

Introduction:

Self Advocacy

Self-Advocacy is basically voicing or making your wishes known to get what you need or request that something changes in order to make your life better. Most of us have self-advocated in some form throughout our lives, even just telling a loved one how you are feeling and asking them to do something for you – it might be small things, but we may struggle to do it effectively when we're trying to get the right care and treatment for our mental health or physical health needs.

The aim of this toolkit is to help you to develop the skills and approach to become an effective self-advocate. It aims to help you to identify what information and support you might need, how to get it, and how it will improve your life. The majority of this toolkit focuses on informal ways to getting your voice heard and achieving your goals because that is usually the most effective way to resolve issues, discussing with the person/professional who can do something to change things, or fix the issue.

These tips and guides can be used for any circumstances, but in the below examples we are looking at how to use them to access treatment for mental health and physical health related issues.

Creating a plan:

Having an idea about what you want to achieve or what outcome you'd like to see is a key step in self-advocacy, and this worksheet can support you to think clearly and make a plan of what actions you'd like to take and what the desired outcomes are.

The first step in self-advocacy is to identify what you need and want and the steps you will need to take to get there - to develop a plan. It is best to identify and work through the starting point of where you are now, what outcomes you want to achieve, and what steps you need to take to get to the outcome. It is also good to think about alternative outcomes too. The most important thing to remember is that ***you are the expert on your needs and conditions!***

Self advocacy planning tips:

Take notes of phone calls you make and receive in relation to your issue. Record the date, time, name and their contact details.

Ask for any decisions made by professionals to be put in writing, including the reason why they made that decision.

Try to put any medical/treatment requests in writing to the hospital or service, and keep a copy yourself.

At any appointments, take notes and write down any actions that professionals have agreed to do. Ask them to confirm their actions in a letter to you, and any timescales.

Be as prepared as you can, take your time, and keep all paperwork/notes in a safe place.

Don't be afraid to be persistent, and assertive. If you are unhappy with the outcome or response, you can escalate this to a manager.

Additionally, the NHS and Local Authorities have a hierarchical structure, so you can escalate your concerns upwards.

All NHS Services have access to a PALS service, who you can contact if you are unhappy with your treatment or appointment.

If you are unhappy with treatment from a GP, you can request to see another GP in the same practice. Ask for a GP who specialises in your condition.

There are Independent NHS Complaints services in most regions, who can help you to complain and exercise your rights.

Don't be afraid to ask for help. There are services out there to assist you with complaints and concerns, most of these services are free of charge too.

Navigating your self-advocacy journey

What is the issue? What would you like to change?

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What is your goal? What outcomes would you like to achieve?

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What information do you need in order to achieve your goal or outcome? Where can you get that information?

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What support might you need to achieve your goal? Where can you get that support? Who can help?

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Who is the decision-maker's (for example, GP/CPN/Consultant) that you need to influence to achieve your goal? What actions can you take? Who do you need to speak to?

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I will call/meet with/write to by the following date:

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If the person does not resolve the situation by the following date then I will call/meet with/write to.....

Documents/reports/letters/correspondence that I will need to progress my issue or take with me:

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What is my alternative plan if the above steps don't work or achieve my desired outcomes?

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Appointment plan:

Appointment Date:

Place:.....

The appointment is with:

What is/are their role(s)/job title(s):

Reason for the appointment:

Questions/Points I want to raise/Symptoms I want to mention:

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Information I need to take with me:

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Appointment actions record:

Treatment/action plan:

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Who is responsible for the treatment/action plan:

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What is the timeframe for the treatment/action plan:

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Date and time of the next appointment:

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Tips for making a phone call:

State your name and what you need – be brief – it is often helpful to have a sentence or two written down for the initial conversation.

If the first person you speak to can't help you – ask to be put through to someone who can.

If the person you need to speak to is not available – ask when they will be so that you can ring them at a more suitable time, or ask to leave your details for a call back.

Ask for the direct dial number of the person you want to speak to, so you can avoid having to go through reception/another person each time.

Make a note of the name and role of the person you are speaking to. Keep a record of the date, time and service you called. Write down the telephone numbers.

Try and keep calm and clear on the phone even if you are upset and frustrated. Focus on your goal and the outcomes you want to achieve. **Don't forget to listen!**

Always be polite – the person who answers the phone and to the person who is responsible for making the decision. Often services have 'zero tolerance' policies.

If people don't ring you back or the situation is not resolved – ring again, don't be afraid to escalate to a manager or senior person.

If you are unsatisfied with the result of the call:

Ask why the person can't help. Write down the answer they give you. Ask for them to put that decision in writing to you along with the reasons. Ask if there is another agency/person that may be able to help you.

If the person you speak to is rude or unpleasant – ask to speak to their Line Manager.

Tips for attending a meeting or appointment:

You might be going to your GP or CMHT to discuss your mental health for the first time or to ask for a referral to another service, or you might be meeting with your psychiatrist to request a referral for more intensive and specialist treatment. It's essential that you're prepared; that you have an overall plan - the following questions and tips can ensure that you get the best from any meeting or appointment you might attend.

- Plan out your expectations: What outcome do you want? Feel free to use the planning sheets above.
 - What information do you want to get across? What questions do you want to ask and have answered?
 - Who is going to be present in the meeting? What are their roles? Why are they there?
 - Where is the meeting taking place? Is that somewhere you can get to? Would you prefer a 'virtual' meeting online, or a telephone meeting?
- ❖ Consider taking someone with you both for moral support but also to help you to self-advocate – they can act as a prompt if you forget to ask something, they can be

helpful for remembering who said what in the meeting and they can make notes during the meeting of the main points discussed and any actions agreed.

- ❖ Have the points that you want to raise written down in front of you so that you can see them in the meeting.
- ❖ Try to find out who is going to be at the meeting - names and role descriptions. If you have concerns about anyone being at the meeting - don't be afraid to ask the reasons for them being there or request that they leave.
- ❖ Be punctual – make sure you know where you're going and how to get there.
- ❖ Don't forget to take any documents with you that might be relevant.
- ❖ When the meeting starts, if there are no formal introductions, ask for people to introduce themselves so that you know who everyone is. Are there people at the meeting that you weren't told about? Don't be afraid to ask for them to leave if they are not directly relevant to your care & treatment.
- ❖ Don't be put off by authority figures. Be polite but don't be talked over - if this happens, wait until the person stops speaking and then make your point.
- ❖ Monitor how you're feeling - do you need to ask for a break?
- ❖ Don't be afraid to make notes in the meeting about what is being said/agreed - particularly the responses to the specific questions that you wanted to raise and who responded.
- ❖ If you don't understand or aren't clear what is being proposed by the people present, ask for clarification e.g. if you're going to be referred for treatment: clarify who's going to refer you, how soon are they going to make the referral, what's the treatment, (is the referral dependent on securing funding, how does that work, etc), who's going to treat you – what's their expertise in treating your mental health condition and related disorders, what are the waiting times like, what support will you get in the meantime, who will keep you updated with developments?
- ❖ Don't forget – you don't have to agree to anything there and then – if you want time to think about things or talk through treatment suggestions with family and friends, ask for that time and agree a timeframe for telling the meeting attendees of your decision.
- ❖ If there hasn't been enough time for you to say everything you wanted to say and you have felt rushed, then you could ask for a follow-up meeting or send a letter with your additional concerns/points and request a written response, again ask for a

timeframe of how long you should expect to receive a response.

- ❖ As the meeting is coming to an end, try to summarise to those that are attending, your understanding of what has been agreed or ask them to do so for you.
- ❖ Don't forget to ask for timeframes for any actions agreed at the meeting/appointment.
- ❖ Depending on the type of meeting/appointment you might want to ask for minutes from any meeting to be emailed/posted out to you or you could email your own summary of the meeting to the professionals involved in the meeting, and those who supported you to self-advocate.
- ❖ Don't be afraid to ask about follow up appointments, and when to expect the next appointment to be.