



advice and support for older age

**Independent
Age**

Factsheet

Independent advocacy

An independent advocate can support you when you are dealing with difficult issues and help you to get the care and support that you need. An advocate helps to ensure that you can express your wishes and views when in contact with authorities like your council or the NHS.

This factsheet looks in more detail at what independent advocacy is, when it may be needed, and how to access it.

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Independent Age provides advice to help people claim benefits, access social care and stay independent at home. Our local volunteers provide friendship visits and calls for lonely older people. To find out how Independent Age can help you, call us FREE on **0800 319 6789** or visit **independentage.org**



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The information in this factsheet applies to England only. If you're in Wales, contact Age Cymru (0800 022 3444, agecymru.org.uk) for information and advice. In Scotland, contact Age Scotland (0800 470 8090, agescotland.org.uk). In Northern Ireland, contact Age NI (0808 808 7575, ageni.org).

1. What is an independent advocate?

An independent advocate is someone who you have asked, or given permission, to represent you. Your advocate can be a neighbour, a friend, a relative, a volunteer from an advocacy organisation or a paid independent advocate.

What does an independent advocate do?

An advocate will:

- help you to speak out and have your views, wishes and rights taken into account by your family, carers or professionals when decisions need to be made which affect your life
- make sure you have all the information you need to make informed decisions and choices
- support you to voice your decisions and views, or speak on your behalf. This may include making sure your views and wishes are explained and fully considered, as well as making sure that your rights are understood and defended.

To do this, an advocate might go with you to meetings or interviews in a supportive role, or write letters on your behalf.

What makes an advocate independent?

An advocate must be truly independent for the service is to work. Some professionals, such as a social worker or nurse, may have an advocacy-type role as part of their overall job description. However, if your problem is connected to the policies or practices of social services or an NHS hospital, then it may be inappropriate for the social worker or nurse to act as your advocate. There may be a conflict of interest, where the professional can't fully act on your behalf as they have to be loyal to their employer. As a result, your voice may not be heard properly.

There are many independent advocacy organisations where the advocates are not employed by the organisations providing the service you are unhappy with or want to access (such as NHS services, council support, or a care home). See chapter 11 for details of independent advocacy organisations.

2. Why independent advocacy is important

If you, your relatives or health and social care professionals all have different opinions on what care or support is best for you, you may feel powerless or unable to voice your own opinions. You may find it daunting or feel unable to influence or challenge the decisions that affect your life. If you're unhappy with your care or the situation you're faced with, you may need to challenge the individual or organisation causing the problem. This can feel intimidating and stressful.

An independent advocate can help you to overcome these challenges. The advocate will talk to you one-to-one and then support you to voice your views and wishes, or express your them on your behalf. They can devote time to you and be on hand to respond to changes to your needs and situation. In its simplest form, advocacy can mean just listening respectfully to you.

Good to know

Very often, advocacy support is available free of charge.

3. What independent advocacy is and is not

Independent advocacy is:

- being on your side and believing in you
- speaking on your behalf or supporting you to speak
- providing information and discussing options
- enabling you to make informed decisions and choices
- ensuring that your rights, views and wishes are acknowledged and taken into account by others
- putting aside the independent advocate's personal values
- trying every possible way to achieve the outcome you want or have a right to.

Independent advocacy is not:

- influencing you to make a decision
- making a decision for you
- advising you on what to do
- persuading you to do what other people want you to do
- doubting what you say or want
- counselling you
- speaking for you when you want to speak for yourself.

Independent advocacy isn't usually about legal representation. However, your independent advocate could appear in court to speak on your behalf, such as at a deputyship hearing.

To do...

If you need specialist legal advice about problems with care, you could contact Civil Legal Advice. They can also advise on legal aid eligibility (0345 345 4345, gov.uk/civil-legal-advice).

The Law Society website also provides contact details of solicitors (020 7320 5650, lawsociety.org.uk). Free initial legal advice may also be available via the Disability Law Service (020 7791 9800, dls.org.uk).

4. Types of independent advocacy

There are different types of independent advocacy. The main types are:

- crisis (or issue-based) advocacy
- citizen advocacy
- self-advocacy
- non-instructed (or 'best interests') advocacy
- NHS Complaints advocacy.

Crisis advocacy

This is the type of advocacy that people need to access most often. Crisis advocacy tends to be short-term, lasting anything from one day to six months, although it can be longer depending on how complex your situation is. The advocate will focus on one issue or aspect of your life (for example, your wish to challenge the decision to discharge you from hospital to a care home). The advocate will stay involved until you get what you want, or until they've tried every possible way to achieve this.

Citizen advocacy

Citizen advocacy can be more long-term than crisis advocacy. It matches people with disabilities to advocacy partners who are members of their local community. The partnership takes more time to form as you will be spending more time together, so it's important that you feel comfortable together.

Citizen advocates are there to support you in many aspects of your life and may be able to advocate on a number of issues on your behalf. They may not belong to a specific advocacy scheme – for example, they may be a neighbour or a volunteer from your community.

Peer advocacy is a form of citizen advocacy when the advocate and the person share similar experiences or environments.

Self-advocacy

Self-advocacy is about speaking up for yourself and making decisions about issues that affect your life. Self-advocacy schemes help you to build your confidence using tools such as assertiveness training to help you to set out your preferences. It may be an option if a group of you are affected by the same issue (for example, a residents' group in a care home).

Non-instructed advocacy

Non-instructed advocacy, or 'best interests' advocacy, supports people who need an advocate but can't tell the advocate what they want. This may be because of communication difficulties, learning disabilities or late-stage dementia. Non-instructed advocacy represents what the person's wishes and preferred choices would be, if they were able to express them. This is achieved by:

- trying different ways to communicate with the person
- ensuring they're not ignored when decisions are made
- gathering information about them and building up an idea of their past views and preferences
- ensuring every possibility is looked at
- treating the person with respect.

NHS Complaints advocacy

An independent NHS Complaints advocate will be able to help you complain about treatment or care you may have received from the National Health Service (NHS). This could include complaining about your GP, dentist, hospital or mental health services.

A NHS Complaints advocacy service may be able to help you understand the complaints process, support you to write letters or attend meetings with you. You usually have to make your complaint within 12 months of the problem with your NHS care. Contact NHS Complaints Advocacy to find out more (0300 330 5454, nhscomplaintsadvocacy.org)

To do...

Discuss which type of advocacy is best suited to your situation when you approach an organisation about getting advocacy support. See chapter 11 for details of organisations that offer advocacy.

Good to know

There are also specific independent advocacy services to represent people who are subject to the Mental Capacity Act 2005, the Mental Health Act 1983 and the Care Act 2014. For more details, see chapters 5, 6 and 7.

5. Advocacy for people who lack mental capacity

Mental capacity means having the ability to understand, retain and use information to make and express decisions about your life. You are considered to lack mental capacity if you're unable to do one or more of the following:

- understand the information relevant to the decision
- retain the information long enough to be able to make a decision
- use or weigh up the information to make your decision
- communicate the decision by any possible method.

Assessing someone's mental capacity

It should never be assumed someone doesn't have mental capacity. It's important, particularly if there is a dispute or difference of opinion, that someone's mental capacity is assessed by a trained professional such as a GP, psychiatrist, speech and language therapist or social worker. Loss of mental capacity isn't always permanent. It could be temporary or change over time. Someone may be able to make some decisions but not others. The assessment should look specifically at the issue being considered.

Advocacy for someone who lacks mental capacity

Advocacy for someone who lacks mental capacity is important because:

- all steps should be taken to help someone who may lack mental capacity to make their own decision, or take part in the decision making
- their past wishes, views or beliefs should be taken into consideration when important decisions about their care about being made. An advocate can ensure their wishes are taken into account by those involved in their care

- other people, such as family and friends, who are interested in that person's wellbeing should be consulted when a decision is being made on their behalf
- someone who lacks mental capacity may not be able to process complex information, but may still be able to make one-off important decisions or voice opinions. An advocate can help them understand all the facts to make that decision
- an advocate can ensure their rights, needs and wishes are taken into account by those involved in their care if there's a conflict of interest, such as a dispute among family members about what's best for them.

If a person who lacks mental capacity can't make a decision themselves, despite help, any decision made on their behalf must be made in their best interests.

Independent Mental Capacity Advocates (IMCAs)

An Independent Mental Capacity Advocate (IMCA) may get involved if a serious welfare decision needs to be made about someone who lacks mental capacity, such as a decision about medical treatment or where they should live. This is more likely if the person doesn't have any family or friends that can be consulted, or if it would be inappropriate or impractical to consult them. Council or NHS staff must refer people to an IMCA if they need to make such a decision and don't have someone else to represent them.

The IMCA will meet the person to gather as much information as possible about their wishes. If it's not possible to establish what the person thinks about a decision, the IMCA should act in their best interests and represent the person's rights and past wishes (if known) to the professionals involved in their care and treatment. The Social Care Institute of Excellence has a list of IMCA providers (020 7766 7400, scie.org.uk/publications/imca/find).

6. Independent Mental Health Advocates (IMHAs)

If you're detained under the Mental Health Act 1983 or are a subject to a Community Treatment Order (CTO), you will qualify for support from an Independent Mental Health Advocate (IMHA).

An IMHA can give you information about your rights under the Mental Health Act and other aspects of your care and treatment. They can help you get their views and wishes heard and help with appealing against a section. Mental health professionals must allow IMHAs access to your medical records if they're given permission to do so. An IMHA can work alongside other advocacy services and Independent Mental Capacity Advocates (IMCAs).

An IMHA service will be commissioned by a local authority but they should be independent of anyone who has been involved in your treatment.

If you need an IMHA, you can contact one directly or ask a health or care professional to get in touch on your behalf. If you don't want an IMHA's help, you don't have to speak to one.

A hospital manager must inform anyone who is detained under the Mental Health Act, or subject to a CTO, about the IMHA service and help them to get an advocate. See chapter 11 for contact details of other organisations that may be able to help you find an advocate who is trained to work with people living with mental health issues.

7. Care and Support Advocacy

If you have contacted your council to ask for their support to meet your care needs, they may have a legal duty to arrange an independent advocate for you.

Under the Care Act 2014, councils must provide an independent advocate when someone is unable to communicate well or needs support to understand the issues being discussed with social care professionals. This only applies if:

- you don't have an 'appropriate person' (like a friend or family member) to support you. This could also apply if there is a conflict between family members, or if your family don't agree with your care decisions.

and you have substantial difficulty with any of the following:

- communicating what you want to say
- understanding the information given to you, or remembering it
- weighing up the information you are given in order to make decisions about your support.

Sometimes, you may still be able to get an independent advocate even if you have an appropriate person to help you, if you've been in hospital for more than four weeks or a care home for more than eight weeks and the council agrees that it would be in your best interests to have an advocate.

The council has a duty to arrange an independent advocate at important stages of getting services, including:

- your care needs assessment
- when they are putting together your care and support plan
- when they are reviewing your care
- when meeting with professionals to discuss concerns about your safety, for example.

The council should consider whether you qualify for independent care and support advocacy right at the start of the assessment process. You (or your friends or carers) can also make a request.

If you disagree with the council's decision, you can contact Independent Age for advice (0800 319 6789, independentage.org).

Good to know

Even if the council doesn't have a duty to provide you with an independent advocate, you can still arrange one for yourself. Ask the council which local advocacy organisation they use, or contact one of the organisations listed in chapter 11.

For more information about getting support from your local council, read our factsheet **Assessment and services from your local council** (0800 319 6789, independentage.org).

8. How does independent advocacy work?

Step one: Meeting your advocate

Once you have contacted an advocacy organisation, an advocate should meet you to discuss the support you need. If you live in a care home, sheltered housing or are a patient on a hospital ward, they should first, for security reasons, notify the care home manager, charge nurse or warden of their planned visit. They should explain:

- their role
- how they would support you
- what the advocacy organisation does.

Your conversation should be confidential so you can speak openly about the issues affecting you.

Step two: Giving your advocate permission to represent your views

Although the independent advocate should listen to the views of others such as your GP, carers, social worker and family, their most important concern should be how you see the problem and what you want to happen.

Once the independent advocate knows your views and wishes, they need your permission to advocate for you. (There are some types of advocacy where someone isn't able to give their permission – see chapter 5.)

If you give permission then the independent advocate should then ask you how you would like the problem to be resolved. You can change this outcome at a later date if you wish. Your advocate should make sure you're fully informed of any developments to the situation.

Step three: Speaking out

The independent advocate should support you to speak out or represent your views, wishes and rights to those involved in your care, such as professionals, carers and family. This could be done by letter, telephone or in person (for example, by attending a case conference or a meeting with you or on your behalf). The advocate may also explain your views and wishes in terms of your legal rights. For example, they may tell the professionals involved in your care that not only do you want to go back home, but you have a legal right to decide where you live.

Who is in charge in advocacy work?

You should always be in charge. You have given your views and decided on the outcome you want. You can also end the advocacy partnership at any time, whether the outcome you asked for has been achieved or not. The independent advocate shouldn't try to persuade you to continue the process. It is your decision.

9. Examples of how different types of independent advocacy can work

Example 1: Susan: Crisis advocacy

Susan wanted to complain about her care worker, who the council had arranged to come round once a day and help her to get washed and dressed. She was worried about making a complaint, in case her care suffered as a result. She also didn't want the council to think that she was ungrateful for the help that they had arranged for her.

She talked to a local advocacy organisation, and felt reassured when they listened to her concerns and said that they could voice her concerns to the council on her behalf, and if this didn't resolve things, they could help her to make a formal complaint through the council's complaints process.

Example 2: Arjun: Care and support advocacy

Arjun is getting a bit forgetful and frail and feels that he needs some support to help him manage at home, but doesn't know where to start. He has no relatives or friends living nearby. He feels that the care system is complicated and confusing, and is worried about contacting the council as he is not sure if he is entitled to any help.

Arjun could contact an advice service like Independent Age (0800 319 6789) to find out what he is entitled to and how to get help. An advocate could help Arjun through the system by attending any assessments or meetings with the council with him, and making sure he understands his care options and rights.

Example 3: Anita and John: NHS Complaints advocacy

While Anita was in hospital, she was told that she shouldn't go home once she was discharged, as her care needs were too great and she would be better off in a care home. Anita didn't want to move into a care home, and didn't feel like anyone was listening to her.

John was surprised when the discharge date he was given was so soon after his operation – he didn't feel well enough to look after himself at home, and no care had been arranged to help him. He wanted to challenge the discharge date, but didn't know how.

An independent advocate could ensure that Anita and John's voices and rights are listened to by the professionals planning their discharge. If Anita and John were then not happy with how their hospital discharge went, they could get support from an NHS Complaints advocacy service to make a complaint.

Example 4: Emil

Emil is being emotionally abused by workers in his nursing home. He feels intimidated and alone. He could contact an independent advocate to talk in confidence about his situation. He could then decide whether or not to take up the offer of advocacy to help him feel protected and stop the abuse.

10. Dealing with potential problems

Sometimes, professionals, carers or family members don't understand how independent advocacy should work. They might not understand your right or need to have an independent advocate. This can mean they don't work with your advocate in the way they should. For example, they may not work with your advocate or keep them involved, or may even refuse to deal with them.

Your independent advocate should work to overcome these issues. For example, they could explain the purpose of advocacy to avoid any misunderstandings. They may need to reinforce what their role is, and how vital it is that your views are heard. If necessary, they could make a formal complaint on your behalf.

11. Useful contacts: Accessing independent advocacy

You can refer yourself to an independent advocacy organisation, or get the help of a friend, relative or carer to do so.

A professional who feels that you may benefit from an independent advocate can also make a referral (and in many cases, they will have a legal duty to do so).

If you live in a care home, you may also be able to ask the care home manager and/or care workers for help to access independent advocacy. The care home staff have a duty to tell you about independent advocacy services.

Your local council should be able to tell you about local advocacy schemes.

Age UK Advocacy Services

The Age UK Access to Advocacy Service (0800 169 6565, ageuk.org.uk) is available to anyone who needs information, advice, signposting or a referral to one of its advocacy services. The service is free, confidential and impartial. Ask your local Age UK if they offer an advocacy service.

Mind

Mind (0300 123 3393, mind.org.uk) is a mental health charity with local branches throughout the country. Some offer advocacy services for people with mental health problems.

National Coalition of Advocacy Schemes

The National Coalition of Advocacy Schemes (07821 688454, cacoalition.org.uk) promote and support informal community based advocacy (citizen advocacy) schemes.

Older People's Advocacy Alliance (OPAAL)

OPAAL (opaal.org.uk) is a national organisation supporting, promoting and developing independent advocacy services for older people. OPAAL has an online database of local independent advocacy schemes for older people.

Patients Advice and Liaison Service

Patients Advice and Liaison Service (PALS) offices are available in all hospitals and offer confidential advice, support and information on health related matters to patients, families and carers. PALS may also be able to advise you on local advocacy schemes.

This factsheet has been put together by Independent Age's expert advisers. It is not a full explanation of the law and is aimed at people aged over 60.

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- remember Independent Age in your will and benefit from our Free Wills offer to supporters.

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