

Factsheet

Independent advocacy

An independent advocate can support you when you are dealing with difficult issues. An advocate can support you to make sure your views are heard and your rights are upheld when dealing with authorities like your council or the NHS.

This factsheet looks at what independent advocacy is, when it may be needed and how to get it.



Call free on 0800 319 6789

Visit www.independentage.org

About Independent Age

Whatever happens as we get older, we all want to remain independent and live life on our own terms. That's why, as well as offering regular friendly contact and a strong campaigning voice, Independent Age can provide you and your family with clear, free and impartial advice on the issues that matter: care and support, money and benefits, health and mobility.

A charity founded over 150 years ago, we're independent so you can be.

The information in this factsheet applies to England only.

**If you're in Wales, contact Age Cymru
(0800 022 3444, ageuk.org.uk/cymru)
for information and advice.**

**In Scotland, contact Age Scotland
(0800 12 44 222, ageuk.org.uk/scotland).**

**In Northern Ireland, contact Age NI
(0808 808 7575, ageuk.org.uk/northern-ireland).**

In this factsheet, you'll find reference to our other free publications. You can order them by calling **0800 319 6789** or by visiting www.independentage.org/publications

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1. What is independent advocacy?

Advocacy services help you communicate your views. Advocates can take action to secure your rights, represent your interests, request things you need and challenge decisions.

What sort of things can an independent advocate do?

You might consider getting an advocate to:

- help you to express your views, wishes and rights, or speak on your behalf to family, carers or professionals when decisions need to be made that affect your life
- make sure you have all the information you need to make informed decisions and choices
- make sure your views and wishes are explained and fully considered by the authority you are dealing with, as well as making sure that your rights are understood and defended.



Good to know

Usually, an advocate will be instructed by you. This means that you should decide what they support you with.

Who pays for advocacy support?

Very often, support from an advocate is available free of charge.

In some situations, you will have a legal right to statutory advocacy services (see chapters 5 and 7 for details). You cannot be charged for these services.

2. Why independent advocacy is important

Helping you to get your voice heard

If you, your relatives and health and social care professionals have different opinions on what care or support is best for you, you may feel powerless or unable to voice your opinions. You may find it daunting or feel unable to influence 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. Sometimes you might feel able to do this yourself, but at other times 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 they can express them on your behalf.

The advocate will take the time to understand your situation, concerns and views. They should listen without judgement to you and provide a level of support that matches your wishes. Typically, this might include the advocate going with you to meetings or interviews to support you, or writing letters on your behalf.

Making decisions for people who lack mental capacity

Independent advocacy can be incredibly important for people who have lost the mental capacity to make decisions for themselves. Non-instructed advocates can act on behalf of people who have lost mental capacity – acting to make sure decisions are made in that person's best interests. See our factsheet **Manging my affairs if I become ill** for more information about making decisions in someone's best interests.

Non-instructed advocates can also act with or for people who are unable to give a clear indication of their views or wishes in a specific situation. See chapter 7 for more information.

3. What makes an advocate independent?

It's important that your advocate is different to the people who are employed to organise or give you care and support. This is so that the advocacy they provide is effective. 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 because they have to be loyal to their employer. As a result, your voice or views may not be heard properly.

Independent 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). They are usually employed by an advocacy organisation or charity. These charities are sometimes commissioned by councils but are run separately from the council and NHS. See chapter 9 for details of independent advocacy organisations.

4. What independent advocacy is and is not

Independent advocacy is:

- being on your side and respecting your wishes and feelings
- supporting you to speak, or speaking on your behalf if you can't or prefer not to
- providing information and discussing options with you
- 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 may be able to appear in court to speak on your behalf, such as at a Court of Protection hearing.



To do

If you need specialist legal advice about problems with care, you could contact Civil Legal Advice to find out whether you would qualify for legal aid (**0345 345 4345**, [gov.uk/civil-legal-advice](https://www.gov.uk/civil-legal-advice)). They can also give you details of organisations or solicitors dealing in legal advice about care.

Make sure you use a solicitor who specialises in the relevant area of law. They don't have to be local to you. Most specialist solicitors are experienced at working from a distance.

The Law Society website also provides contact details of solicitors (**020 7320 5650**, [solicitors.lawsociety.org.uk](https://www.solicitors.lawsociety.org.uk)). Free initial legal advice may also be available via a Law Works legal advice clinic ([lawworks.org.uk](https://www.lawworks.org.uk)) or the Disability Law Service (**020 7791 9800**, [dls.org.uk](https://www.dls.org.uk)).

5. Different types of independent advocacy support

The range of services available and who provides these services varies between areas. You can discuss which type of advocacy is best suited to your situation when you approach an advocacy charity.

See chapter 9 for details of organisations that offer advocacy.

Community advocacy

Community advocacy services support people whose issues fall outside statutory advocacy services. You don't have a legal right to community advocacy services, so these services are sometimes called non-statutory advocacy. Community advocacy is usually free.

There are different roles within community advocacy. Some community advocates are professionals or volunteers who work for an advocacy charity. Other community advocates may simply be family and friends who understand how advocacy works and who have been asked to support someone, perhaps during a crisis or throughout a longer period.

Formal community advocacy services are often commissioned by local councils, so what is offered may depend on what they can afford and who they decide needs the service most. Ask your local advocacy charity what services are available in your area.

Community advocacy services are most commonly used by people who are in a crisis and need some short-term support to resolve a particular situation. However, for people who need longer-term support, perhaps because they have difficulty managing several different aspects of their life, there are citizen or peer advocacy services, where you are partnered with someone from your local community who can work with you for as long as necessary and support you with a range of issues.

Example: Susan

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, help her to make a formal complaint through the council's complaints process.



To do

Contact Older People's Advocacy Alliance (OPAAL) (opaal.org.uk) to find a local advocacy service.

Issue-based advocacy

If you want to make a complaint about the NHS, or if you've experienced domestic, sexual or gender-based abuse, there are specific advocates who can help you.

NHS Complaints advocacy

An independent NHS Complaints advocate will be able to help you complain about treatment or care you have received from the NHS. This could include complaining about your GP, dentist, hospital or mental health services. NHS Complaints advocacy is free, independent of the NHS and confidential.

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. Services differ by area, so ask your local Healthwatch about what's available in your area (healthwatch.co.uk/your-local-healthwatch/list).

Example: Anita

While Anita was in hospital, her hearing aid went missing. No one helped her find it, despite her asking, which made her stay more difficult and stressful. She then had to pay towards the cost of replacing her lost hearing aid when she left hospital.

An NHS complaints advocate could help Anita make a complaint about her unhappiness at not being supported and having to pay towards a new hearing aid.

Domestic, sexual or gender-based violence advocacy

If you have experienced domestic violence, sexual abuse or gender-based violence and you need help to stay safe, there are specialist advocates who can provide practical and emotional support. You could get help from:

independent domestic violence advocates (IDVAs), who support victims of domestic violence

- **independent sexual violence advocates (ISVAs)**, who support people who have experienced sexual abuse or assault
- **independent gender-based violence advocates (IGVAs)**, who support victims of gender-based violence, such as female genital mutilation, 'honour'-based violence and human trafficking.

They can support you to create a safety plan, and work with different agencies involved in keeping you safe from further harm and/or pressing charges against the perpetrator.

Contact Refuge for information and help finding an appropriate advocate (**0808 2000 247**, refuge.org.uk).

Statutory advocacy services

In some situations, you have a legal right to an advocate to support you, and you should get help to arrange this. The sections below explain the circumstances in which you may be entitled to statutory support from a particular type of advocate.

Independent Mental Health Advocates

If you're detained under certain sections of the Mental Health Act 1983 or are a subject to Community Treatment Order or guardianship, you will qualify for support from an Independent Mental Health Advocate (IMHA). You must be helped to get an advocate.

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 your views and wishes heard and help appeal against a section. Mental health professionals must allow IMHAs access to certain parts of your medical records, if they're given permission by you to do so.

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.



Good to know

Detained patients who lack capacity to make certain decisions may also be eligible for an Independent Mental Capacity Advocate (IMCA). See chapter 7 for information about what an IMCA can do.



To do

Contact Mind (**0300 123 3393**, [mind.org.uk](https://www.mind.org.uk)) or Rethink Mental Illness (**0300 5000 927**, [rethink.org](https://www.rethink.org)) for more information and help to find an IMHA.

Care and support advocacy

Getting care and support from the council can be complicated. If you would have substantial difficulty in making arrangements with the council, then the council must ensure that you have advocacy support. This is also the case if there is a safeguarding issue involving the council. They may need to refer you for support from a care and support advocate (sometimes called a Care Act advocate).



Good to know

Carers who are eligible for support can also have a care and support advocate to help them in their carer's assessment.

You must be offered a care and support advocate if:

- you have substantial difficulty with understanding, remembering or weighing up information, or communicating what you want to say, and
- there is no appropriate person (like a friend or family member) to represent and support you.

An appropriate person should be someone who isn't paid to support you. They should have the ability and knowledge to be able to help you participate as fully as possible in the process, and they can only act as your appropriate person if you agree.



Good to know

Even if you have a family member or friend involved in supporting you, this doesn't mean they have to be your appropriate person.

Speak to the social worker if you disagree with their decision to make someone your appropriate person. Getting an advocate doesn't mean your family and friends can't still be involved, however.

If you qualify, the council has a duty to provide independent advocacy, not just at your care needs assessment, but also at other important stages of getting services, including:

- 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 – this is usually called a safeguarding enquiry or review
- when your needs are being assessed jointly with the NHS or clinical commissioning group and your local authority.

In some situations, even if there is someone who wants to support you, the council must appoint a care and support advocate, for example, if they are not satisfied that the person is acting in your best interests. If you don't want an advocate at this point, and you have capacity to make decisions about your care needs, then you can refuse their support.



Good to know

If you lack mental capacity to make decisions about your care, the council may have a duty to arrange an IMCA. For more information, see chapter 7.



To do

If you disagree with the council's decision not to provide you with an independent advocate, you can contact Independent Age to arrange to speak to an adviser (**0800 319 6789**).

Even if the council doesn't have a duty to provide you with an independent advocate, you might be able to get help from a community advocate. Ask your local advocacy charity or contact one of the organisations listed in chapter 9.

Example: Arjun

Arjun's father has short-term memory loss and needs some support to help him manage at home. Arjun lives far away from his father and works full time – his father has no other relatives or friends living nearby.

Arjun contacts the local council to request a care needs assessment for his father and raises his concern that he cannot be present to support his father. The council agrees with Arjun that his father has substantial difficulty understanding and remembering information relating to the assessment process and may not be able to express his views or opinions as a result.

As there is no other appropriate person to support him, they arrange for a care and support advocate to meet with his father before the assessment to discuss the process and his situation. The advocate also supports him during the assessment itself.

6. How does independent advocacy work?

Step one: Meeting your advocate

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 will usually, for security reasons, notify the care home manager, charge nurse or warden of their planned visit. They should explain:

- their role
- how they can support you
- what the advocacy charity does
- the confidentiality policy of the charity they work for.

Step two: Instructing your advocate

Instructing an advocate simply means explaining to them what you want them to do. They need to understand the situation you are asking for support with, and how you want to try to resolve it. It can help to give the advocate an overview of what others involved in your care, such as your GP, carers, social worker and family think. They can look at any letters and documents you have been given, as long as you give them permission to do so. However, the advocate should focus on understanding your view about the situation and what you want to happen.

The advocate will usually create a plan with you that documents the problems and what steps you will take together to address the issues you bring up. You can change this plan at a later date, if you wish. You will usually be asked to sign the plan to show you're happy with it, and your advocate will usually also sign the plan and actions they have agreed to undertake. Your advocate should make sure you're fully informed of any developments to the situation.

Step three: Speaking out

If you're instructing the advocate, they should always work within the plan you created with them. (There are some types of advocacy where someone isn't able to give their permission – see chapter 7). They shouldn't do anything they haven't agreed with you. 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 highlight that you are legally entitled to the things that you would like to happen, for example, if you have a right to a care needs assessment from your local council.

Who is in charge in advocacy work?

In instructed advocacy, 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.

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. In some situations, they could also remind professionals of their legal duties – for example, if they have a duty to provide you with certain information or advice. If necessary, they could make a formal complaint on your behalf.

7. Advocacy for people who lack mental capacity

What is mental capacity?

Mental capacity means having the ability to understand, remember and use information so you can make and express decisions about your life.

Wherever possible, people must be supported to make decisions about their lives before assessing whether they might lack capacity to make that decision. However, even with support, some people may still be unable to make a decision.

You are considered to lack mental capacity if your mind or brain is impaired in any way and 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.

Loss of mental capacity isn't always permanent. It could be temporary or change over time. Some people may have capacity to make some decisions but not others. Any formal assessment of capacity should look specifically at the decision being considered at the time it needs to be made.

It should never be assumed that someone doesn't have mental capacity to make a decision. Even if someone makes an unwise decision, that doesn't necessarily mean they lack capacity to make the decision.

When someone lacks capacity to make a decision at the time it needs to be made, there is a legal duty to make a decision for them. This is called making a 'best interest decision'. Where there are several options in the person's best interests, the decision made should be the one that affects the person's rights and freedoms the least. See our factsheet **Managing my affairs if I become ill** for more information about the process for making best interest decisions.

What does a non-instructed advocate do?

As part of making a best interest decision, professionals should identify and take into account the person's beliefs, wishes and feelings as well as any past wishes. Non-instructed advocates work to identify what these are, protect the person's right to be involved in decisions about their life and make choices where possible. The advocate doesn't make the decision themselves.

Non-instructed advocacy methods vary, but usually include:

- trying different ways to communicate with the person, and involving them as much as possible
- treating the person with respect and spending time with them to understand their wishes, feelings and preferences
- gathering information about them, for example, by speaking to people who know them well, and building up an idea of their beliefs, preferences and past wishes
- ensuring the person's views are heard in decisions about them so they are given equal treatment and access to services
- ensuring every possibility is looked at and that their human rights have been considered and are protected
- challenging decisions that do not appear to be in the person's best interests and/or are overly restrictive.

Independent Mental Capacity Advocates

An Independent Mental Capacity Advocate (IMCA) supports and represents people who lack capacity to make some important decisions. An NHS body or local council must appoint an IMCA if:

- someone lacks mental capacity, and
- they don't have any family or friends that can support them, or where it would be inappropriate or impractical to consult them, and
- a decision needs to be made about serious medical treatments or a long-term change to where they live, or
- they are being assessed for, or are subject to, a Deprivation of Liberty Safeguards authorisation.

The NHS or council may also decide to appoint an IMCA in other situations, for example, if there are safeguarding concerns or their care review is considering a change of accommodation.

The IMCA will meet the person they're supporting and get the views of family, friends and professionals caring for them. They can also consult relevant health and social care records. They will consider all the information and then write a report to help decision makers act in the best interests of the person.

An IMCA must have specific experience and training. The Social Care Institute of Excellence has a list of IMCA providers (**020 7766 7400**, [scie.org.uk/mca/imca/find](https://www.scie.org.uk/mca/imca/find)).



Good to know

If you qualify for IMCA support, you will usually also be eligible for a care and support advocate for other social care decisions.

Example: George

George had a bad fall in his flat and had to be admitted to hospital. George has dementia and received two visits a day from carers. He was more confused than usual in hospital and couldn't remember all the details about what help he might need. The hospital was busy and the doctors felt it was in George's best interests for him to continue recovering in a residential home, while the council decided where he should live. George wanted to return home, but didn't want to contradict medical advice and agreed to move to the residential home.

When George arrived at the residential home, he found it difficult to adapt to the environment and he wanted to return home. When he told his carers, they said he couldn't because he might fall again without support. However, they spoke with the council and asked them to assess the restrictions George was under while he was living in the residential home. The council appointed an advocate (an IMCA) for George. The advocate talked to George about his care. While George wasn't able to fully tell the advocate what care he might need at home, he made it clear that he wanted to return home.

The advocate asked the council to urgently reassess George's care needs and look at what options were available for him to live in a less restrictive manner at home. The advocate asked for a best interest meeting to discuss George's concerns. His social worker suggested that George's care needs could be met at home with support from carers four times a day, and a personal alarm. The advocate spoke with George, who said he would be happy with this. The advocate relayed his view to the social worker, who liaised with the homecare agency and got a company to install the alarm. George returned home two weeks after the meeting.

Other advocacy support for people without mental capacity

Depending on your situation and the issue you need support with, you may be offered a different type of advocate to an IMCA – for example, a care and support advocate may be the appropriate person to support in certain circumstances (see chapter 5).

8. 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 be clear about your wishes, for example, when talking to your health professionals. These schemes may bring together groups of people who use the same services or are affected by the same issue. This may be an option if a group of you are affected by the same issue (for example, a residents' group in a care home).

Anyone can set up a self-advocacy scheme. Some charities offer support with them. Your local Healthwatch can help you find advocacy services near you (**03000 683 000**, [healthwatch.co.uk/your-local-healthwatch/list](https://www.healthwatch.co.uk/your-local-healthwatch/list)).

9. 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 should be able to tell you about independent advocacy services.

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

Age UK advocacy services

Some local Age UKs have an advocacy service (**0800 169 6565**, [ageuk.org.uk](https://www.ageuk.org.uk)). It's free, confidential and impartial. Ask your local Age UK if they offer an advocacy service.

Mind

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

National Coalition of Advocacy Schemes

The National Coalition of Advocacy Schemes promotes and supports informal community-based advocacy (citizen advocacy) schemes (**07821 688454**, [advocacynatcoalition.org.uk](https://www.advocacynatcoalition.org.uk)).

Older People's Advocacy Alliance (OPAAL)

Older People's Advocacy Alliance (OPAAL) is a national organisation supporting, promoting and developing independent advocacy services for older people (opaal.org.uk). OPAAL has an online database of local independent advocacy schemes for older people (opaal.org.uk/locations).

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 ([nhs.uk/service-search/other-services/Patient-Advice-and-Liaison-Services-\(PALS\)/LocationSearch/363](https://nhs.uk/service-search/other-services/Patient-Advice-and-Liaison-Services-(PALS)/LocationSearch/363)). PALS may also be able to advise you on local advocacy schemes.

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The sources used to create this publication are available on request. Contact us using the details below.

Thank you

Independent Age would like to thank those who shared their experiences as this information was being developed, and those who reviewed the information for us.

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