a professional has been really helpful – do ask them if there is a way to feed back how helpful they've been.** Professionals will often only hear what they're doing wrong so showing your gratitude will encourage them to keep helping you where they can.
- **You can add different stock phrases even if the meeting has not gone as you hoped.** Eg: *"Thank you so much for your time."*, *"I know this was a difficult meeting and we didn't always agree but I really appreciate you talking to me and listening to my concerns."* and *"I understand that you can't agree to what I'm asking for and I also understand that is not your decision so I don't blame you. If there's anything you can do to support my request when I speak to your manager, I'd appreciate it."*
- **It might help to let them know you will follow up with an email that outlines what was decided and any questions that you have.** By being proactive in this way, you are in the position of power and miscommunications will be less likely to happen. They cannot claim you have agreed to something further down the line if you have an email clarifying that you do not agree sent straight after the meeting.



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. 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.



Different ways to ask for what you want

You may be wondering how to make your request. Depending on the nature of your request, it is sometimes easier to discuss the subject face to face or over the phone. It is then 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 if your emotions are involved..

It's a good idea to 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.



If you need to complain, we have a template you could use if needed as a starting point here: carersuk.org/media/veuffntc/cuk-complaints-letter-template-d2.pdf

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.

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.

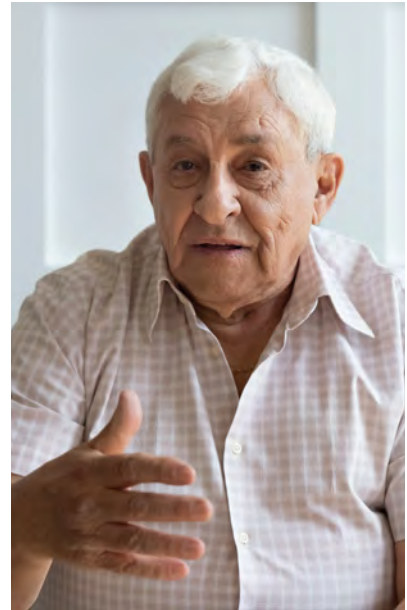
Assertiveness

Assertiveness is about being direct about what you need, want or feel and standing up for yourself in a way that respects other people. In the last chapter, we have covered that you have legal rights as a carer. Having this knowledge is powerful and can help you be assertive. In brief, you have the right to:

- a carer's assessment
- a care needs assessment for the person(s) you look after
- ask for flexible working/ carers' leave
- have your views and needs considered 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.

You can read more about your rights related to caring under the Care Act 2014: legislation.gov.uk/ukpga/2014/23/contents



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:

- Finding the time to ask or keep fighting for help becomes exhausting in itself.
- Feeling undeserving of help or that other people need help more so you won't ask.
- Feeling like you don't understand 'the system' or don't know what help is available or how to get it.
- Feeling like the other person/professionals are the expert so you can't question their decisions even if they don't feel right for you or the person(s) you are caring for.

How can you get better at being assertive?

Here are a few suggestions:

Your thoughts

- **Being really prepared** will give you confidence to be assertive.
- **Try to have a positive outlook** – it makes it more likely you will have a positive outcome.
- **Write things down** so you have clear goals and a structure to follow.

TOP TIP



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

- **Practise what you are going to say in a mirror or with friends** so you have a clear idea how you are coming across and to take away any fear of speaking out loud.
- **Remember that you have a right to ask for help** (such as a carer's assessment or flexible working) if you need it.
- **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.
- **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 'Recognising your feelings'.

Your attitude

- **Assume the professionals are a team with you with a shared goal** – unless shown otherwise.
- **Be willing to listen to the other person** (the social worker, the GP) and hear what they have to say – and why.
- **Create a list of what you will compromise on and your non negotiables** (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.

During meetings

- **Make sure you're speaking to the right person.**
- **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.
- **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 TIPS



Be willing to compromise on the things that you can live without.

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 – this is sometimes referred to as the 'broken record' technique.

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 billions of pounds a year.
- They may be the experts in the system, but you and the person(s) you care for are the experts in your situation.



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.** Read our assessments guide for details of what is possible, referencing the Care Act 2014 so that they know you are informed of your rights. For example, you may need respite once a week so you can de-stress at the gym or have driving lessons so you can get the person you care for to appointments more easily.

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.

Our '[Toolkit for support](#)' can offer some helpful ways to document this.



- **Be as specific as you can.** For example, say you want support with housework once a week as you spend XX hours a week caring and are unable to do both.
- **Explain why this will help you** or the person you are caring for. For example, say it will give you some 'you 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 or practise recording this on your phone and watching it back.

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 gain extra support for the care needs of the person(s) you're looking after.

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 see if there is a local carers' organisation near you.

On page 23 you can also find the contact details of sources of professional advocacy support.

How to negotiate – with advanced notice

- **Step 1** – Preparation is key – see page 13.
- **Step 2** – Clarify in writing the parameters of the meeting ahead of time eg who the meeting will be with, the purpose of the meeting, how long it will be. Include what your priorities are and what you hope to achieve.
- **Make your case as briefly, clearly and confidently as you can**, trying to stick to the facts.

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.

- 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, there may be a discussion. **Ask them to clarify anything that's unclear or that you don't understand.**
- **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 and don't be afraid to say no.
- **Be prepared for some give and take in your negotiations:**
 - » **Include areas where you can be flexible and areas you must insist upon.** *Eg, you might be flexible about the day that respite is on but must insist that the respite service has experience of adults with autism.*
 - » **Make sure the concession is something you can live with and that your overall position has improved.**

Negotiating on the spot

Sometimes you may not be given 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.

Example of what to say:

"No I can't agree to that without time to think about it. I would hate to waste all of our time having to revisit an incorrect decision later."



David's story*



David cares for his wife, Claire. David 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.

A friend suggests that David contacts social services to get help so Claire can go to a day centre on weekdays and David can have a break. The friend also encourages him to contact his local carers' centre to ask them how he can access day care for Claire and find out about other support.

A social worker comes to the house a week later. David is under the impression this is to reassess Claire's needs but the social worker says it is just an initial meeting to get to know Claire and David and she has a number of clients in crisis that she has to visit that day.

David feels frustrated but stays calm, maintaining eye contact and expresses his need for a time when he can sit down with the social worker and discuss how the department can help him and Claire, particularly around daycare, as he feels unable to carry on with things as they are.

**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 (including assessments)
- being refused an assessment
- 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.

Importantly, making a complaint can lead to getting the right services put in place or an assessment carried out. It can also be helpful to receive an apology, find out what went wrong, and make sure it doesn't happen again to you or anyone else.

TOP TIP



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

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.

Doing some preparation can help

For example, if you and/or the person you are caring for have been refused an assessment, you could check:

1. The council's guidance and
2. The national guidance to understand the assessment process.

Additionally, Carers UK and other charities can offer guidance and resources to help you navigate the process.

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, POhWER (who provide advocacy services), Advicelocal or the Carers UK Helpline (advice@carersuk.org).

Making 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 (and if needed, 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. You could also refer directly to legislation to back up your point (see chapter one, 'Understanding your rights' for more details).
- Keep a copy of your letter and any response.

TOOLKITS AND TEMPLATES



Our toolkit can help you keep track of dates and measure how much care someone needs: carersuk.org/help-and-advice/practical-support/carers-assessment/toolkit-for-support

You can also download a letter template and read our online guide to complaining about care services at: carersuk.org/making-complaints



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.

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

If you're not happy with the response to your complaint, you can take it further. Your next step depends on what you're complaining about.

If your complaint is about the council, you could consider contacting the **Local Government and Social Care Ombudsman (LGSCO)**. They also look at complaints about social services departments and adult social care providers such as care home and home care providers. They are a free service and will investigate your complaint in a fair and independent way.

If LGSCO finds your complaint is justified, they will write a report recommending what the organisation should do to put things right.

If your complaint is about the NHS, a government department or a public organisation, contact the **Parliamentary and Health Service Ombudsman**. They are a free service. They don't look at the outcome of a decision but how the decision was made and whether they followed the right procedures.

If you have a concern about the care provided by a health or social care service, contact the **Care Quality Commission (CQC)**. They monitor and inspect all organisations providing care in England including care homes, home care agencies, GP practices and hospitals.

The CQC can't resolve your complaint, but they may use the information you give them during their next inspection. If it's a serious safeguarding matter, they may take immediate action. By hearing about your recent experience of care, the CQC can help make care better for everyone. You can also provide feedback (good or bad) here: [cqc.org.uk/give-feedback-on-care](https://www.cqc.org.uk/give-feedback-on-care)

Getting help with making a complaint

If you want support with making a complaint about the NHS, contact your local Patient Advice and Liaison Service (PALS). You can find PALS in your local hospital or search online: [nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals](https://www.nhs.uk/service-search/other-health-services/patient-advice-and-liaison-services-pals). As well as helping you make a complaint, they will be able to arrange an independent advocate for you – someone who can help you get your voice heard. Find out more about PALS at: [nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service](https://www.nhs.uk/nhs-services/hospitals/what-is-pals-patient-advice-and-liaison-service).

At the time of publishing, this process is still in place but please be aware that this may change as a result of the NHS review.

If you would like support in making a complaint, there may be a local carers' organisation near to you that could offer help and assistance. See: [carersuk.org/local-support](https://www.carersuk.org/local-support)

You can also find out about advocacy support by contacting a specialist organisation like POhWER or VoiceAbility.



CONTACT BOOK

Local Government and Social Care Ombudsman (LGSCO)

T 0300 061 0614

lgo.org.uk/contact-us

Parliamentary and Health Service Ombudsman

T 0345 015 4033

ombudsman.org.uk/about-us/contact-us

Care Quality Commission (CQC)

E enquiries@cqc.org.uk

T 03000 616161

[cqc.org.uk/contact-us/how-complain/complain-about-service-or-provider](https://www.cqc.org.uk/contact-us/how-complain/complain-about-service-or-provider)
[carersuk.org/cqc](https://www.carersuk.org/cqc)

Patient, carer, citizen and charity networks

transform.england.nhs.uk/key-tools-and-info/involving-people-and-communities-in-digital-services/patient-carer-charity-and-citizen-networks



ADVOCACY SERVICES

Someone to speak up for you (advocate)

[nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/someone-to-speak-up-for-you-advocate/](https://www.nhs.uk/conditions/social-care-and-support-guide/help-from-social-services-and-charities/someone-to-speak-up-for-you-advocate/)

POhWER

E pohwer@pohwer.net

T 0300 456 2370

[pohwer.net](https://www.pohwer.net)

VoiceAbility

E helpline@voiceability.org

T 0300 303 1660

[voiceability.org/](https://www.voiceability.org/)



Recognising your feelings

Anxiety	27
Stress	27
Anger	27
Guilt	28
Loss	28
Getting help with these feelings	29
Understanding family relationships	29
Taking care of yourself	30
Reflecting on how you think	31
Final thoughts	32

Recognising your feelings

Even when everything is going right, caring can be physically and emotionally draining and, understandably, many carers experience complex feelings and burnout.

When the system isn't working and you feel like you're fighting for help and support every step of the way, these feelings can become even more complicated. This chapter covers some techniques to help.



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. But there may come a time when you feel you can't control the situation anymore and need some urgent help. To find out more about where you can turn for support, see our guidance: carersuk.org/help-and-advice/practical-support/getting-help-in-an-emergency

As a carer, it's easy to dismiss your own needs and put the person(s) 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 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."*
- *"Whatever I say, nothing will change."*

Stress

We all know what it's like to feel stressed. It can leave us with feelings of worry and loss of control. As a carer, it's especially important to look after your own emotional and physical 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, family member or counsellor about how you are feeling. Sometimes it helps to open up. Also see 'Getting help with these feelings' on page 29.

Safe ways of letting out anger

- Walk away from the situation before it becomes a row. Going for a short walk or a jog 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 anger by writing down all your angry thoughts and then rip up the paper and throw it away.
- There are a number of apps that can support you with expressing anger, for example through meditation or coping strategies.

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 talk about feeling guilty: for asking for help, not doing enough for the person(s) they care for, or because they sometimes resent being a carer, for example. These feelings are normal and understandable.

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 get support.

We have further guidance and coping mechanisms on our website: carersuk.org/help-and-advice/your-health-and-wellbeing/coping-with-guilt-resentment-and-other-difficult-emotions



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 deeply 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.

For further support, see our online guidance: carersuk.org/help-and-advice/practical-support/coping-with-bereavement



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. 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 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. Sessions are generally limited to between six and twelve 50-minute sessions, usually once a week.

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' organisation may provide low-cost counselling or refer you to organisations that offer support.

Sessions with a private counsellor cost anywhere between £10 and £70 depending on where you live. Contact the British Association for Counselling and Psychotherapy (BACP) to find a qualified counsellor.

On page 34 we have also listed some charities that can help offer free emotional support.

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.co.uk/about-therapy/using-our-therapist-directory

T 01455 883300

bacp.co.uk

NHS Talking Therapies

nhs.uk/mental-health/talking-therapies-medicine-treatments/talking-therapies-and-counselling/nhs-talking-therapies

Carers UK online meetups

For anyone who is unable to leave their own home easily, these free sessions can be a great source of emotional as well as practical support.

carersuk.org/help-and-advice/your-health-and-wellbeing/online-meetups

TOOLKIT FOR SUPPORT



Using resources within this toolkit to document what you do will enable you to actively show other family members the realities of caring and indicate if you need to consider other care options.

carersuk.org/help-and-advice/practical-support/carers-assessment/toolkit-for-support

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. As well as spending time with supportive people, there are different ways to cope with stress management such as practising mindfulness and seeking professional support. Family counselling can also help to resolve relationship issues. See page 29 for some suggestions.

Internal affirmations and spoken statements

It may also help to practise some internal thought affirmations that reassert your sense of power such as these:

“I cannot control how others treat me, but I can control whether I stay and listen. I can control whether I take any notice of what they are saying.”

“I don't agree with what they are saying and I am choosing to disassociate from it and not react.”

Or spoken statements that could help dispel a sense of conflict, even if you disagree, could be along these lines:

“Thank you for your suggestion. I'll consider that and make the decision that suits us best.”

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.

Mindfulness and relationship support

Mindfulness is a practice that helps you to become more aware of what is happening for you in each moment. Practising mindfulness can help you to feel calmer, more grounded and more able to manage stress and emotional difficulty. Our mindfulness hub for carers offers an introduction to some simple techniques: carersuk.org/wales/help-and-advice/your-health-and-wellbeing/wellbeing-hub/mindfulness-for-carers

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/get-help

Carers UK's Carers Connect forum

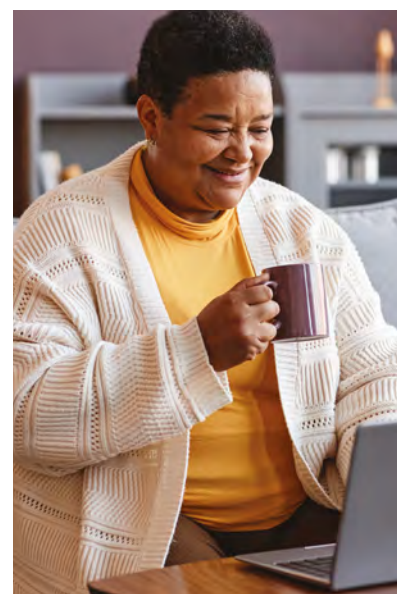
Carers Connect is an online forum you can join. It is a warm and welcoming online community where you can talk to other carers about what's on your mind and get support from people who understand. Get support from other carers: carersuk.org/forum

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 toolkit which is available on our website: carersuk.org/help-and-advice/practical-support/carers-assessment/toolkit-for-support



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 has happened. You can use this tool with any difficult situation and work out how to communicate differently next time.

REFLECTING ON EVENTS



Visit carersuk.org/self-advocacy to download our 'Reflecting on events' tool.

Challenging negative thoughts

Sometimes negative thoughts are a defence mechanism to protect ourselves from disappointment. After all, if we're expecting the worst and it happens, we can tell ourselves it's okay because we didn't expect anything better.

However, thinking in this way can stop us from seeing things objectively, and means we don't see positive outcomes when they take place. Someone may say *"no one listens to me"* after attending a meeting where they have been asked to discuss their concerns at length. Sometimes it can be helpful to see events from a fresh perspective with more positive alternatives.

Tackling unhelpful 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 do this 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.

'Take the thought to court': 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. See the example in the right-hand column.

Final thoughts

We hope this guide has helped you feel more confident when advocating for yourself and the people you care for.

Understanding your rights, how best to communicate your needs and process your emotions is a real skill and takes practice.

We hope you can use the information and advice to achieve the best outcomes for you and your family.

Carers UK is always here to help and support you so do not hesitate to get in touch if and whenever you need to.

TACKLING NEGATIVE THOUGHTS

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."

About Carers UK

Carers UK is here for everyone who cares, 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. Carers UK is here to make life better for carers.



- We offer information, advice 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 to join us, support us or access our online resources.

With your help we can make life better for carers.

Further information

You can find more of our resources at: carersuk.org/help-and-advice

References and sources for this guide

Carers UK

carersuk.org/help-and-advice

Carers Wales

carersuk.org/wales/help-and-advice/your-health-and-wellbeing/wellbeing-hub/mindfulness-for-carers

Hub of Hope

hubofhope.co.uk

Gov.uk

legislation.gov.uk/ukpga/2014/23/contents

Mind

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

NHS

nhs.uk/mental-health

nhs.uk/conditions/counselling

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

Open University

open.edu/openlearn/mod/oucontent/view.php?id=87006§ion=1

POhWER

pohwer.net

Samaritans

samaritans.org/how-we-can-help/contact-samaritan

Shout

giveusashout.org

VoiceAbility

voiceability.org



Keep in touch

Carers UK 20 Great Dover Street, London SE1 4LX

T 020 7378 4999 | E info@carersuk.org | carersuk.org

Carers UK Helpline

T 0808 808 7777 | E advice@carersuk.org

Please check: carersuk.org/help-and-advice/helpline-and-other-support for up-to-date opening hours.



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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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