



FTWW

We want to make our information as accessible as possible. If you need the information in our Self-Advocacy Toolkit in a different format, such as large print, plain text, or a printed paper copy, please let us know by emailing admin@ftww.org.uk and title the email, 'Self-Advocacy Toolkit information request'. We'll get back to you as soon as we can. Thank you!

***My Voice Counts* Self-Advocacy Toolkit.**

One of FTWW's main aims is to give those we support the confidence and skills they require to speak up about their health and related needs.

FTWW's *My Voice Counts* self-advocacy toolkit has been coproduced with our members. It aims to provide you with tips, advice, and skills that could be helpful in accessing the care and support that's right for you.

Scroll down to read each of the five sections of the toolkit below, followed by some useful scenarios, and our *My Voice Counts* checklist.

Learn about Self-Advocacy and Build your Skills.

Section 1: Why are women's health concerns not always heard?

At FTWW, we know that many women and people assigned female at birth report finding it difficult to have their symptoms taken seriously. Sometimes they describe this as feeling like they're 'not heard' when trying to explain the impact of their symptoms on their lives. They report this happening with family and friends, in education settings and workplaces, with healthcare professionals, and decision-makers.

In 2022, NHS Wales conducted a 'women's health' survey which had almost 4000 responses – the top priority for almost all of those responding to the survey was 'to have their voice heard' in healthcare settings.

Some of the key barriers experienced by our community are described below:

1. Symptoms dismissed as 'normal'.

There is lots of research to show that, sometimes, it can be more difficult for women to be taken seriously because some of the health issues we experience can be considered a 'normal' part of life. This is especially the case for menstrual health symptoms, such as period pain or heavy bleeding.

2. Women's issues are taboo.

Another reason why we might delay or find it difficult to seek help for our health issues is because they can sometimes be considered 'taboo'. This is where people think it isn't polite or acceptable to talk about particular body parts, symptoms, or feelings. We might also be embarrassed to talk about these kinds of issues.

3. Gender stereotypes affect perceptions.

A third reason why many of us can find it more difficult to have symptoms and health issues taken seriously is because of gender stereotypes and biases. This is where old-fashioned ideas and societal views about women and our personalities can affect how other people see and treat us. For example, women are sometimes described as being 'over-sensitive', 'over-emotional', 'attention-seeking' and not very stoical or brave. These misconceptions can bias other people towards women's reporting of symptoms so that when we reach out for help, we're wrongly viewed as making a fuss about nothing. This can make us both reluctant to ask for support and cause delays to our receiving the care we need.

How these barriers affect access to healthcare.

We know that experiencing these barriers can make it difficult to seek help from those around us, sometimes including our doctors.

Many FTWW members tell us that they have to try many times to receive the right attention or care they need. They tell us that they feel as though their concerns are dismissed or not actioned. They tell us that they can become exhausted and stressed-out by the process of trying to access services.

However, it's really important to be aware that if your symptoms are having a negative impact on your life, such as making it difficult to do daily activities, sleep, or concentrate, you should try to secure help and support as soon as possible. This can stop symptoms getting worse and, potentially, prevent the underlying cause getting more difficult to treat. At least, seeking support can be a first step in reducing the impact of symptoms on your life.

Section 2: What is 'self-advocacy' and why is it important in healthcare?

Self-advocacy is where a person has the ability to understand, communicate, and assert their own needs, rights, and interests. It enables us to make informed decisions about the things that matter to us and enables us to take more control of our lives. It is especially important in healthcare where we need to explain our symptoms and what will help us to have the best outcomes possible.

It's very important that women have the skills to advocate for themselves in healthcare settings because evidence suggests that we are more likely than men to experience diagnostic delays and gender prejudices which can make it more difficult for us to get the treatment we need. These are often described as 'gender health inequities'. For example, in Wales, evidence shows that it takes 26 GP appointments and almost 10 years to get a diagnosis of endometriosis, a condition as common in women as diabetes or asthma.

Studies also show that women have to make more appointments than men to get a diagnosis of the same condition, for example, coronary heart disease, where it's reported that GPs feel much more confident diagnosing this in men than in women.

Similarly, with colorectal cancer, data shows that women tend to wait longer than men after first noticing symptoms and then need more visits to the doctor to get a diagnosis. And when it comes to pain management in emergency settings, evidence shows that men are more likely to receive pain relief, with women being offered sedatives instead.

We are also more likely than men to live with chronic illness and disability as we age. Accessing the right support early on can help to prevent our health getting worse and impacting different aspects of our lives, such as staying in education or work, maintaining relationships, and financial security.

Why speaking up about your health can be difficult.

You might find self-advocacy in healthcare settings challenging for the following reasons:

1. You're poorly – if you are tired, in pain, or experiencing problems concentrating or thinking clearly, this can make it much harder to clearly explain your symptoms and their impact on you

2. There are communication differences or challenges – if you don't speak English as a first language, have additional learning needs, or are neurodivergent, you may find it more difficult to find the words you need to explain your issues. You may also find it more difficult to focus on the things the doctor needs to know to help you.

3. There may be power imbalances – the doctor is often seen as the person with the scientific and clinical knowledge that you as a patient don't have, so you may feel

anxious about how they view you and your experience. Also, the GP will usually be the person who has the power to refer you on for further investigations or treatment, so you might feel as though you have to convince them to take you seriously and act on your concerns.

Section 3: Four easy steps to getting started with self-advocacy

If you are ready to improve your self-advocacy skills, here are a few important steps to getting started:

1. Think about your health priorities.

Spend some time thinking carefully about what is affecting you and what is most important for you to address. Begin by making a list of your symptoms, issues, and their impact on you and try to rank them in order of importance, so you can be clear in your own mind about what to tackle first.

2. Carry out research.

If you have a diagnosis, or more than one, try looking it up on trusted resources, such as the NHS website A-Z, or specialist charities, so you can find out more about your health condition(s) and how they might impact you. This can help you to understand the facts about your condition and validate your experience, so you feel more confident. It can also help you to learn how those health issues present and might be treated, so you can track how these things relate to your case. This will enable you to better communicate your experiences and needs effectively and efficiently.

3. Know your rights.

The right to health is protected under international law. Article 12 of the 1966 International Covenant on Economic, Social and

Cultural Rights (ICESCR) states that everyone has a right to the highest possible standard of physical and mental health. The UK signed and ratified the ICESCR in 1976. Knowing this can help give you confidence in asking for a second medical opinion or challenging where you think you are being denied the care you need, perhaps because you don't live in the 'right' health board.

4. Begin the journey to valuing yourself.

When struggling with our health and related challenges, it can be all too easy to start doubting ourselves and feeling less worthy of fair treatment. Try instead to see how resilient you are as a person living with health issues; recognise that you are worthy of time and attention, that you deserve to be heard, taken seriously, and supported.

Top tip: Write down, 'I am worthy of self-care and the care of others'; say it out loud, say it to your reflection in the mirror – regularly practise self-validation. It might seem silly at first but the more you say something, the more it will become imprinted on your consciousness and you can start to believe your own worth!

If you're able to start growing your ability to self-advocate, you could find that your stress levels reduce. This is because you will know that you are on a journey to asserting yourself, making your voice heard, and being in more control of your situation. Also, when we're less stressed, we can find that our health conversations go better, because we're more able to concentrate on what's being said and play a more active role in decision-making.

Section 4: 15 practical self-advocacy tips

With our community, we've developed 15 tips to help you better advocate for yourself and get the support and care you need.

1. Seek out support from allies.

Whether that's a trusted family-member or friend, or from peer-support groups where there are others with the same health issues. Support from peers can help to validate your experience, provide solidarity, and enable you to become more confident.

2. Prepare for healthcare appointments by making clear notes.

Make sure you write down your priority symptoms, issues or questions in advance to help guide your conversation. Most GP appointments will last around 10 minutes, so practise keeping these lists clear and concise.

3. Use evidence and guidance from trusted sources.

When you are making notes, you can also include key points and recommendations from trusted sources including the National Institute for Health and Care Excellence, usually known as NICE. NICE produces guidance for the NHS and wider health and care system which healthcare services and professionals are normally expected to follow.

4. Book a double appointment.

If your appointment is in general practice and you think you might need a little bit longer to discuss things, ask if it is possible to book a double appointment when you make contact with the practice.

5. Focus on around three priorities once you're in the doctor's office.

If you say at the start of your appointment that you have three things you need to discuss, you can work out what the top priority is together. Sometimes, you might manage to get through all three, especially if they are connected, but other times, you might only have enough time to look at one in detail.

Top tip: The human brain will tend to treat the first piece of information presented as the most important, so lead with that rather than leaving it until the end.

6. Provide specific details about your symptoms.

If you're looking to discuss symptoms, it can be helpful to include when they happen, such as dates, times, or any 'triggers' that might have caused them or made them worse, and how long they lasted. Symptom trackers can be a useful way for you to keep an eye on symptoms and when they occur or are at their worst. You might use apps on your phone for this – or you can also use a paper diary or calendar.

7. Explain how symptoms are impacting your life.

When discussing symptoms, it can be easier for other people to understand their seriousness if you focus on how they impact aspects of your daily life. For example, does a particular pain stop you exercising, make it harder to breathe, or cause you to wake up from sleep? If a symptom has stopped you going to work, you could say how many times this has happened in a certain period of time.

8. Make sure you are clear about what you want from your appointment.

Alongside your list of top issues or priorities, write down exactly what you want to come out of the appointment, so you can keep referring back to this, such as a particular investigation, treatment, or a referral.

9. Bring along a loved one, close friend or advocate.

Remember it's OK to take someone with you if you feel you need support to express yourself and your needs. Have a preparatory conversation with them before the appointment and share your notes, so that they know and understand your experiences, priorities, and goals. It's important that they appreciate what's important to you, and don't ask questions that you haven't agreed with them beforehand.

Top tip: Signpost your family member, friend, or advocate to our **'Supporting Others and Helping them Cope'** advice page.

10. Know your rights as a patient.

This includes the right to information, informed consent, and the right to refuse a course of action or treatment.

11. Get a second opinion.

In Wales, you should not be refused a second opinion, so if you feel you would benefit from talking to a different healthcare professional, you can ask for this. If you're being seen in general practice, there might be someone more specialised in your particular health issues or needs in the practice, such as a GP specialising in 'women's health', so don't be afraid to suggest this.

Top tip: If you feel your GP and you might benefit from more specialised advice about your symptoms or next steps, you can ask them if they are able to use ‘e-consult’. This is an online platform that enables healthcare professionals in primary care to seek advice and guidance from secondary

12. Ask for more information or services.

If you feel you might benefit from other sources of support whilst waiting for next steps in your healthcare journey, you can ask to be signposted to additional information, services or organisations.

Top tip: If your GP is unsure what patient information, services, and support are available in your locality, you can ask them to look at their ‘Community Health Pathways’ website, to which all GP practices in Wales have access. This should give them links to relevant support outside of the practice.

13. Be clear about next steps.

End the appointment by clarifying next steps and dates by which you should expect to hear something, such as receiving a referral letter. If necessary, you can ask to have these written down or write them down yourself and have the healthcare professional confirm what you’ve noted.

Top tip: Consider using **FTWW’s MY VOICE COUNTS checklist** ahead of, during, and after your appointments.

14. Remember to follow up.

Always follow up on appointments, tests, and waiting lists if you don't hear anything within the time-frame expected. If you feel you're not getting the answers you need, you can express a concern to the GP Practice Manager, hospital, or health board. If you don't feel confident doing this, there are organisations to support you.

15. Schedule in some 'recovery time'

Whether you go to your appointment alone or with someone else, make sure to allow time afterwards to 'come down' from what can often be quite a stressful situation. It doesn't matter if the appointment was in a healthcare or employment setting, or somewhere else, discussing personal health issues, their impact, and making important decisions about your life and wellbeing can feel challenging and emotional. Some people prefer to have time and breathing space to process these feelings before going back over the appointment or reading their notes. Others prefer to check their notes and get them in order before putting them aside for a period of rest and recovery. Whatever works best for you is fine.

Section 5: 13 techniques to help handle health conversations.

Practise the techniques below to improve your self-advocacy skills:

1. Be assertive rather than aggressive.

Women in particular often worry that expressing their wishes will see them labelled as bossy or aggressive. It's important to understand that this is often based in gender stereotypes and prejudices which aren't true or helpful. We have just as much right to have our healthcare needs met as anyone. Sometimes

this means we have to question attitudes which see our experiences and voices dismissed or silenced. However, we can do this in a way which is clear and confident without being confrontational and causing ourselves and others to be angry or upset. Being assertive can help you to get your point across in healthcare conversations and appointments. It can enable you to come out of them feeling more confident that you've said what you needed to say, and achieved the outcomes you wanted to achieve. There are key communication strategies that can help you be more confident and assertive when discussing your health needs which we've described below. Some of these techniques might be new and unfamiliar to you, so you might wish to try them out and practise with a friend, family member, or someone else you trust!

2. Listen to yourself first.

Your inner noise – anxieties, distrust, previous frustrations – can swamp what you want to say and the goals you have for the appointment. Accept that it's OK to feel like this. Take a breath and before engaging, pause.

3. Be present.

Focus your attention on the person in front of you – it's difficult but you can practise grounding techniques to help you, including 'box breathing' or 'tapping' to keep yourself focused on the conversation rather than your inner noise.

4. Hold the gaze.

Eye contact can help to show sincerity and that you're listening. However, we know that 'holding the gaze' isn't always easy, especially for those who are neurodivergent, or simply introverted or shy, but you can practise using a mirror or with people to whom you are close and feel more confident.

5. Be honest about the challenges you face.

Say up-front that you find certain things about communicating or engaging in appointments difficult, demonstrating you are both self-aware and honest about your own challenges – this in itself can help to open up dialogue.

6. Rehearse and use confident phrasing.

Use phrases such as:

‘I’m concerned about...’

‘This is affecting my daily life’

‘I’d like to explore the options’

‘Could you explain the reasoning’

‘What are the next steps’

‘Why?’

Phrases like these signal your wish to collaborate with your doctor in decisions about your health and care. The last one is especially important if you’re advised that you’re not eligible for a particular course of action, such as a referral. You can also ask for your request to be documented in your medical notes.

7. Hold the silence.

Don’t feel the need to fill any silences that take place. Allow both the other person and yourself time to ponder what’s been said.

8. Fogging.

This is a technique that involves calmly letting the other person know that you have heard what they have to say and accept this as their opinion without feeling like you have to justify your own, different, viewpoint. For example, your doctor might say, ***‘Lots of patients report mood swings when using this treatment’***. With ‘fogging’, you might respond with, ***‘I appreciate that being the case. However, I’m experiencing depression that is difficult for me and my family to cope with, so I’d like to talk through some other options’***. Instead of getting flustered or angry, take a

few moments to compose yourself by acknowledging the other person's comments before moving on to your own perspective. In healthcare settings, this type of conversation can help move both you and your doctor towards a solution, sometimes called a 'shared decision'. Fogging can help to avoid confrontation; it shows that you're respectful of the healthcare professional's expertise, but it also maintains a focus on your experience and preferences.

Top tip: For more information about 'shared decision-making' and what this should look like in healthcare settings, you may wish to look at **NICE guidance about 'shared decision-making'**.

9. The Broken Record technique.

This is a technique that can be helpful in situations where you need to assert your position without losing your temper, or losing track of your goals because you are too upset to think clearly. Clearly state your key point, priority, or goal. Calmly repeat it without over-explaining. Make sure to keep breathing so you remain calm, and stay focused on your point to avoid being distracted. As with the fogging technique, you can acknowledge the other person's perspective to show you value their input, without it detracting from your own viewpoint. For example, you might say, ***'I understand what you mean about mood swings being typical for this treatment and that it's considered a good choice for my condition, but I'd still like to try a different approach'***. By using the broken record technique, you can maintain your assertiveness and ensure that your needs are heard and understood.

10. The Sandwich technique.

This technique is also known as the ‘feedback sandwich’, because it frames constructive criticism, your request, or goal, between two layers of positive remarks. For example, you might say, ***‘I really welcome your perspectives on this. However, I am concerned about the impact this current medication is having on my mood and need to discuss another way forward. Thank you for helping me go through the options’.*** The approach is designed to make your feedback or difference of opinion easier for the other person – in this case, the healthcare professional – to accept. It can be helpful in making the interaction more positive and constructive.

11. Be your authentic self.

Whether this is needing to cry or use your own words for things, such as slang, don’t let it worry you. Sometimes, trying to hold back from crying or trying to use language that isn’t familiar to you can take so much effort that you can’t concentrate on what you need out of the appointment. Remember, it’s OK to cry. Sometimes, the anticipation of an appointment, or talking about the impact symptoms are having on your life can make you feel tearful. It can often be better to let those feelings out and have a cry than try so hard to keep your emotions bottled-up that you can’t focus on what’s being said. Doctors say that they won’t be surprised if you do cry and that you shouldn’t worry about doing so. Many appreciate that crying can be a release of tension and have a therapeutic effect. You might also need to use your own language or terminology to describe symptoms or body parts – and that’s OK too. Your doctor should ask you to explain a bit more if they’re puzzled, including if you’ve mispronounced things. It doesn’t matter – what matters is that you both eventually get to a shared understanding and can take things forward together.

12. Ask questions.

It's important for you to understand what's going on with your body, including whether there have been any investigations or tests from which you need to know the results. Don't be afraid to ask for results and next steps to be explained to you and for answers to be written down, or a leaflet to be given to you so you can read back at your own time.

13. Reflect back.

Check your understanding by repeating back to the doctor the core of what you've heard so that they can clarify anything you might have misheard or misunderstood. If there's something you don't understand, don't be afraid to politely interrupt and ask. You are the one in charge; the appointment is about you! And if you haven't managed to cover everything, ask to make another appointment.

Self-Advocacy in Action: *My Voice Counts* Scenarios.

Now read examples of how to use the skills you've learned.

Scenario 1: You're having side effects, but you feel that the doctor dismisses your experiences by saying that this treatment is the best one for your condition.

'Thank you for outlining the benefit of this particular treatment, which I understand. However, I've noticed that since starting it I'm having what feels like constant period pain and spotting. It's making it very difficult for me to manage and I'm having to take time off work as a result. I'd appreciate us looking at different options, please'

Scenario 2: You've read that a referral to secondary care should be offered for your condition, but your doctor is reluctant to make one as the waiting list is so long and they are concerned about you managing whilst waiting.

'Thank you, I appreciate you explaining the length of the waiting list. However, I've tried a couple of different treatment options now and I'm concerned that my symptoms are getting worse. I think it's best for me if I go on the waiting list for secondary care at this point. I've checked NICE guidance and it confirms this as a next step. Thank you for making the referral for me. I'd also welcome some support whilst waiting, if you could suggest any services available in this area.'

Scenario 3: You are struggling to follow all the details of what you're told during your healthcare appointment.

'Thank you for explaining all the details about my condition and treatment options. However, I find it difficult to remember everything we discuss and need some more time to think about it all. Please could you write down today's key points or give me a leaflet so I can get back to you with my decision. Would it be possible to make a second appointment in two weeks' time? Thank you for this.'

Scenario 4: You feel that your doctor is more focused on your mental health and that your physical health needs are being blamed on this.

‘I agree that my mental health isn’t the best it could be. However, living with the physical symptoms that I have is stressful and impacting on lots of aspects of my life. I feel that if we could work together on managing the physical symptoms, my mental health would improve’.

(And, if you would like, you could also ask for a referral to counselling or mental health support for those wider psychological impacts caused by living with a chronic condition).

Please read on for our ‘My Voice Counts’ checklist (next page).

FTWW's Self-Advocacy Checklist

We've designed a simple checklist for better self-advocacy based on the phrase **MY VOICE COUNTS**.

- ✓ **M**aking time for
- ✓ **Y**ou

- ✓ **V**oicing your symptoms, needs, and wishes
- ✓ **O**wnership – it's your health; you are in control!
- ✓ **I**nformation – have your notes ready in advance
- ✓ **C**almly and confidently asking for clarification
- ✓ **E**xpressing your expectations

- ✓ **C**ollating your notes after the appointment
- ✓ **O**bserving how you're feeling
- ✓ **U**nderstanding what happened
- ✓ **N**ot dwelling on negative feelings about yourself
- ✓ **T**aking care of you
- ✓ **S**eeking additional support if needed

My Notes