



Taking Control

A guide to self-advocacy

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Rethink
Advocacy



What is advocacy?

Advocacy is taking action to help people say what they want, secure their rights, represent their interests and obtain the services they need.

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So, what is self-advocacy?

Self-advocacy is being able to speak up for yourself and being able to ask for the things that are important to you. Self-advocating is saying what you think and asking for what you want and need, this is because you know you best and people need to listen to you if you are not happy or you want something to change.

Why is being able to speak up for yourself important?

It is important because if you are not happy with the way something is done or the situation you are in then people making decisions about your life have to listen.

Speaking up for yourself means you will be able to:

- take responsibility for yourself
- make sure people are listening to you
- say what you think and feel
- speak up for your rights and the things you believe in
- make choices and decisions that affect your life
- decide what you want and then plan to get it.

Here are a few examples of when being able to self-advocate is useful:

- When you are going through an assessment or review process, for example, care planning
- When you want to make a complaint
- When you are unhappy about your medication and want it reviewed or changed
- When you feel you are not being listened to.



To self-advocate you will need to:

- know what you want to achieve
- be confident to say what you want
- be confident to make decisions for yourself
- understand your own strengths and weaknesses as there will be some things that you do not feel able or comfortable to do on your own and you need to think about who can help you.

What might stop you from self-advocating?

- Finding it difficult to assert yourself; not being confident to say what you want to people, particularly those in positions of power
- Being worried about how you communicate with people and finding it difficult to get your views across
- Not having the knowledge to make a strong argument
- Being worried about what might happen if you speak out
- Not being used to speaking out or actually having people listen to you



It is important that you think about what skills you might need to work on to help you self-advocate more effectively and see if you can find ways of developing those skills.

Assertiveness and self-confidence

There are many resources on the internet to help you think about being more assertive. Often it is simply having the confidence to speak up when you know the person you are talking to does not think the same.

The situation

A friend has made plans to go shopping with you on three occasions and has cancelled each trip at the last minute.

Non-assertive response would be...

Would be not saying anything at all or saying “yes that is fine”.

An unhelpful response would be to get angry as this could result in you losing your friend completely.

Assertive response would be...

We have made plans to go shopping three times and every time you have let me down at the last minute. As I had arranged my weekends around these trips, it left me with nothing to do. If we make another arrangement and you have to cancel, please can you let me know well in advance so I can make other arrangements.

Having the knowledge

- knowing your rights

Before you start to self-advocate and decide who you need to go to with your issue, you will need to understand if you have rights under English Law, or organisational policies.

For example, your issue may be a Human Rights issue or an Equalities issue in which case you need to understand the law. It might be a complaint about how an organisation's policy is being applied to you. If you are unsure and need to find out if you have rights, you can use the internet, or you can contact local organisations who can help you, like Citizens Advice.

The British Institute of Human Rights has an online toolkit that you can use to help you work out if the issue with your care or treatment is a Human Rights issue or not. You can access this at bihr.org.uk

Rights or preferences

Some of things you might want to change are individual preferences. Although everyone is entitled to say what their preferences are, if you have no rights under law or a policy it is possible your request will not be met.

An example might be that you are requesting a change in care worker just because you prefer someone else on the team.

Although the decision maker will need to consider your request, if there are reasons why this cannot be accommodated then the request can be refused without breaking any law or policy.



How do you self-advocate?

Have a plan

Having a plan is important because it helps you think in a logical way. By really thinking about what you want and how you can get it, the actions you will need to take will become clearer. Having a plan will mean you are more likely to resolve the problem quickly.

When you are making your plan, you will have to think about the people you need to speak to and the best way of doing this. You will also have to think about the actions you will need to take. Examples of some actions are:

- making phone calls
- going to a meeting
- writing a letter of complaint, or
- filling in a formal complaint form

You don't have to make your plan on your own. Asking someone else to help you might help you do it more quickly and easily. You will find an example **self-advocacy plan** at the end of this booklet. Some of our advocacy services also offer self-advocacy workshops. Please check our website rethink.org for services near you.

The **self-advocacy plan** will help you think about the problem step by step; breaking it down in this way will make it seem more achievable. You may have lots of things in your life you want to sort out but remember it is easier to focus on one issue at a time and it will feel less overwhelming than trying to deal with everything at once. If you have more than one issue that you want to resolve, then you need a plan for each one as the approach on how you tackle them is likely to be different.

To complete the self-advocacy plan you will have to think about the following:

1. What is it you want to speak up about or change?
2. What do you want to achieve? Have you considered solutions to the problem yourself?
3. What facts do you know?
4. What additional facts or information might you need regarding this situation, such as laws, rules or policies?
5. How can you go about gathering this information?
6. Is there anyone who can help you?
7. Who will you need to speak to (who is the person that will be making the decision)?
8. What will you do if the plan doesn't work?

Effective communication

As well as having an effective advocacy plan, it is important to plan how you communicate what you want to say whether that is face to face or on the phone. If you are not a very confident communicator, being prepared for meetings or telephone calls is very important. Writing down what you want to say before going to the meeting or making the call will help you clearly state what you want to say.

If you are going to a meeting, and are nervous about going on your own, try and take a friend with you who can help you keep on track and make sure you get your points across.

While you are self-advocating it is important to keep a record of what you are doing so you know what was said and what actions were agreed.

This is very important if you need to follow an appeal process or the issue you are dealing with goes on for a long time as it can be hard to remember things that happened a while ago.

Always keep notes of all conversations that you have regarding the situation. Your notes should include the following details:

- date and time of contact
- full name of the person(s) you saw or spoke to
- the person's job title
- who they work for, for example, the council or the GP surgery
- their telephone number, and
- a brief note of what was discussed and any agreed actions.

So, if someone says they will call you back in a weeks' time you have a record of this and will remember when to follow it up. At the back of this booklet you will find an example Contact Record for recording all of your contacts, whether by phone, email or face to face.

Do's and don'ts for effective communication



Do Show positive body language

50% of our communication is non-verbal, this includes body language. So be aware that your body language will be sending signals to the other person.



Do Think before you speak

Think about how what you are going to say might affect the person you are talking.



Do Try active listening

Being able to listen to what a person is saying is a skill; focus on listening to what people say, this will help you understand what people are saying to you. Showing you are listening also tells the person that what they are saying is important to you.



Do Stick to the point

Try to stick to the topic of discussion so what is being said is relevant.



Do Be confident about what you are saying

You are entitled to your view, especially when decisions are being made about you, so believing in what you are saying will help make it come across confidently.



Do Think about your tone

Think about your tone, before speaking. Sometimes, it is possible to come across as too assertive, abrupt or blunt. Responding to something you don't agree with in a stropky or blunt manner can lead to the other person responding in the same way. This can increase the risk of a confrontation.



Do Be open to feedback

Communication is a two-way process. Try and accept feedback, reflect on what you are being told and think about how you might be able to get your views across in a different way if the person says they do not understand you and if you do not understand clearly what people are telling you. Ask them to explain it differently and don't be afraid to ask someone to speak in more simple language or more slowly.



Don't Interrupt people

It is very rude to interrupt a person while they are speaking. If you really feel you must interrupt someone try to do it politely. Say "excuse me" and ask the person if you can interrupt, remember whatever you want to say must be important enough to justify your interruption.



Don't Be confrontational or abusive

It can be easy to get angry if you feel people are not listening to you or you may feel very defensive if you think what someone is saying to you is wrong. Try to listen to what is being said and control yourself to respond in a calm way. Shouting over other people will not mean your point of view is heard over others.

Making a complaint

One of the most common ways of self-advocating is making a complaint. If you have had a poor experience you might want to make a complaint.

All organisations will have a complaints procedure which you will need to follow to make a complaint.

The process could involve making a complaint by phone, or in writing by email or post. You can make complaints verbally and no organisation should refuse a complaint if it is not in writing, especially if you have difficulty writing things down.

You may want to complain if you feel that a service:

- has not treated you with respect
- has given you the wrong care or treatment
- did not help you quickly enough
- did not do enough to help you, or
- was taken away sooner that it should have been

When you make a complaint make sure you explain:

- what has happened
- why you are not happy, and
- what you would like to happen next.

Making complaints is important because it could help make things better for you or other people in the future. There is often a time limit for making complaints, so you will need to check with the organisation you are complaining to what the time limits are.

If your complaint is about an NHS service, then you may be able to get some support through your local NHS Complaints Advocacy Service. Your local NHS Trust will be able to tell you who provides this service in your area.

At the end of this leaflet you will find a sample Complaint Letter that you could use when raising a complaint. This could also be used to help you plan out your complaint if you have to make the complaint verbally.

You can find further sample complaint letters on the Citizens Advice website at [citizensadvice.org.uk](https://www.citizensadvice.org.uk).



Finally...

Sometimes self-advocating can be challenging as you may be putting yourself into situations where there could be possible conflict. In these situations, it is important that you consider how you will look after your own wellbeing.

There is a lot of information available to help you manage your wellbeing and details can be found in the useful resources section at the back of this booklet.

Remember, although self-advocating may be hard, it will also be rewarding. Even if you do not always get the result you want, you will have had the opportunity to have your say and been listened to, which is a very powerful and satisfying thing to do.



Top tips for self-advocacy



- 1 This is your life and you have a right to be in control, be listened to and have choices.
- 2 Try not to be intimidated by authority; learn to question responses that you do not agree with.
- 3 Always try and deal directly with the person who makes the decisions.
- 4 Don't give up because the person you are dealing with does not have the power to make the change you are requesting.
- 5 Find out who does and go up the 'chain of command'.
Always ask for decisions in writing.
- 6 When you get official letters always read the small print carefully.
- 7 Always get the name of any person you are dealing with and record the date, time and detail of the conversation.
- 8 See if you can find local organisations that could help you, like Citizens Advice, Age Concern, Alzheimer's Society etc. or any other organisations who support people on low income, elderly, or people with disabilities.
- 9 Often you will have the right of appeal so make sure you use this right, and make sure you do it in the right timescale.
- 10 Don't be afraid to make mistakes, this is how we learn.

Sample contact record



Date and time	Type of contact e.g. phone, email etc	Name of person and their job title

Notes of conversation	Agreed actions and who is responsible	Date to be completed by

Sample Contact list



Name:	
Job title:	
Organisation:	
Phone:	
Email:	

Name:	
Job title:	
Organisation:	
Phone:	
Email:	

Name:	
Job title:	
Organisation:	
Phone:	
Email:	

Sample advocacy plan



**What do I want to speak up about or change?
This is my advocacy issue (stick to one issue per plan)**

I want to complain about the fact that Joe Bloggs has not completed a proper care plan for me and so I am not getting the services that I need to help me manage on a day to day basis, and it is affecting my health which is getting worse.

What do I want to achieve? What is my goal? Have I considered if there are any solutions to the problem myself?

1. I want my care plan reviewed
2. I want more activities and opportunities to help me get out and about

Is there anything I need to think about that would stop me from getting this? What can I do about it?

I don't feel confident writing letters, but I can see if I can find someone to help me write them. I feel intimidated by people in authority, but I feel strongly that I am entitled to better services, so I need to try to be confident to say that I am not happy.

I am not sure where to go to find out information about what I am entitled to, a lot of it is online and I am not good with computers. I can see where I can get help using a computer, like at the library.

Is there anyone who can help or support me? (e.g. to write letters, attend meetings or provide moral support?)

1. My wife and my daughter have said they can help me write letters.
2. My daughter is happy to come to a meeting with me.
3. My son in law says he will come to the library with me to find information online and he said will ring the local Citizen's Advice office for me.

Who do I need to contact to resolve my advocacy issue? (this will be the person who will be helping with the decision)

Organisation: Community Mental Health Team
Role: Complaints Manager
Name: Sue Smith
Contact Details: 01234 567891

Is there a process I need to follow? For example, a complaints appeal procedure? Have I got a copy of the complaints policy?

There is a local authority complaints procedure, I can find this on their website, but Alice Jones on the Council switchboard said they could send me a copy.

What method of communication should I use? What will be the most appropriate way for me to address my advocacy issue?

Write a letter and send a copy in the post and by email to the Complaints Manager.

Do I have rights (laws or policies) which could help me get what I want? What are they?

The Department for Health's 'Refocusing the Care Programme Approach and Guidance' says I am entitled to a clear plan when I am getting help under the Care Programme Approach. Page 18 of the guidance says that: "The assessment and planning process should aim to meet the service user's needs and choices and not just focus on what professionals and services can offer. It should address a person's aspirations and strengths as well as their needs and difficulties." I do not believe that the CMHT are supporting me in this way and my illness is worse.

Do I have rights (laws or policies) which could help me get what I want? What are they?

1. A copy of the letter I had from Joe Bloggs after my second meeting with him when I asked about my care plan.
2. A copy of the letter I sent in November 2022 explaining that my health was getting worse as proof I have asked for help before.
3. A copy of The Department for Health's 'Refocusing the Care Programme Approach and Guidance'.

Sample complaint letter



Private and Confidential

COMPLAINT

[Your name] [Your address]
[Day] [Month] [Year]

Complaints Manager
[Service you are complaining about]
[Address]

Dear Sir/Madam,

Complaint – Lack of a care plan

I would like to complain that my care coordinator, Joe Bloggs, has failed to complete a care plan for me. I feel that I have not had the services I am entitled to, and my health has deteriorated as a result.

My difficulty getting a care plan

I started getting help from your service in April 2022. Joe Bloggs became my care coordinator. Since then, I have asked about getting a care plan on the following occasions:

- April 2022 – When I first started with the team,
- May 2022 – On my second meeting with Mr Bloggs,
- June 2022 – September 2022 – On every further meeting with Mr Bloggs,
- November 2022 – I wrote to Mr Bloggs explaining that the lack of a care plan was having an effect on my health, and I did not get a response.

I have enclosed a copy of the letter I sent to Mr Bloggs in November 2022.

I have still not had a care plan, and Mr Bloggs has said that I could be discharged from the team because I have not seen him since November 2022.

As you will be aware, the Department for Health's 'Refocusing the Care Programme Approach' guidance says that I am entitled to a care plan when I am getting help under the Care Programme Approach.

The effect on me

This situation has affected me in the following ways:

- [My recovery from my illness has been set back]
- [List any other concerns depending on your situation]

What I would like

As a result of this complaint, I would like:

- [List what you would like]
- [An explanation about what my diagnosis means],
- [An apology from the staff who said inappropriate things].

I look forward to receiving your acknowledgement of this letter. I would like you to carry out a full investigation into my concerns and provide a response in accordance with your complaints procedure.

Yours faithfully,

[Your name]

Support and information



Rethink Mental Illness provide a range of resources on mental health, living with mental illness, support for carers and information about rights. rethink.org.uk



Citizens Advice provide a range of advice on benefits, work, debt and money, consumer rights, family, housing, law and courts, immigration and health at citizensadvice.org.uk



Age UK offer information and advice on money and legal, health & well-being, care and support, travel and hobbies and work and learning at ageuk.org.uk



Carers UK provide information and advice on benefits and a range of other support for anyone who is a carer. carersuk.org



Mencap (the voice of Learning Disability) provide a range of information and advice including benefits, transport, employment, health and the Mental Capacity Act at mencap.org.uk



British Institute of Human Rights their "Know Your Human Rights" tool aims to support people with mental health and/or mental capacity needs to know when their rights might be at risk and how to use the law to resolve these issues. bihr.org.uk



Alzheimer's Society offer a range of information and advice for people with dementia and their carers including legal and financial. alzheimers.org.uk

This is not an exhaustive list of support available. In addition to national organisations, there will be local charities who may be able to help you. Your local authority should be able to provide you with information on local support available to you.

Rethink Mental Illness is well known as a leading provider of services for people living with mental illness.

We also run a number of advocacy services across England providing advocacy under The Care Act, The Mental Health Act and the Mental Capacity Act.

Our advocacy services offer support to a wide range of people, including people with learning, physical and sensory disabilities, as well as mental illness. An advocate is usually provided to people who have no one else to help them and who need support with issues related to care and support needs.

Many of our advocacy services also offer community, peer and citizen advocacy for people in the area. More details about services near you can be found on our website at rethink.org.

Rethink

Advocacy

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rethink.org

Leading the way to a better
quality of life for everyone
severely affected by mental illness.

For further information
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