



INTRODUCTION TO SELF ADVOCACY



**A handy toolkit for anyone who wants to
have their voice heard**



The Essential Self Advocacy Toolkit was co-produced with The Stanleys Self Advocacy Consultation Group.

Stanleys Community Centre is a registered charity that provides advocacy and self advocacy advice to people in Morecambe and Heysham. Stanleys say; "We aren't just a community centre, we are a grass roots charity, supported and led by the people of the West End of Morecambe."

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INTRODUCTION

In this toolkit you will find tips and ideas to help you speak up for yourself and start your self advocacy journey. It has been created by people from Lancashire, who all have personal experience of struggling to be heard when trying to get the services and information they need. The toolkit is full of tips and ideas to help anyone on their self advocacy journey.

Advocacy Focus supports people when they have health and social care issues and don't feel they are being heard or that their views are being respected. The three steps to self advocacy outlined in this toolkit can be used in every area of your life when you feel you are not being heard.

The three steps are:

Knowledge. Skills. Confidence.

A unique aspect to the Essential Self Advocacy Toolkit is the Self Advocacy Charter created by the Stanleys group. The charter sets out the core principles of being a self advocate. It asks professionals to understand it, respect it, and take the views of self advocates seriously. It acknowledges that we can all get better at expressing ourselves and become more confident. The toolkit recognises that there are significant barriers to self advocacy, many of which, were identified by the individuals who supported us in creating this toolkit.

This toolkit focuses on becoming a self advocate within the health and social care world, however, the tools and approaches can help you to speak up, be heard and be respected in every area of your life.

Self advocacy and the purpose of this toolkit, is for you to decide what you want, then develop and carry out a plan to help you get it. You can take control of your own health and wellbeing and ensure that the self advocacy approach is agreed and supported by professionals you are working alongside.



WHAT IS SELF ADVOCACY?

When important decisions are being made about your life, Advocates stand by you to help you understand your rights and what you are entitled to. Advocates support you to make your own decisions, express your views and be heard.

Advocates know that you are the expert of your life – they will support you to express your wishes and feelings and take control of your situation.

Advocacy is having someone on your side when important decisions are being made about you. An Advocate cannot tell you what to do, only you can make decisions about your own life. An Advocate will inform you of your rights and what you are entitled to, but cannot promise that you will get your desired outcome. An Advocate will support you to be listened to and have your wishes and feelings respected and acknowledged.

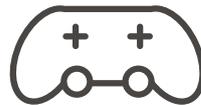
SELF ADVOCACY IS:



Learning about your rights



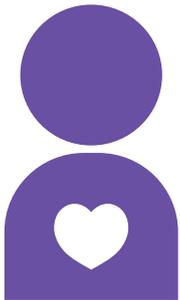
Speaking up for yourself so that you are heard



Taking control and making decisions about your own life



Accessing the information you need



- *You are an expert in your own life and should be involved in any decision that affects you.*

Sometimes it can be difficult to speak up for yourself; especially if you are not feeling very confident, feel afraid, or are unable to communicate in a way professionals understand. See page 54 for further professional help and support.

If you would like to learn the basics of self advocacy and how to advocate for yourself, then continue reading. We will help you understand the three core principles to being your own best advocate and our Tools section will then help you practise everything you've learnt.

➤ Summary:

Self advocacy is about gaining the knowledge, learning the skills and developing the confidence to communicate what's important to you.

BEING A SELF ADVOCATE

By Kirsty Heath

I care for my dad and fight his corner. In my head, getting him what he needs is most important. All my attention is on him. I do find it hard to say no to him but by doing that, I'm forgetting about me.

Being a good self advocate is going to meetings on my own, standing up for myself and fighting for my rights in any situation. Self advocacy gives me the skills and knowledge to become more assertive about my needs and things I want.

But being a self advocate isn't easy. People may say they find it easy - for them it might be. But for many people it's hard to do even simple things, like making an appointment or a simple phone call.

Learning self advocacy skills helps us move forward in our lives, the skills that we learn and practise will help us become strong people. I learned about advocacy when I was getting no money at all and not taking care of myself because my dad always came first.

I came to Stanleys Community Centre because I didn't know where to turn and it was all getting too much for me. I got the help I needed and now I want to learn those skills so I can do things myself.

I have helped to create this self advocacy toolkit to help you on your journey. I hope you find it useful.

Best wishes, Kirsty



"For many people it's hard to do even simple things, like making an appointment or a simple phone call."

THE SELF ADVOCACY CHARTER



KNOWLEDGE

SKILLS

CONFIDENCE

The Self Advocacy Charter is made up of three steps that can help us to improve the way we communicate. It was first drafted by The Stanleys Self Advocacy Consultation Group.

"I would like to be given the chance to speak up for myself and realise the more I do this, the better I will become. I am not a trained professional, but I know that I am responsible for my own actions and want to get better at using my self advocacy skills. As a self advocate, I am learning about human rights and I am committed to speaking up for myself and others."

- I will make sure I'm fully clued up so I can speak clearly for myself.
- I will have a clear understanding about my issues and my goals.
- I will ask you to avoid any unnecessary jargon so I understand.

KNOWLEDGE

- I will do my best to keep calm and listen to what you are saying to me. I ask that you also listen to me.
- I will try to lead the process as I see myself, as the expert of my own life.
- Every time I speak up for myself, I hope to build on my successes and my failures, to develop my self advocacy skills and my self-esteem.
- I am aware that my personal life experience might cause me to have prejudices about people, including professionals involved in my life. Knowing this, I want to treat everyone fairly and respect that we all have different views.

SKILLS

- I ask that you are respectful and don't judge me.
- I expect confidentiality and my business to be kept private.
- I may wish to use self advocacy tools, such as the Self Advocacy Speaking Out Cards.
- I am part of a wider network of people learning to speak up for themselves and will support others who are self advocating.

CONFIDENCE

10 TIPS FOR SELF ADVOCACY

CHANGE HOW YOU LOOK AT THINGS

1

Try and view your situation as something you can change and take control of.

Example - Joe doesn't get on with his doctor and feels as though he doesn't understand him or his needs. Joe has felt like this for quite a while now. Joe wants to take charge of the situation and get the support he needs. Joe asks for new doctor.

FIND WHAT YOU NEED

2

You are the expert in your own life and you know what is best for you. Sometimes people will think they know better and you will disagree. It's important to remember that nobody knows you better than you do. Search for information about your rights and support groups that can help you get the outcomes you need.

Example - Jane has to meet her social worker, Jane isn't sure if she can have a friend with her who knows her well. Jane asks her local advocacy service for help. They let her know that she can have someone supporting her, whether that's her friend or an Advocate.

BE PREPARED

3

In any conversation or meeting preparation is key. By using these tools you will have a clear plan of the issues you want to raise and the best way to get them across.

Example - Alisha has had a social care assessment and her social worker wants to arrange a care package for her. Alisha knows that she can ask for direct payments so she can employ her own personal assistant (PA). She contacts her local independent living service for information about how she can manage her money and employ a PA. Alisha gets her direct payments.

DO IT FOR OTHERS

4

You may find it is easier to help others before you help yourself, many people do. It's good to help others but not at the expense of your own health and wellbeing. Self care is very important and can improve our mental, emotional, and physical health, and can reduce anxiety. Once you have mastered good self-care, you are in a better place to help others. Getting involved in your community will help you connect with others who may have had similar experiences. You don't need to be an expert, but if you wish to help others yet don't know how, why don't you become an Advocacy Friend via our online training course? Head to www.advocacyfriends.org.uk.

Example - Shezad has completed his Advocacy Friends course. He now feels confident to speak up for himself but wants to help others. Shezad uses the information sent to him from his training and starts to work with local people he knows. He learns about different issues he hasn't experienced before and starts to build on his own knowledge and resources. Shezad is able to speak up for himself and others as a result.

It's hard to ask for help sometimes and you may not always feel able to self advocate. There is support out there for you, whether that be a family member, friend, community support group, professional advocacy, or online resources. Don't be afraid to seek out help, ask someone you feel comfortable with to get the ball rolling for you'.

Example - Mike has a meeting with a personal independence payments assessor, he's never done this before. Mike contacts Welfare Rights who are able to tell him what he needs to know to get ready for the assessment. As a result, Mike feels more confident and prepared for his meeting.

5

ASK FOR HELP

BE CLEAR

6 People don't need to know everything about you, just what you need them to know. Make sure you clearly voice your concerns, wants and needs so people can help you to the best of their ability. If people don't understand you the first time, think about a different way of doing it.

Example - Marissa had a lovely meeting with her nurse, and had a nice general conversation with her but nothing really got done. Marissa wrote down her key points and called her nurse to make sure that her important issues were dealt with.

IF YOU DON'T UNDERSTAND - ASK!

Don't end a conversation with a professional until you are sure you have understood everything. If you don't understand something - ask. If you don't feel able to, use the cue cards in your tools section to help you.

Example - Josie always feels tongue tied with her doctor, he speaks too fast and she doesn't have time to think about what he is saying. Josie doesn't feel able to get her words out. She uses the self advocacy cue cards and asks her doctor to slow down. The doctor speaks more slowly and Josie then has time to think and ask questions.

7**LEARN TO NEGOTIATE**

You need to work out what's important to you. Can you compromise on what you need or want? Can professionals? Write down what can and can't be changed and begin to negotiate if you can't reach your desired outcome.

8

Example - Arthur really needs support to help him get out to the shops. He likes to go swimming three times a week, but social services can't manage this. Arthur agrees to let one swimming session go, so that he can get to the shops with help.

KEEP GOING - BREATHE

Speaking up for yourself can be really hard but remember to keep going. As you practise your new skills, your confidence will grow. You may have the odd set back but don't let this stop you. Remember to take a break if you need it, ask for more time and follow the 10 steps again until you reach success.

Example - During meetings, Francis gets upset. She asks for time to go out of the room, takes her time to calm down and manage her feelings. Francis looks at the points she needs to communicate. Francis goes back into the meeting, with a fresh view of things. Francis makes sure she is heard.

9**10****ARE YOU CONFIDENT?**

Confidence is just a feeling. Like a muscle, it needs exercise to get stronger. When you feel under pressure, sometimes you don't feel strong enough to speak up about the things that are bothering you. Confidence needs time to grow; be kind to yourself and allow it to happen naturally.

Example - Mary had never spoken in a meeting before she learned to self advocate, Mary practised with her friends and family and for the first time in her life she asked two questions!

WHAT OUR SELF ADVOCATES SAY

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"Self advocacy is telling those who support me how they can best do it!"

"These skills should be taught in schools. There are so many problems in schools it would help the kids."

"Nothing stops me talking confidently, but I need support with reading and writing."

"My husband would struggle to be a self-advocate. He's intelligent and articulate, but he can't read. Even when he's prepared, he struggles to keep calm when professionals talk to him, then he can't say what he wants. He has loads of confidence but when there's an authority figure, he melts. He would struggle to do a six week course because he would forget it straight away. I am his advocate."

"Be strong, stand up for yourself."

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"I'm a dyslexic and I have to tell people. I've got voice recognition for my computer. I had a breakdown because of the pressure and I didn't know where to go for support. GP didn't help. When I needed to do an Occupational Therapy assessment I was told I couldn't take someone with me. I wasn't allowed any support from a friend or anyone."

"Self advocacy is speaking up for myself."

"A client I worked with is a father with learning difficulties, the issue was guardianship of his children, he has speech difficulty and this gets worse when he's agitated. I was on the 'other side' but I had to help him calm down and help the professionals understand him. He was bombarded with information.."

"Knowledge is power."

"Gives me the chance to be who I want to be."



MORE INFORMATION & RESOURCES

Health and Social Care Complaints Self Help

Our self help guide takes you through the steps of making a health or social care complaint and how to advocate for yourself during this process.

Resources and Factsheets

We have a full library of Easy Reads for advocacy services and a range of easy to understand factsheets on our website.

COMING SOON - Informal Patients / Independent Mental Health Advocacy / Community Treatment Order Self-Help Guides

Our self-help toolkits provide practical help and support written in plain English, for people experiencing or recovering from mental ill health, under the Mental Health Act.

Justice for LB Toolkit

The Justice for LB Toolkit is a resource aimed at helping those with learning difficulties become more involved with their care assessments. It also provides important information and guidelines about working with people who have learning disabilities and communication or cognitive issues.

advocacy focus

JUSTICE FOR LB TOOLKIT



Advocacy Focus has developed this toolkit for professionals who work with...



Communication Toolkits

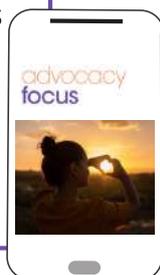
Our Communication Toolkits can help anyone who struggles to communicate verbally with a comprehensive guide of symbols and pictures.

Becoming Your Healthy Self

A new monthly mental health and wellbeing toolkit that will help you tackle a range of emotions and disorders.

COMING SOON! The Advocacy Focus, MyFocus Self Advocacy App

All the tools from this toolkit in interactive format, plus more tips on how to self advocate!



Download these and more from our website at advocacyfocus.org.uk

FURTHER HELP AND SUPPORT



If you, or someone you know needs further help and support, here are some helpful organisations below:

Local advocacy service	Type in advocacy and your county, town or city into a search engine i.e. 'advocacy in Lancashire.'
Citizens Advice Bureau	Can provide you with advice about money, legal, consumer issues and other problems you may be facing. They will know of specialist services in your area that will be able to give you the information that you need
Shelter	A housing and homelessness charity.
Welfare Rights	Usually a service run by your local council that will help with information about benefits.
Samaritans	Support for anyone in emotional distress or mental health crisis.
Hub of Hope	A free app that searches mental health support based on your location.

- Helplines and charities for your condition or situation – There are lots of national free advice services that are issue or condition related, such as Parkinson's UK and Alzheimer's Society. You can type in any medical condition or issue into a search engine, followed by the words 'helpline UK' to find a number to call. Don't be afraid to call, these kind of advice services talk to hundreds of people everyday and are there to help.

Get in touch with Advocacy Focus

If you have a question about this Toolkit or need some more information about advocacy, please get in touch.

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