

Being Heard: A self-advocacy guide for carers





Introduction

Carers UK is a charity set up to support those who care for loved ones who are older, disabled or seriously ill.

We support carers, influence policy and campaign to make life better for carers.

This Guide stems from work carried out by Carers Scotland and the Scottish Government. It has been updated by Carers UK to reflect the situation for carers in England.

This Guide to self-advocacy is the main element of our wider Toolkit to give carers the practical guidance they need to get their voices heard in these complicated and challenging circumstances.

The Carers Self-Advocacy Toolkit

The Carers Self-Advocacy Toolkit is a group of integrated resources produced by Carers UK that carers can use on a needs basis.

The Guide offers signposts and links to other elements of the Toolkit that carers can access for more information.

A number of these resources provide specific techniques explored in the Guide and these 'satellites' can be downloaded electronically, or accessed at carersuk.org/self-advocacy or by contacting the Carers UK Adviceline on **0808 808 7777** or at advice@carersuk.org.

All the other documents mentioned in the Guide can also be accessed on the website or by contacting us.

What is self-advocacy?

Caring can be rewarding in its own ways but it can also be very isolating, and carers may not know what help to ask for, how to ask, or indeed who to ask. Self-advocacy means enabling a person to get their own voice heard. For a carer this means speaking up for themselves and for the person they are caring for. There is nothing mysterious about self-advocacy; it's just about someone knowing how to communicate their concerns in a way that gives them the best chance of getting a positive outcome.

This Guide

The system

The first part of the Guide looks at you and 'the system' and offers information on the external environment you may find yourself in and the rights that can help you get your voice heard.



p04

Communicating effectively

The second part looks at skills around communication, assertiveness and negotiation and offers practical advice on getting the best out of interactions with others and how to make a complaint.



p10

Emotions & thinking

The third part takes a look at the 'inner' factors that may affect the ability of you to get your voice heard. Issues like difficult emotions, stress and family relationships are explored and ways to cope with these feelings are offered. We also explore how new ways of thinking and greater self awareness may help you to be heard more easily.



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The system

Introducing the system 06

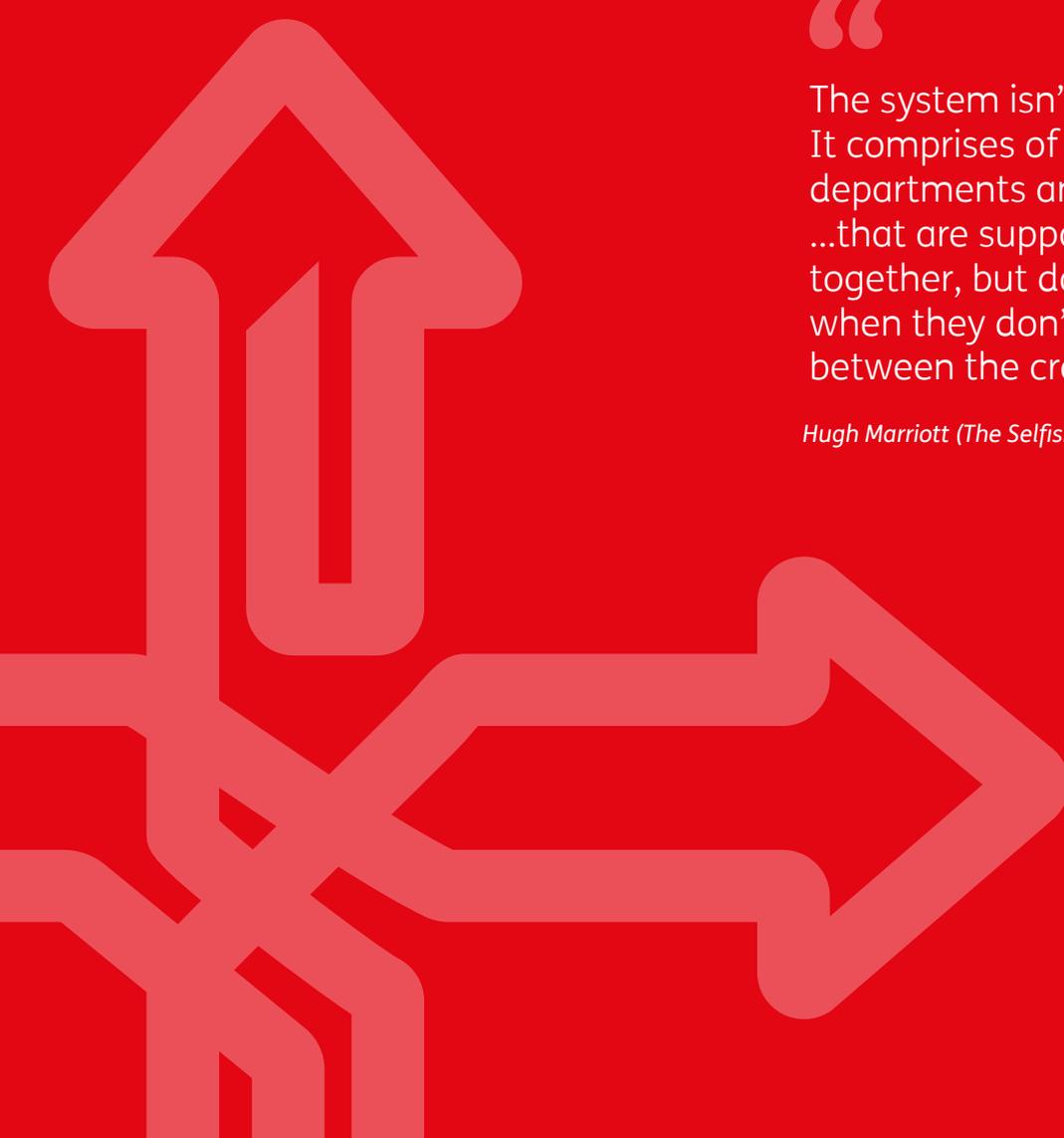
The rights of carers 08

“

The system isn't really a system. It comprises of a collection of departments and a range of services ...that are supposed to fit snugly together, but don't always. And when they don't, the carer can fall between the cracks.

”

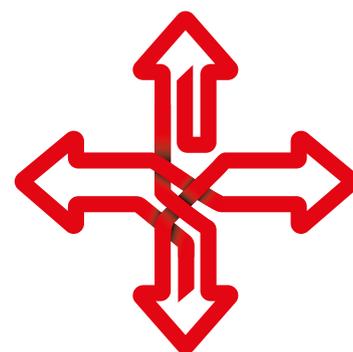
Hugh Marriott (The Selfish Pig's Guide to Caring)





The system

In this section, we take a look at the relationships you may have with organisations and services that are involved with the person you care for.



So ‘*the system*’ is a bit like looking at a cityscape. From a distance it looks like one big structure, but closer up there are big buildings of all different shapes and sizes, built at different times for different purposes. It is very common for one public sector organisation not to talk to the other, due to different funding or administrative arrangements. Sometimes, cross-working between organisations can be affected by professional rivalries or historical differences. It is also common for different organisations within ‘*the system*’ to be using different databases, making the sharing of information difficult. It’s also useful to remember that in many places service providers have big caseloads and can be slow responding to new requests.

However it’s important to see this bigger picture because if you are feeling isolated, exhausted and stressed, it’s most likely that one department hasn’t passed on information to the other and your request is spiralling down one of these cracks. That’s why as a carer it’s useful to be aware of how ‘*the system*’ works (or doesn’t) and be able to be armed with techniques to get your message heard and acted on. However there is an obvious imbalance of power between a carer and ‘*the system*’ and a culture which may not always recognise carers as equal partners. This can make it very difficult for an individual carer to have their needs fully heard.

The UK Government’s responsibilities to carers

The UK Government has a wide range of responsibilities to carers. They are responsible for the welfare benefits system and set the laws around what local government should provide in terms of services and support to carers and disabled people. They also set the over-arching funding around health and social care services as well as overall strategic direction, although many local areas determine exactly how they wish to provide support.

The main Government website gives you an overview of all the Government services: www.gov.uk

Laws are passed through Westminster: www.parliament.uk

The UK Government is also responsible for equalities legislation – such as the right to freedom from discrimination – and employment policy – such as the right to ask for flexible working. NHS England sets out priorities for the NHS in England and how they will deliver them. It also commissions some services directly. When it comes to local government and local health services, who is accountable to whom, who makes decisions and how this all works is complex.

What has ‘*the system*’ got that you need?

The local social services department of your local council provides things like carers’ assessments and assessments for community support. They either provide or commission an organisation to provide services like community alarms, meals at home, homecare, day-centres, respite and residential care. They are also the gatekeepers to other services such as supported accommodation, housing services, drug and addiction services and language services. They can also signpost you to voluntary services in the area.

Your local council administers Council Tax Reduction/ Support assistance, Housing Benefit, Council Tax Discounts and exemptions and Local Welfare Provision (for individuals in financial distress). It can offer help to individuals to make benefits claims and funds organisations locally to help people manage their money – often called ‘income maximisation’. It also facilitates other forms of help such as Disabled Facilities Grants for home adaptations and Blue Badge schemes to help with disabled parking.

The local education department of your local authority provides pre-school education, primary and secondary education, college education and training and additional support for learning.

Your local health services are more complicated. They are made up of:

- **GP practices** – which are often independent, but come under a general medical services contract where they have to provide certain services. These often have community teams and specialists attached – such as community nurses, midwives, health visitors etc. Some practices are large with many staff and GPs, while others are very small. Some large GP practices also offer a broader range of services and in the future may provide a wider range of services out of hospital. GPs are the gateway to almost all specialist consultants and support.
- **Pharmacies** – community pharmacies are often privately-run businesses, but they provide vital NHS services such as prescriptions services, as well as other core NHS services such as health checks, diet advice, flu jabs etc.
- **Dentists** – these can provide NHS and private dental services.
- **Local hospitals** – these are usually called NHS Trusts and may be small hospitals or very large centres of excellence. Some have A&E departments, specialist treatment centres, physiotherapy, maternity services etc. Some are called NHS Foundation Trusts. These have a different legal basis and unique governance arrangements with greater financial and administrative independence. They are accountable to local people, who can become members and governors.
- **Local mental health trusts** – these are local organisations that supply mental health services. Some may have community support with specialist mental health workers and some also run specialist secure units.
- **NHS 111** is a non-emergency telephone service.
- **NHS Choices** is an online health information system that provides information and tips around a range of health issues, as well as local contacts for all NHS services and how to make complaints. www.nhs.uk

Each of these bodies will make decisions about their own services. The main planning bodies locally are the Clinical Commissioning Groups. These are led by GPs and commission services locally from hospital trusts, GP practices and other bodies. NHS England also commissions services such as A&E, maternity and mental health services.

There is a joint planning body between health and the local council. This is called the Health and Well-being Board and it is run by the local council and includes health bodies. They decide overall what is needed to plan for improving the health and well-being of the local community in that area. You can find the Health and

Well-being Strategy on your local council's website.

The Department for Work and Pensions (DWP) administers the main welfare benefits such as Carer's Allowance, disability benefits and other welfare benefits including state pensions. It also delivers services through local jobcentres.

How does 'the system' see you?

This is a really interesting question. Although there are rights for carers enshrined in UK law, in practice, they can sometimes be a challenge to realise. Carers are not always treated as equal partners in care, although the recognition of carers among policy makers is slowly improving. There are also examples of where carers are given equal status and services are trying to support them as best as possible – but it's a mixed picture and is influenced by the approach that key service managers in local areas have towards carers.

Different parts of 'the system' may share information about you as the carer and the person you are looking after (the service user), eg as a result of a carer's assessment. In some ways it's a good thing when 'the system' shares information, which can make it more responsive to need – however they need to handle information in line with Data Protection legislation. Importantly, they should seek to obtain informed consent from you and or the cared for person to sharing information and they should be specific about what information they need to pass on. They should also formally record where consent is given.

What have you got that 'the system' needs?

Remember also that you as the carer are an expert in the care of the person you are looking after. You are the one who spends longest with the person and you know their history and achievements, their likes and dislikes and what works best for them. You are the one who sees to them when they have a bad day (or night) and you may be on hand any hour of the day or night to care for them. Believe it or not, this insight is all very useful information for care professionals, even if they don't tell you personally.

Added to that, you don't get long holidays, a union and coffee breaks like other professionals get and you are very unlikely to go on strike. Unlike paid staff, you're indispensable. So in terms of asking for things to help you care, you really are worth it.

The rights of carers

Until recently, carers' and service users' rights to social care in England has been hard to understand, and determined by a maze of confusing laws from 1948 to the present day.

The implementation of the Care Act 2014 in April 2015 means the law is a bit simpler now, as it includes all the laws governing adult carers caring for adults. This new Act has consolidated many of the old laws and has also introduced important new rights for carers.

Successive governments have produced Carers Strategies. These are policy documents produced in consultation with carers. The most recent one – in 2010 – was called *Recognised, Valued and Supported*. It emphasised the importance of:

- identifying carers early on, recognising their contribution and including them in designing local provision as well as in planning for individual care packages
- support for carers to fulfil their educational and employment potential
- personalised support for carers and those they support to have a family & community life
- support for carers to remain mentally and physically well



Other legislation and policy relevant to carers

Care Act 2014

All carers, like the people they care for, now have a right to an assessment of their needs, and any carer who appears to have needs for support should be offered an assessment by their local authority. This is regardless of the amount of care they provide or the level of need of the person they care for. The assessment must consider ability and willingness to care, whether the carer works or wants to work, education, training and leisure and what the carer wants to achieve (usually called 'outcomes').

There are new national eligibility criteria for both carers and adults with care needs. If carers meet the carer eligibility criteria there is, subject to a financial assessment, a legal duty on the local authority to meet their assessed needs. Previously local authorities could provide support to carers, but they didn't have to as there was no legal duty. This is an important new legal entitlement for carers, which puts them on an equal footing with those they care for.

If families want to move to a new local authority area, the new authority must carry out an assessment, and develop a care plan for the service user and carer to ensure there is no gap in care. If the new authority decides to reduce the care currently provided they must set out their decision in writing. If they have failed to carry out their duties by the time the move takes place they have to accept the old care plan and provide the same level of support until they have completed their own assessments. This is to help people move without the risk of a gap in their care support.

Disabled children are entitled to an assessment by adult social services before they reach 18 years old to help ensure a smooth transition from children to adult services. If this doesn't happen, then adult services have to continue to provide the same support that the child and family received from children's services.

Carers UK has a detailed factsheet about carers' assessments which you can download for free at carersuk.org/careact.

To get a printed copy contact the Carers UK Adviceline on **0808 808 7777** or email advice@carersuk.org

Children and Families Act 2014

This is another new law introducing Education, Health and Care plans for some disabled children. It also includes new laws affecting young carers and parent carers. It does this by amending the Children Act 1989, and puts in place a new duty to carry out a young carer or parent carer's assessment where there may be a need for support or on request. Carers support is provided as part of the whole family approach to care for disabled children under the general powers set out in s17 of the Children Act. Access to these is usually subject to local eligibility criteria. Parents of disabled children have a right to an assessment under this legislation.

Carers (Recognition and Services) Act 1995

This Act is still kept in part, but only 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.

Employment Act 1996 and the Work and Families Act 2006

These laws give carers limited rights to emergency unpaid time off to care for a dependent and give carers the right to request flexible working to fit in with the responsibilities of caring. The feedback from carers is that, whilst not perfect, flexible working is highly valued in the workplace as helping carers to juggle work and care.

Equality Act 2010

This is a wide-ranging piece of legislation and brings a number of equalities-related pieces of legislation under one Act. The Act includes protection for carers (who are looking after someone with a disability) from discrimination and harassment in the workplace and in services on the basis of their association of someone with a disability.

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/mentalcapacity

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, which is not necessarily the next of kin or the carer. More information is provided here: www.rethink.org/carers-family-friends/what-you-need-to-know/nearest-relative-rights-information

Further reading

Carers and their Rights (edition 6)

A guide to the law relating to unpaid carers in England *Luke Clements 2015 for Carers UK*

Carers Rights Guide 2016: Looking after someone
Carers UK

Communicating effectively

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Communicating effectively



In this section, we look at communication issues that you may experience with ‘the system’ and explore some methods of communication and ways in which you can communicate effectively.

We also explore assertiveness and negotiation skills and how to make a complaint.

What is communication?

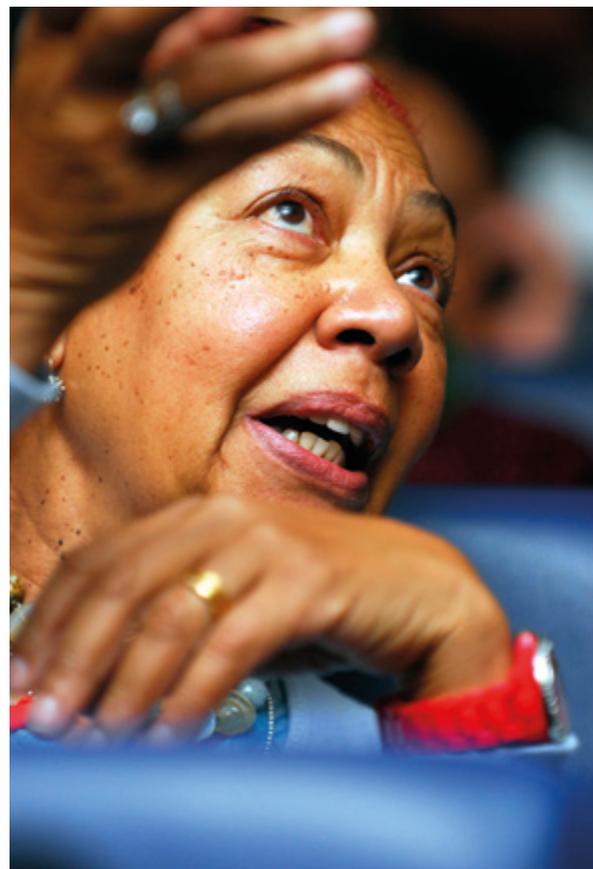
When we talk about communication between individuals and organisations it is about the flow of information between the individual and the organisation - for example between you as a carer and your GP Practice, or between members of the same organisation – say two social workers working in the same office.

Why is communication important?

Communication is important because it’s how we give and receive important information. As carers you may also need to persuade and influence someone – all these things are different ways of communicating.

What sort of a communicator are you?

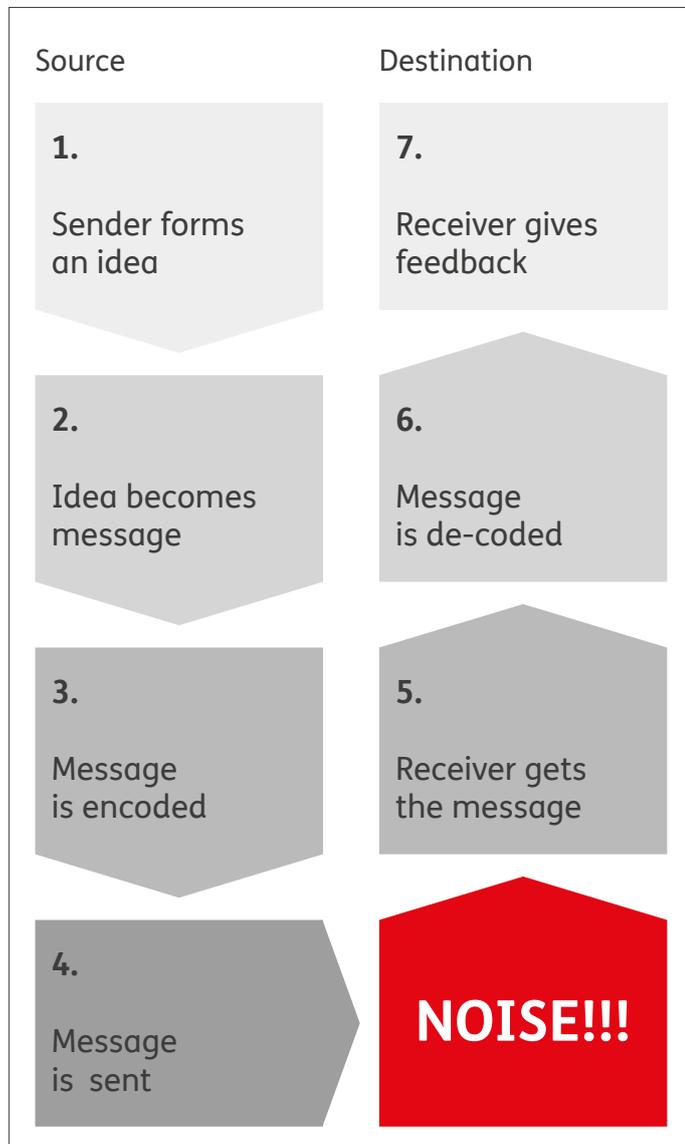
See the Satellite exercise to discover what kind of communicator you are and how you come across to others.



Visit [carersuk.org/self-advocacy](https://www.carersuk.org/self-advocacy) to download ‘How do you communicate?’

What happens when communication takes place?

Communication is a process and the diagram below demonstrates each part of the process. This model is adapted from Shannon C E & Weaver (1949).



This illustrates the complexity of the communication process.

Stages 1 and 2 are when the person is working out what he wants to say, and at stage 3 he is deciding on the words to use and how he is going to say them.

After the message is sent (stage 4), the receiver hears the words (stage 5) and then decodes the words (stage 6), giving them his own interpretation.

The issue here is, has the receiver interpreted the words in the way they were meant (stage 2)? Based on the receiver's interpretation, he will respond back to the speaker (stage 7).

Mis-communicating

Problems can occur when the message is 'encoded' inappropriately by the sender, say by choosing the wrong word, or giving it an emphasis that did not match the feeling behind it. Alternatively, the message may be 'decoded' incorrectly by the receiver of the message, so the message gets misinterpreted or misunderstood. When we ask for things, there is always the possibility that the person listening to our message will not really 'get' what we are saying.

These misunderstandings are called 'noise' as they get in the way of the true message being heard.

For example, Jim is a carer who is not getting respite he needs is advised by a friend 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."

The carer does not 'encode' the gravity of his situation in his message. The worker does not 'read' the seriousness of his situation and 'decodes' his message as wanting 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 the sender the information he's really looking for.



Common barriers to communication

It is very easy for our messages to be misunderstood by the listener. Below are some examples of noise.

- The person you are speaking to may not be fully listening.
- You may not speak clearly enough for the person to understand.
- You may use 'tone' of voice eg that makes it difficult for you to be heard. ie too soft or too harsh.
- The way you ask for things may be unhelpful. "Give me this now or else!" or in an unhelpful way "I know that you'll say no but..."
- Having distractions – you may be trying to do something else when you ask for something, or the other person may be doing something else while you are talking.
- There may be background noise going on when you are talking to someone - they may be hearing other conversations when we are speaking.
- If you are over friendly they might be thinking 'why is this person acting all friendly with me?' and may get a bit suspicious - and won't listen to what you are actually saying.
- If you are rude or offensive – so the listener is more focused on reacting verbally than trying to understand how you are really feeling.
- Making things personal – "you are incompetent!". This is when your human defences and emotions become involved – then things tend to go downhill and it can be difficult to re-establish a good relationship with the person.
- Your body language may be telling a different story to your voice. eg folded arms, avoiding eye contact may be seen as 'negative' by the person you are speaking to.
- Not having enough time to get your points across.

Ways to communicate effectively with someone

When you are communicating with someone else, you may not be in control of the environment you are in or how much the other person is really listening. However, there are some things you can do to give yourself the best chance of getting your messages 'decoded' accurately:

- Be polite
- Stay calm
- Try and keep the discussion objective (ie keep judgements at bay if you can). E.g "paid workers coming to care for my Mother rarely speak to her" rather than "paid workers swan in and always ignore my Mother, which is cruel".
- Try and separate the person from the behaviour. Eg if someone stresses you, 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 in your request ie "I would like to speak to you about getting respite" rather than "I was wondering whether I could get a bit of a break."
- Be specific in what you are asking for. Instead of saying "I can't cope anymore" say "I'm exhausted and I need a few days respite as soon as possible."
- Stay focused – stick to the point you want to make and remember your purpose for making contact with the other person. Write down the points so you have them in front of you.
- Repeat your request. It is common for carers to feel that professionals are side tracking them – so keep the discussion on what you want to discuss and don't be afraid to repeat your request during your discussion.
- Listen to what the other person says. It is easy to carry on thinking about other things when someone is responding to us – you can miss important bits of information!
- Ask for clarification if you do not understand what the other person is saying eg if they are talking in jargon or abbreviations.
- Don't be afraid of silence – it can give you and the other person a chance to think calmly - it could be a sign that the person is giving what you say serious consideration.
- If you can, be sensitive to the needs of the person you are speaking to. Eg if the receptionist at the Doctor's surgery looks stressed "I can see you are very busy, please can I just have a minute of your time?"
- When you get an answer to your query, thank the person - everyone likes to be thanked and it might make things better for you the next time you need to speak to them.

So getting back to Jim, he could communicate his need as follows:

“Hi, can you tell me about your advocacy service as I really need some support in getting respite. I’m very stressed about this right now.”

Body language

It’s also worth pointing out that communication isn’t just about talking! In fact, research suggests that between 50% and 80% of communications are non-verbal.* If that is true, it suggests that an awareness of your body language and vocal tone is very important.

The area of how body language is ‘read’ by others is a complex area and specific body positions and facial expressions can be interpreted in different ways, depending on the context of the communication. However a few things are worth doing if you are communicating with someone face to face.

- Sit square, with both feet on the ground – this helps you get attention and also helps you listen to the other person.
- Try to sit with an open posture with arms and legs uncrossed, as 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/shakes of the head.
- Establish eye contact with the person you are talking to but try not to stare as this can be a bit off-putting as well, but meet up with the person’s eyes every few seconds.
- Lean forwards towards the person you are talking to in a way that makes you look interested in what they are saying.
- Try to relax as much as you can, take some deep breaths and keep your shoulders relaxed and try if possible not to fidget.

▶▶ Visit carersuk.org/self-advocacy to download ‘**Behaviours and body language**’

Vocal tone

Of course it is not possible to dramatically alter the tone of your voice. However it is worth trying to remember to speak clearly, slow down speech (when emotions are running high we can speak too quickly). Also try lowering the tone of your voice as well as this conveys a sense of authority to the person you are speaking to.

*www.businessballs.com/body-language.htm

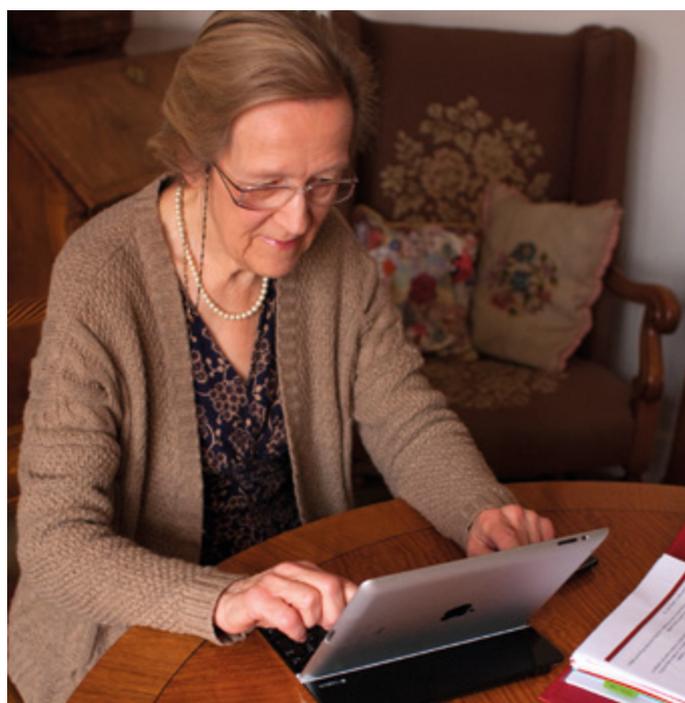
Methods of communicating your needs

There are a number of ways in which you can ask for things as a carer. It may be face to face if services are provided in the home or if you attend meetings. These days with the growth of email, letters are used to a lesser extent. Generally speaking, if you want to ask for one small thing, face to face or on the telephone is perhaps the most effective communication method. If you wish to make a complaint or have a list of things to say, a letter or an email allows you to specify everything (and also to provide a record of what you have said) is a good way forward. Keeping written records of communications is very important, if you can.

Email

Email is fast and efficient and it enables you to track your written discussions with professionals. However, there’s a catch. It is very easy to mis-communicate when using email. Because of the way we use emails it’s surprisingly easy to give the wrong impression of your tone and meaning. So use emails with care.

▶▶ Visit carersuk.org/self-advocacy to download ‘**Email etiquette**’



Assertiveness

What is assertiveness?

Assertiveness is the ability of someone to say what they want in a way which also respects the rights of others. It is based on honest and direct communication and enables a person to stand their ground while also respecting other opinions. It's about being understood and creating win-win situations. Others respond to assertiveness by feeling equal and knowing where everyone stands.

To help you to be assertive, it is important to recognise that you have rights. We have seen that as a carer you have rights to ask for things. If you are providing 'regular and substantial care' you can ask for a carer's assessment and you have a right to ask for an assessment of needs for the person you care for. You also have a right to ask for flexible working and your views and feelings should be taken into consideration by social service and health professionals. As citizens of the UK everyone has rights in other areas such as in education, religion, gender, consumer issues, race or class and there is now legislation that protects our human rights and national care standards that seek to respect the dignity and independence of people receiving services.

A Professional *"We are holding a meeting to discuss your Mother's care at 10am tomorrow and we'd like you to be there."*



What assertiveness is not

When we are communicating or asking for something there are four main types of behaviour that we can adopt. Assertiveness is one of them and here are the other three along with responses to the meeting invite ...

Passive behaviour

Passive behaviour avoids conflict, gives in to others and is not able to express feelings. This behaviour may lead a person to accept what others have agreed as they don't feel they can challenge decisions. Passive behaviour may lead the person to want to run away or avoid the issue. Others may respond to passive behaviour with resentment or impatience because of the lack of response from the person behaving passively.

"Oh, um, well OK, that should be fine. Thank you"

Aggressive behaviour

Aggressive behaviour is about the person getting what they want at the expense of others. Aggressive behaviour can come in the form of bluntness, rudeness, being loud, being threatening, interrupting others and acting regardless of anyone else concerned. Aggressive behaviour can be due to all sorts of factors, including stress, exhaustion and frustration. Aggressive behaviour may be effective in the short term as the person who shouts loudest tends to get attention quite quickly. However, over the long term, this behaviour is likely to lead to less positive outcomes.

"So you expect me to drop everything to suit you lot?"

Manipulative or passive/aggressive behaviour

Manipulative behaviour uses emotions to encourage others to meet their needs. A person behaving in this mode may mislead others to achieve their goal and control situations. Manipulative behaviour is sometimes used by a passive-behaving person if they haven't got the confidence to be assertive. It may be quite effective in meeting needs short term, given the imbalance of the carer-system relationship. However, others may see this behaviour as mistrustful or two-faced.

"I'm going out of my mind, are you trying to finish me off?"

As individuals, we tend towards one of these behaviour modes for most of the time. However it is quite normal for a person to shift from being passive, assertive aggressive and manipulative, depending on whom they are dealing with and their state of mind at the time.

Assertiveness can be a difficult mode to adopt because there has to be a balance between standing your ground

– which takes a lot of courage if you tend to behave mostly in passive mode - and having restraint if you tend towards a more aggressive mode of behaviour. Being honest and upfront about your objectives would be the biggest challenge if you tended towards manipulative behaviour.

 Visit carersuk.org/self-advocacy to download **'How assertive are you?'**

Rights and responsibilities of assertive people

We mentioned at the beginning of this section that assertiveness was a lot to do with claiming rights. As a carer you have a right to:

- State your own needs and set your own priorities as a person.
- Be treated with respect as an intelligent, capable and equal human being.
- Express your feelings.
- Express your opinions and values.
- Say “no” or “yes”.
- Make mistakes.
- Change your mind.
- Say “I don’t understand” and to ask for more information.
- Ask for what you want.
- Not take responsibility for other people’s problems.
- Deal with others without being dependent on them for approval.

However, with rights come responsibilities and for you to adopt an assertive approach it’s important to bear in mind that you have the responsibility to:

- Believe in yourself.
- Respect the rights of others.
- Hear the feelings and opinions of others
- Treat others with respect
- Respect different cultures and lifestyles
- Seek solutions that are OK with you and the other person

Why may you find it difficult to be assertive as a carer?

Some rights may be difficult to claim if your life experience has left you feeling uncomfortable in taking time for yourself or making your own decisions. These feelings are especially true of carers, whose lives tend to revolve around someone else. In fact, there are many reasons why you may find it difficult to stand up for your rights:

- You may be too busy to ask for something or to keep on asking for something.
- You probably think of the others before yourself.
- You may feel that you do not deserve things to help you.
- You may not have the energy or strength to say ‘no’ anymore.
- Your confidence has been undermined by ‘the system’.
- You may have been brought up to believe that to ask for things is cheeky.
- You may become very frustrated with how ‘the system’ responds to you.
- You may think that it is your duty to do everything for the person you care for.
- You or the person you care for may be reluctant to accept help from outside the family.
- You may just find it hard to say ‘no’.

 Visit carersuk.org/self-advocacy to download **'How you see your own needs'**

How can you become better at being assertive?

The following are a few ways to help you become more assertive.

Inside your head

- Have a positive attitude – if you are positive about the outcome it makes it more likely that you will have a positive outcome.
- Remember that you have a right to ask for help if you need it (a carers assessment, asking for flexible working).
- Have as much self-awareness as possible about 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 ‘Thinking about your thinking’.

Claim your rights

- Make sure you are 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 the detail of what you want to ask for so it's clear in your head and be specific.
- Choose the right time to ask for things to make sure the person gives your request their full attention.
- Say ‘I’ not ‘we’ - “I would like my complaint dealt with within the next seven days”.
- Ask for enough time to make a big decision rather than feeling pressured to decide there and then.
- Stand your ground on things that you really need. Repeat your request if necessary in a firm way – the ‘broken record’ technique.
- If you are a naturally quietly-spoken person, raise your voice when you are speaking – even if it feels unnatural at first.
- Ask for specific information if the speaker is being vague or talking in jargon.

Your responsibilities

- 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 if possible on the things that you can live without (see the section on negotiation).
- Believe in yourself and treat yourself with the respect that you show others.
- Know your own needs (see section on self awareness) and take some time to appreciate the possible needs of others.

A Professional *“We are holding a meeting to discuss your Mother’s care at 10am tomorrow and we’d like you to be there.”*

You could respond with *“Thanks for asking me. However, tomorrow will be difficult for me. Could we re-arrange for some time next week please?”*

For more tips on how to be more assertive or to understand the needs of others see the following Satellites.



Visit carersuk.org/self-advocacy to download **‘How to be more assertive’**

Influencing and negotiating

This part of the guide is about how to ask for things in an effective way and it looks into the process of negotiation. We go in to some detail about the things that need to be in place to enable you to negotiate effectively.

Influence

Influence is having some level of 'say' over what decisions are made - and as a carer working in 'the system' of scarce resources and tighter budgets, the ability to influence others even in a modest way a good one to have.

Influencing sounds very difficult, but it's possible for anyone to develop an effective influencing technique by using these guidelines.

Be aware of your own role and ability to affect decisions

- You are an equal partner in care and your views and opinions should be taken into account when decisions are being made about the person you care for.
- It is likely that the organisation you are dealing with has a policy to say that carers should be supported as much as possible.
- 'The system' needs you to carry on caring and you can use this to get your voice heard.
- You may well be the one that knows the most about the person being cared for.

Capture the attention of the audience with facts

- Describe the impact of the difficulties on your life. Eg the fact that you haven't had a full night's sleep in the last 8 weeks; you are on the point of giving up your job, the GP has increased your anti-depressants, you feel you want to hit the person you are caring for. Health and social care have a duty of care to you as well and remember - they would rather you carried on caring - so specific facts about how this is affecting you should make them sit up and listen.
- Give the worst day scenario. Because carers naturally tend to be nice people, they tend to underplay their own sufferings. Don't tell lies, but clearly explain difficulties you may be experiencing - mental, physical and emotional.
- Say how the situation is making you feel.

Know what you want to ask for

- Find out what you want first of all, by doing your homework, or asking someone else to find out for you. Eg finding out about short breaks in accessible accommodation in the Lake District.
- Try and be as specific as you can in what you are asking for eg a week-long break with the person you care for in an adapted hotel you have found near Lake Windermere.
- Explain why this will help you or the person you are caring for eg it will give us some 'us' time without housework, cooking and routine and will allow you both to be your old selves for a few days.

Use language in an assertive way

- Try and avoid an argument that goes like "other people get everything they ask for but we get nothing." This is not likely to be helpful in being heard.
- If you are talking to someone, slow down your talking pace, lower the tone of your voice and speak as clearly as you can. You can practice this in day to day conversation with people.
- Give your voice 'light and shade' otherwise known as 'inflection' which helps keep the person listening to what you are saying.

See the part of the Guide on effective communication and assertiveness for more information.

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

What is negotiation?

Negotiation is a way to influence others. A definition of negotiation is “the basic means of getting what you want with others” or “finding the terms of agreement” with another person. It is a process where agreement or compromise is made (*Fisher and Ury 1012*).

In a caring context, this could arise when you want to ask for a specific service or if you feel something has gone wrong with the care of the person you are looking after and you need to see improvements. Negotiating is a normal and everyday part of life, within families, at school, at work, at home and in social places, as well as with ‘the system’.

Negotiation skills

Effective negotiation skills are a very important element of getting your voice heard. These skills can be learned by anyone, however, it’s a good idea to build your skills on smaller issues to give you the confidence to tackle the bigger issues. If the thought of negotiating with professionals is something you really don’t feel are ready to do (and that is totally understandable) – contact your local carers centre to see if they can help you, or offer training in speaking up for yourself. You can contact us or check our website carersuk.org to find your local carers centre.

Negotiation can be done formally at meetings or via letters and emails. It can also take place informally, such as when you are speaking to a social worker who is visiting the house, or when you are speaking to your GP. The key thing to remember is that **all parties need to gain something of value in exchange for any concessions they make. So be prepared to make a compromise.**

Preparation

Before you start negotiating, think about what you want. Write down your objectives. Once you have identified your objectives you will then have a better idea of what exactly you want and how you will go about getting it. Write down the benefits of the thing you want and if possible, how any changes could be made. If you find yourself in a situation where you are put on the spot and have to negotiate there and then, we would suggest asking for more time to think, to enable you to do your preparation and discuss with any relevant people.

▶▶ Visit carersuk.org/self-advocacy to download ‘**Preparing to negotiate checklist**’



Proposal

Present your initial proposal as confidently as you can, so the other side listens to what you say. When you are speaking, emphasise the need to reach agreement. As we discussed in the sections on communication and assertiveness, stick to the facts and try and leave emotive words out of what you are saying. Also explain any conditions attached before making your initial offer. Summarise your proposal briefly and then stop talking so people know you have finished speaking and to allow them to digest your words. In short, put your case as succinctly as you can but make sure you have enough time to get your points across.

▶▶ Visit carersuk.org/self-advocacy to download ‘**Being objective**’

Debate

After you have listened to their response, a debate may start. Ask for clarification on anything they have said that is unclear or that you don’t understand. Look for any mutual points shared between you and the other side and think about the points that you are willing to concede. If there are major differences between you and the other side, decide if you need to make a counter proposal in response to the other side’s proposal.

Once both parties have explained their arguments, there may be a long discussion about the underlying facts about the situation. This debating time is crucial in the negotiation process but it might be difficult so try and keep calm and work on forming a bond with them.

▶▶ Visit carersuk.org/self-advocacy to download ‘**Your needs, their needs**’

▶▶ Visit carersuk.org/self-advocacy to download ‘**Mind your language**’

Bargaining

This stage is the key point of the negotiation process, where compromises will be made. Make sure that any compromise you make will still enable you to end up with a better situation than you had before.

- Ask for a break if things become too confusing
- Write things down if you can.
- Ensure you have enough time.
- Keep it objective and focused on a solution that meets both parties' objectives as much as possible.
- Don't agree to an offer that is unacceptable to you.

Negotiation can be brought to a successful conclusion only when both parties have made concessions that are mutually acceptable. You may therefore have to make concessions. If you have to make concessions it is important to take a long term view of what you could reasonably accept.

- Judge how much ground you have to yield – put a value on what you are prepared to give so that it can be matched with concessions from the other side.
- Compromise without losing face – if you have to backtrack on a point you had said was non-negotiable, you can say “since you have changed your position on ... I may be able to change mine on....”
- 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 get the luxury of having the time to prepare your case for a future meeting. Maybe you are asked to agree to something quite out of the blue, where you haven't got all the information you need to hand and you haven't had the chance to work out your concessions and bottom-line objectives.

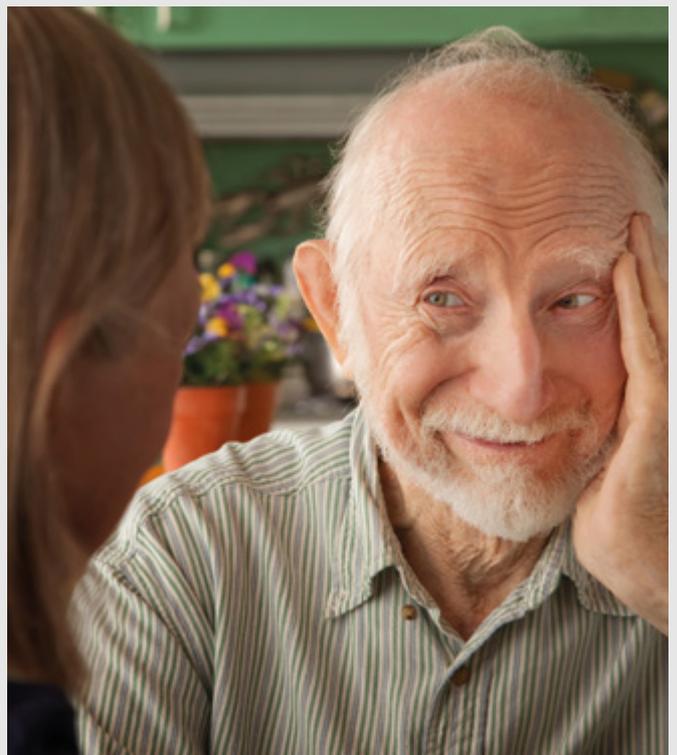
In these cases, ask for more time, rather than just agreeing to something there and then. Go through the preparation stage and ask for help from family or friends or your local carers centre to gather all the information you need.

Remember, you are an equal partner in care and you should be fully involved in your caring role. Plus, *'the system'* wants you to carry on caring, which gives you at least some bargaining power in this relationship.

Case Study

Bill is the sole carer for his wife Jean. Bill can't leave Jean alone for too long and now needs more help with personal care. Bill is starting to get tired and irritable himself and he sometimes feels unable to cope. A friend suggests that Bill contact the social services to get help so Jean could go to a day centre on weekdays and Bill could have a break. The friend also encourages him to contact his local carers centre to ask them how he could access day care for Jean and for any other help that Bill could tap into.

A social worker has arranged to come to the house a week later. Bill is under the impression this would be to re-assess Jean's needs but the social worker says it was just an initial meeting to get to know Jean and Bill and she has a number of clients in crisis that she has to visit that day. Bill 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 Jean, particularly around daycare, as he feels unable carry on with things as they are.



Making a complaint

If something goes wrong with the services being provided, you may want to find a way to put things right. Many people find making a complaint very difficult - you may be feeling frustrated and angry, or the thought of complaining might be frightening or may make you feel like you are moaning.

Local public bodies have to provide services within a framework of laws and guidance and both you and the person you care for have a right to receive services that keep you safe and that support you. Your complaints or concerns should be treated with respect and courtesy.

You may wish to make a complaint when:

- You/the person you care for have asked for a service but it has not been provided.
- The service that has been arranged is not suitable.
- You/the person you care for is not happy with the quality of service they are receiving
- You/the person you care for is not happy about treatment received in hospital.
- You/the person you care for is paying too much towards the cost of the service.
- There have been delays or mistakes when dealing with you or the person you care for.
- You/the person you care for is not happy with the level of training or skills provided, or people do not turn up on time.
- You/the person you care for have not been treated with respect.

Going about making a complaint

Use the complaints procedure of the organisation or department concerned. They should be able to send you a copy of their complaints procedure or at least explain to you on the phone how it works and how long after the event you have to complain. Many organisations also have their complaints procedure on their website. Usually you will be asked to try and resolve the issue informally with the person in the service with whom you have day to day contact. If it is not resolved satisfactorily here, contact their boss, working your way up the organisation. If you go straight for the top boss, bypassing lower levels of management, it's likely your complaint will just be delegated downwards, causing delays in getting your complaint investigated. They should also be able to give you a timescale in which you can expect a response – it's often within 28 days but it may vary from place to place.

Doing your preparation

Check out the policies of the organisation you would like to complain to. For example, if you think the person you are looking after is being charged too much for a service, it's a good idea to check their own guidance and national guidance about the particular issue, eg in this case it would be the Council's own Charging Policy and the National Charging Guidance. The key is to see if the organisation is a) following its own charging policy and b) national guidance.

If you are buying services privately, the company or organisation should be publishing their charges and terms very clearly in your contract.

If you don't have the time or resources to do this research, it might be an idea to ask for help with this from a family member or friend who is able to help you. If no one comes to mind, try your local carers centre, your nearest citizens advice bureau or the Carers UK Adviceline (0808 808 7777 or advice@carersuk.org).

Writing your letter of complaint

- Ask for a copy of the organisation's complaints form. They should be able to send you a copy or direct you to the relevant part of their website or explain it on the phone.
- Complain as soon as possible after the event. Some organisations have a time limit for the lodging of complaints.
- Write a letter of complaint if you can. Write 'Letter of Complaint' at the top of the letter so that it is clear you are making a complaint.
- Find out the right member of staff and the right address – otherwise the letter could get lost in 'the system'. Phone the organisation to find out if necessary.
- Provide evidence if you can – which means providing any documents that are relevant to the complaint, but remember to keep copies of these documents for yourself! See the Satellite 'Complaints Letter template' for more details.
- Give your contact telephone number, address and if you have one your email address in the letter.
- Keep a copy of your letter and of any response you get back. If someone responds to you by telephone, ask them to put their response in writing, but try and make a note of what they say at the time, for your own records.
- If you are unhappy with the reply you get, write to the person higher up the ladder on the complaints procedure. Once again, find out the name and

address of this person before you write. When you write to them, explain why the response is not satisfactory and what you would like to see done about this situation now.

 Visit carersuk.org/self-advocacy to download 'Complaints letter template'

Local Government Ombudsman service

The Local Government Ombudsman looks at complaints about councils and some other authorities and organisations, including education admissions appeal panels and adult social care providers (such as care homes and home care providers). It is a free service. Their job is to investigate complaints in a fair and independent way. By the time you contact the Local Government Ombudsman service, they expect you to have usually gone through the complaints procedure of the local council or organisation. They will look at your complaint if you have not had a response within a reasonable time – ie 12 weeks.

E advice@lgo.org.uk | T 0300 061 0614 | www.lgo.org.uk

Parliamentary and Health Ombudsman service

The Parliamentary and Health Ombudsman service investigate complaints that individuals have been treated unfairly or have received poor service from government departments and other public organisations and the NHS in England. Like the Local Government Ombudsman, they are a free service and are the final step of the complaints system. They do not look at the outcome of a decision but how a decision has been made and whether they followed the right procedures.

E phso.enquiries@ombudsman.org.uk | T 0345 015 4033 | www.ombudsman.org.uk

Care Quality Commission

The Care Quality Commission (CQC) is the regulator who monitors and inspects all organisations providing care in England, to ensure standards are being met. This includes care homes, GP practices and hospitals.

If you have concerns about care quality and these are not being addressed you can feed this back to CQC. They cannot resolve your individual complaint – that has to be done with the organisation in question – but the information you give may inform the next inspection or, if it is a serious safeguarding matter, they may take immediate action. Find out about the standards you

should expect from a service and how to tell CQC about any concerns you have around care quality:

E enquiries@cqc.org.uk | T 03000 616161 | www.carersuk.org/cqc | www.cqc.org.uk/share-your-experience-finder

Local Healthwatch

Every local authority area has a local Healthwatch – an independent consumer body – which they fund to include the voice of local people in services across health and social care. As well as getting feedback from local people about services in the area – good and bad – they are also part of important planning structures – such as the Health and Well-being Board – which set the local health and care strategy. You can find your local Healthwatch here: www.healthwatch.co.uk

Patient feedback mechanisms for GP practices and hospitals

Every GP practice and every hospital has to have a way of involving patients and the public. From 1 April 2015, all GP practices have to have Patient Participation Groups which gather patient feedback. Most do have PPGs already and this is part of the regulator's inspections (the Care Quality Commission). You can find details of your PPG by enquiring in your local practice, or via your practice website.

All hospitals in England have Patient Advice and Liaison Services, also known as PALS services. They can help with health-related questions, tell you more about the NHS in your local area, help resolve concerns or problems (or how to get independent help) and tell you how to get more involved in your own healthcare. Trusts also have some other specially constituted groups to feedback and you can find out about these from specialist services. You can find out about your local PALS by visiting www.nhs.uk and searching for 'PALS'.

Friends and Family Test

Friends and Family Test is a quick feedback mechanism that is being used across hospital services where everyone using the service is asked whether they would recommend the service to friends or family. The wards and services are then given their feedback and this is also publicly available. It does not replace the complaints procedure.

Local carers support services

Your local carers support services can also help you in making a complaint. Find your local service on our website at carersuk.org/localsupport or by calling the Carers UK Adviceline on **0808 808 7777** or by emailing advice@carersuk.org

Emotions & thinking

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Emotions & thinking



It's difficult to get your voice heard if you are weighed down with heavy and difficult emotions.

If you feel very anxious or angry, it's hard to keep things in perspective and stay objective, or sometimes even rational.

Have you ever noticed that it's much easier to ask for something for someone else than for yourself? This is because when you ask for something for someone else, we are able to adopt a much more objective way of thinking. However, when you want something for yourself, somehow different rules apply a voice in your head that may say "I don't deserve this". Perhaps you are attaching feelings and judgments to your own needs in a way you do not do when evaluating the needs of others. To explore this in more detail, see the Satellite below.



Visit carersuk.org/self-advocacy to download **'How do you see your own needs?'**

The feelings that are connected with caring can be very emotive. They may be around keeping the person safe and protected, safeguarding their dignity and striving to keep them happy and calm. Naturally you want to put the person you are caring for first and you may even dismiss your own needs in doing this.

The first two emotions we look at are anxiety and stress. Anxiety is defined here as a state of worry over a limited time which is not always rational and which tends to focus on one specific issue. Stress is defined here as a longer-term condition with lower-level feelings of loss of control and worry. There are usually a number of factors involved in creating stress.

Anxiety

Many carers experience anxiety when they are asking for things they need, which can inhibit them being able to self-advocate. The primeval 'fight or flight' signals from the brain cause the well-known reactions to anxiety; a racing heart, fast breathing and the instinct to run away or pick up a big stick! Situations where the emotional stakes are high often lead to a high level of anxiety. These feelings can affect your ability to put your views forward and ask for what you want (for the person you are caring for or for yourself). This is because anxiety is often accompanied by distressing physical symptoms and 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.
- People will think I'm stupid.



Visit carersuk.org/self-advocacy to download **'Dealing with anxiety'**

Stress

As a carer, it is important that you also look after your own emotional health. You may be juggling paid work or looking after children alongside caring or you may have had to give up employment to care for a family member. You may have had to make big and unwelcome changes in your life as a result of illness and disability in the family. You may be feeling resentful and or guilty because of the changes – and these feelings are all very stressful. And it's often the case that the expectations carers make of themselves contributes to their stress. Not all stress is negative as it can spur you on to achieve a task, or to get your voice heard, but if the balance tips too far and your stress levels become very high, you may feel unable to cope. When this happens, your ability to self-advocate will be significantly affected.



Visit carersuk.org/self-advocacy to download **'How to manage your stress'**

Guilt

Guilt is a normal and natural human feeling. As children, it can tell us that we may have done something wrong or hurt somebody's feelings and prompt us to put things right. However as we become adults we can use guilt to stop ourselves doing things that are perfectly reasonable. We start to tell ourselves we are not entitled to things and that we have no right to ask for things we might want.

Carers frequently speak about feeling guilty. They may feel guilty about asking for things for themselves or the person they are caring for. Or they may feel they are not giving the person enough care. The person being cared for can also make those around them feel guilty – intentionally or not. It's also possible that a carer may sometimes resent the person they are caring for, or the fact they are carers at all. These feelings are entirely understandable and normal. It is perfectly reasonable not to want to care all of the time, or at all.

However, it's often the case that guilt is used to actually stop us admitting our true feelings to ourselves. For example, a carer may feel a sense of guilt about putting his Mum into residential care to mask the fact that he feels unable to cope. It may help, when you have feelings of guilt to look at your underlying feelings. This can help to minimise the negative effects of guilt, but also pinpoint where you may need to ask for help.

Anger

Carers often say they feel angry or frustrated. Given the everyday challenges carers face, this is both natural and inevitable. These feelings are often repressed if there is no safe place to express them. However, if a carer blows their top when dealing with 'the system' this is likely to be seen as 'aggressive' behaviour which likely to result in the carer's needs not being met.

Safe ways of letting out anger

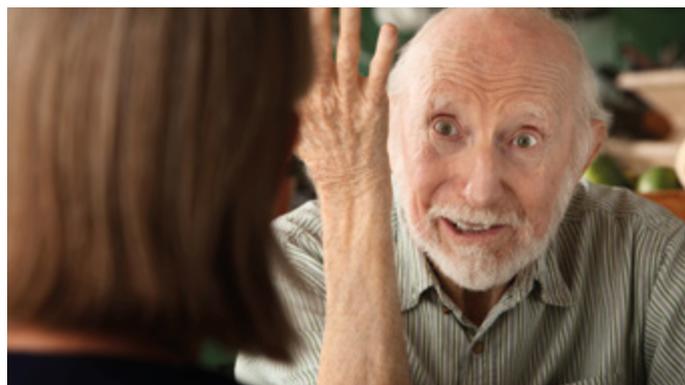
- Walk away from the situation before it becomes a row. Once you are out of the situation, you can take out your frustration on inanimate objects rather than yourself or someone else.
- If you are in a meeting, ask for a five minute break where you can go somewhere quiet and fill up a swear box.
- Try to relax by deep breathing or other relaxation techniques
- If possible, think about something happy for a few minutes, which may make you feel a little bit less liable to explode.

Sometimes anger is a helpful and appropriate response in getting your voice heard. As long as it is focused on the issues and doesn't become offensive or personal as it can make people sit up and listen, perhaps for the first time, to your situation.

However showing anger, when it is threatening and personal does not help you and has negative impacts. Those who readily become angry may be seen as being unpleasant, difficult or dangerous and others may become mistrustful or retaliate with aggression themselves, which makes a constructive relationship difficult to salvage. When you are angry, it is more difficult to see another person's point of view and it also tends to lead to more hurt and isolation. A person who is angry a lot of the time is not nice to be around.



Visit carersuk.org/self-advocacy to download **'Dealing with anger'**



Loss

Many carers are faced with loss – perhaps when the person they are caring for passes away or goes into residential care. If this happens you may feel sad that this part of your life is over and you miss that person very much. However, loss can also be felt in other ways. Perhaps you have had to give up work to care for someone or a poorly relative has had to move in with you for practical reasons. This loss of independence and freedom are less obvious and sometimes less acknowledged impacts of caring. These changes can also lead to a loss of confidence which can affect the carers' ability to get their voices heard and stand their ground with the outside world – and possibly with their family, including the person they are caring for. For a more detailed look at the emotions around loss, see the following Satellite.



Visit carersuk.org/self-advocacy to download 'About loss'



Getting help with difficult feelings

Carers often feel that they need someone to talk to outside the family who can help them through a difficult period in their lives. Admitting that you need help isn't an admission of failure – it is a positive and courageous step to admit you can't do it all yourself and is the first step towards feeling better. Counselling - or 'talking therapies' as they are called now involve you talking to and sharing difficult feelings with a trained person. The good thing is that they are outside the family and they can help you explore feelings that are so difficult to talk about, and how you cope with them. A counsellor will not tell you what to do but will help you come to your own decisions. It is also possible to access family counselling which can help resolve relationship problems.

Referral to a counsellor in the NHS is usually via your GP. Once a referral has been made you may have to wait a while before you get to see a counsellor. Sessions are usually limited to between six and ten 50 minute sessions that usually take place once a week.

You can also access counselling privately – sessions may cost between £30 - £40 for 50 minutes. Contact the British Association of Counsellors and Psychotherapy (BACP).

Your local carers centres may provide counselling at a low charge, or be able to refer you on to other organisations that provide this service for free or at more affordable rates.

▶▶ British Association for Counselling and Psychotherapy

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

T 01455 883300 | www.bacp.co.uk

Understanding family relationships

When it comes to family relationships, most of the rules about communication and assertiveness that have been talked about earlier apply. However, the key difference is that family relationships bring more emotions and history than other kinds of relationships. The fraught area of caring for a family member who is dear to all of the family can bring very real challenges.

Some families get on very well and provide each other with invaluable help and support. However, many families are not emotionally close and rifts, rivalries, personality clashes and family breakdowns are a fact of life. For many people, things can become particularly difficult when a family member becomes unwell or vulnerable. These days it is quite common for siblings and relatives to be spread across the country or even the world. It is also fairly usual for one family member to take on the main caring role, with other relations contributing where and when they can. In many cases other family members may not have any role in caring for their or relative. There is no norm, so as a carer, you just have to work with the circumstances you face.

It is worth remembering that most people have the best intentions for the family member who needs care – even though their ways of doing things may differ greatly to yours. If they haven't got much of a caring role for the person you look after, it may be that they feel guilty about this situation but find it difficult to say. Maybe they don't want to seem like they are interfering in the caring role by taking an active part themselves. Maybe they feel left out or even envious of the closeness you have to the relative you are caring for. Maybe they feel uncomfortable in a caring role, or they think you are happy to carry on providing the amount of care you are providing. If some family members have never been close to the person being looked after, they may try and 'make amends' or on the other hand, they may still want to keep their distance.

If you do have any of these issues in your family, you may not have the ability to 'fix' the problems, so you need to look after yourself as much as you can to prevent further stress. It might be helpful to see the situation from the perspective of the family member who is causing the extra stress. What are that person's needs? What are their key life experiences? What is their self-esteem like? The more you understand them, the more chance you will have to communicate with them effectively and get more co-operation and less tension. Understanding a difficult family member also encourages you to adapt your expectations of that person. If you want to go into this more deeply, have a look at the Satellite below.

▶▶ Visit carersuk.org/self-advocacy to download '**Your needs, their needs**'



If you are experiencing hostility or unhelpfulness from a family member (including the person you are caring for) it's very important that you have a support network around you when things are difficult. 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 are able to - that you are doing your best in difficult circumstances and explain what your needs are.

▶▶ Visit carersuk.org/self-advocacy to download '**How to manage your stress**'

▶▶ Visit carersuk.org/self-advocacy to download '**Mindfulness**'

You could look into family mediation as a means of resolving family conflict to avoid resorting to the law, if the situation becomes that serious. Relate runs services in local areas that look not just at relationships between couples, but other family relationships too. Find out about local support available here:

www.relate.org.uk/relationship-help

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

Thinking about your thinking

We have discussed how ‘the system’ works (or otherwise), the fact that ‘the system’ can be inefficient and confusing and can sometimes seem plain unhelpful. We have explored how you can communicate assertively in this environment. We have also said that as a carer there is a lot you can’t control. You can’t control the law or future, the thoughts, feelings and actions of the person you are caring for and what others around you are doing.

In this part of the Self-Advocacy Guide we consider how greater self-awareness and new ways of thinking could enable you to get your voice heard more effectively.

Self-Awareness

Arguably, something that you are in control of is your thoughts, feelings and behaviours in response to the outside world. The way we think, our attitudes and beliefs are influenced by genes, upbringing and experience. It can be difficult to shift any negative mindsets that have set-in over the years. Sometimes, there may not be an awareness that unhelpful attitudes and beliefs are there.

Adapting your thinking is not easy, and there are probably good reasons why you may have certain attitudes and thoughts towards others or your caring role. And it is not possible or desirable that you change your personality in any way. In fact self-acceptance is an important factor in managing the expectations you have of yourself and others.

When you are trying to get your views heard you will be more effective if you know yourself, ie knowing your own strengths and weaknesses and ‘way of being’. People who have a higher level of self-awareness tend to cope better in times of stress and anxiety and are better at devising practical strategies to get their needs met.

So, what sort of person are you?

In our culture we tend to avoid asking ourselves too many questions about how we feel, our thoughts or our behaviours. But self-awareness means you are better placed to address your underlying needs and to understand how we come across to others.

Use these exercises below to find out more about your personality type.



Do you tend to think things are going to go well and everything will be OK, or do you tend to fear the worst?



Visit carersuk.org/self-advocacy to download ‘**Optimist or pessimist**’



If you had the chance, would you prefer spending time with a large circle of friends? Or do you tend to enjoy spend time alone and spend a lot of time in your own thoughts?



Visit carersuk.org/self-advocacy to download ‘**Extrovert or introvert**’



What sort of a communicator are you? Do you come straight out with how you feel regardless of what the consequences may be or do you tend to bottle things up?



Visit carersuk.org/self-advocacy to download ‘**How do you communicate?**’

To help you become more self-aware, have a look at the ‘Self reflection’ satellite below. This tool encourages you to observe the reasons behind your actions. You can use this to help you understand your thoughts, feelings and behaviour when something negative happened eg when you have an unsatisfactory conversation or you have a run-in with someone.

You can use this tool with any difficult situation you have experienced and you can use it to work out how to communicate differently next time.



Visit carersuk.org/self-advocacy to download ‘**Reflecting on events**’

Disputing negative thoughts

Could it be possible that you sometimes re-enforce negative beliefs because you are expecting the worst to happen? Having negative thoughts is a kind of defence mechanism that we use to protect ourselves from disappointment. However, thinking in this way can prevent us from seeing things objectively and obscures us from seeing positive outcomes when they take place. A carer may say “no-one listens to me” after attending a meeting where she has been asked to discuss her concerns at length. Sometimes it can be helpful to see events from a fresh perspective which offers more positive alternatives to events happening around us.

Thoughts, feelings and behavior

Negative thoughts - so called ‘emotional disturbances’ arise in humans when we have beliefs that:

- I must do well and win approval, or else I am useless
- I must be treated kindly and considerately and justly or you amount to a louse
- I must survive relatively free of pain and to be reasonably satisfied and content.

These are described as ‘irrational beliefs’ because they are subjective (based on perception rather than hard facts) and lead to negative feelings, which go against a natural human desire to be happy.

Opposite are a few examples of irrational beliefs:



Examples of irrational beliefs

“

I should be thoroughly competent and achieving to consider myself worthwhile

”

“

It is awful and catastrophic when things are not the way I would very much like them to be

”

“

If something frightens me, I should...dwell on the possibility of it occurring

”

“

Human unhappiness is caused externally and people have little ability to control their sorrows

”

The ABCDE Model

A post-war psychologist called Albert Ellis devised a way of challenging these irrational beliefs and he was keen to point out that thinking and feeling were closely linked to actions. Thus an **activating event** (A) would lead to an **irrational belief** (B) which could create a **behavioural consequence** (C).

What Ellis did then was to encourage the person with the irrational thought to **dispute** (D) his or her own thinking by finding alternative reasons for A (the event that had activated the irrational belief in the first place).

So, the irrational belief (that is inherently negative) could be replaced with a possible rational belief (that is inherently more positive), which could then ‘allow’ the person to respond more positively in their actions and behaviour.

As a carer who wants to get your voice heard, it may be useful to be aware of this device if and when the need arises. The following is an example...



Challenging an irrational belief

Activating event (A):

Someone talks over me in a meeting

Belief (B)

How could they do this to me?
How awful!

Consequence (C)

I'm not going to say anything else!

or...

Disputed thought (D)

Maybe they are stressed?
Maybe they feel under pressure?

Consequence (E)

I'll ask to finish what I was saying at the end of the meeting

Tackling unhelpful thoughts

When someone is anxious, it's like they are all tied up in a ball of string. It's difficult to see the whole picture and it is usual to focus on bad things and to ignore the things in life that are going well.

Another useful way to dispute unhelpful thoughts is to find a logical way to untangle them and develop a more balanced point of view. One of the most straightforward ways to do this is to write down the evidence for the thought and against the thought, and then come to a more realistic or balanced way of thinking.

See the example in the table below.

What's the evidence?

You can think of it like a jury in a court case. To know the truth we need to string together information - hard facts about what actually happened (and not just what we think happened)

For example, a carer who has experienced anxiety in the meeting thinks "There's no way I will be able to speak." we can look at the evidence both **for** and **against** this thought.

Is the thought actually true??

Evidence For

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

Evidence Against

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

New Thinking

These are the thoughts based on the 'judgement' of the evidence and encourages you to be more realistic in anxious situations.

Tackling unhelpful thoughts

Thought	Evidence for	Evidence against	New thinking
<p>“ I am going to pass out in this meeting with my Mum's social worker ”</p>	<p>“ I feel dizzy and I nearly passed out when I last felt like this ”</p>	<p>“ I have never passed out before. I'll feel better if I sit near the door ”</p>	<p>“ I've not passed out before so chances are I'll be OK and I have an escape if need be ”</p>
<p>“ There's no way I will be able to speak at this meeting, it's too scary ”</p>	<p>“ I'm the only one not to have spoken, my mouth is so dry ”</p>	<p>“ I've spoken before at a meeting. I know exactly what I want to say ”</p>	<p>“ I have the proven ability to speak at meetings to get my point across ”</p>

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Publication code: E9036
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