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EmBody To EmPower

A resource for young women about accessing healthcare in Scotland

From registering with a medical centre, doctor, or dentist, to making appointments, to talking to healthcare practitioners and having treatments, accessing healthcare is a journey. Our research found that young women struggled to access the healthcare they needed and deserved. They want better education for themselves around accessing healthcare, they want to know their rights.

Young disabled women who had to do lots of work to access the healthcare they needed inspired this project. This resource was created by a group of young women who named this project EmBody to EmPower.

If you are a young woman or person of another marginalised gender living in Scotland, this resource will hopefully support you with your own journey to accessing the healthcare you need and deserve.

We know that accessing healthcare is different for everyone. It might be even more difficult or you may face more barriers to accessing healthcare if you are a young person of a marginalised gender; such as non-binary or trans, if you are disabled, or if you are a young person of colour or from an ethnic minority background. We hope that this resource will be helpful for you. At the end of this resource, you can find links to other kinds of support that might meet your specific needs.

"My hopes for the resource is that the next generation won't have to navigate the system in quite the way that we have had to."

-Eleanor, EmBody to EmPower project participant

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KNOWING YOUR BODY

Understanding your body's signals means you can notice when something doesn't feel right. Knowing how to describe what you are feeling, or your symptoms, to the doctor helps them figure out what might be wrong.

We know that often we aren't taught about what is 'normal' and it can be difficult to know when to go to the doctors, especially if you have tried to go to the doctors before and felt unheard or dismissed. To get to know your body's signals, it can be helpful to:

- Track any changes you are experiencing. If you feel something isn't quite right, make a note of exactly what you are feeling, when and how long it lasts. This is also helpful when you are speaking with a healthcare practitioner, as you can refer back to what you have tracked.
- Do some of your own learning about your body.
 <u>These NHS resources</u> cover lots of topics that might help you to understand your body better, like periods, mental health and sexual health.
- Pay attention to what your body is telling you, and don't be afraid to talk to your doctor about any concerns or changes you've noticed.

ACCESSING HEALTHCARE

REGISTERING

Registering with a doctor (GP) is an important step to take when trying to access healthcare. This page has a guide on how to register with a doctor in Scotland. You can download the form, and email it to your GP, or drop it off in person.

If you can't find a GP practice in your area that is accepting new patients, you can get in touch with the registration teams within **National Services Scotland**.

When you are registered, your doctor is available Monday to Friday, 8am to 6pm. You should make an appointment if you:

- have an urgent care need
- have an illness that does not improve with self-treatment, there are some self-help guides from NHS Scotland here
- are worried about your health
- have an ongoing health condition

MAKING AN APPOINTMENT

GPs and Healthcare practices can have different ways of making appointments. Usually, each practice will have its own website with instructions on how to make appointments. This page has lots of information about making appointments.

ECONSULTS

Many practices have the option to start with an eConsult. eConsult is software that allows you to quickly and safely get help and advice from your own doctors and GP practice online, for free, from anywhere. It is a form-based online consultation platform that collects your request and sends it through to your GP practice to decide on the right care for you.

You can find out more about eConsult and whether it is available at your **GP here**.

MAKING A PHONECALL

Almost all GPs now operate through a phone appointment system.

- Often, you call early in the morning (check the time on your GPs website) and join a queue.
- You then speak with a receptionist, who may ask you to describe why you want to see a healthcare practitioner. This is so they can assess what kind of appointment will suit you best, you do not have to tell them everything and you can just give a general description of what you want to speak to a doctor about.
- You can also request a specific healthcare practitioner, for example, if you would rather see a woman doctor or if there is a specific doctor who you have spoken with before who you would like to speak to again.

- You also have the option
 to request a <u>Near Me</u> video
 appointment. This might make
 it easier for you to attend an
 appointment if going in person is
 difficult.
- Phone and video (Near Me) appointments may not be suitable for everything and everyone. There may be a need to see a healthcare practitioner in person for a physical examination or if tests need to be carried out. You may also just feel more comfortable seeing a doctor in person. Your doctor will discuss this with you to help you decide which is the best option for you.

PREPARING FOR YOUR APPOINTMENT

If you aren't sure what to expect at a doctors appointment, this page from YoungScot is a helpful resource.

This page from the NHS also has some really helpful questions to think about before going to your appointment. These are some top tips:

- write down your 2 or 3 most important questions.
- list or bring all of your medicines and pills – including vitamins and supplements.
- write down details of your symptoms, including when they started and what makes them better or worse.
- ask your hospital or surgery for an interpreter or communication support if needed.
- You can take a trusted friend or family member to support you in your appointment too.

It can be helpful to prepare some notes before your appointment. It can be overwhelming being in an appointment, and notes will help you to remember to say everything you want to say. You could include;

- what you are feeling and how long you have been feeling it.
- how it's affecting your day-today life, work and relationships.
- any physical symptoms aches and pains, stomach upsets, difficulty sleeping or sleeping too much.
- any medicines or illegal drugs you've been taking.
- tell them about any stresses, or struggles you are having with your mental health – it's helpful if the healthcare practitioner understands what's going on in your life.

Keeping a diary about your health and symptoms can be really helpful, especially if you have not been feeling right for a while. Endometriosis UK has **this really helpful** pain and symptoms diary, that you can look at if you are experiencing painful periods or other symptoms linked to your menstrual health.

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You can voice record your appointment on your phone using the voice memo function, for the purpose of listening back after so you can remember all that was discussed. It is polite to ask the health care practitioners permission to record before you do so, this counts as 'note taking'.

It can be really hard to share personal things with a healthcare practitioner, especially if you feel embarrassed, scared or confused about them. Remember, they have heard it all before, it is your space to discuss what you need to, and to feel safe and supported.

WHAT CAN A POSITIVE EXPERIENCE OF ACCESSING HEALTHCARE BE LIKE?

Feeling prepared can help you communicate with your healthcare practitioner clearly. Then it's up to them to listen and support you.

You deserve to be **listened to, heard, and believed** by your
healthcare practitioner, and shown **empathy** and genuine **care**.

"I have had a positive experience with a GP who was very supportive and understanding when I asked for help with my mental health. He took the time to listen, ask appropriate and compassionate questions, empathised, checked in with me, explained my options, asked me what I needed and did what he could do to support, he prescribed medication, signed me off from work, proactively checked in with me over the phone to see how I was doing." (survey respondent - SYWS22-23)

You should **feel safe**. For example, if you need an examination, you should be offered the chance to have a chaperone join the examination; and all the steps for the examination should be explained to you.

"The doctor read my notes ahead of my procedure and knew because of my autism, I needed to be told what was happening all the time. It probably didn't take much out of their day or anything just really helped me to keep calm" (group discussion participant, living rurally - SYWS22-23)

You should have a choice and be given the time and space to explore next steps and what supports are going to work for you and your life.

Having a plan or clear next steps are really important too. Your healthcare practitioner should be clear and honest with you about the next steps. For example, timings and how long until you are to receive a follow up, and what is involved in any treatments or procedures.

"Positive experiences are ones where I have been listened to and allowed to have the initiative in my care. Where I have been made aware of all my options, and providers have been honest with me when they are unable to provide care." (survey respondent - SYWS22-23)

STILL NOT FEELING RIGHT? HOW TO PUSH FOR THE HEALTHCARE YOU DESERVE

Advocating for yourself in a healthcare setting is important, you deserve to access healthcare that meets your needs.

All too often, young women feel unheard, not believed, and not taken seriously in healthcare settings. You have the right to make decisions about your own healthcare. You should be working together to come up with next steps that meet your needs.

It is important that you leave your appointment feeling clear about what's next. You can ask them to send you a letter summarising what you discussed in your appointment. Here are some suggestions for things to say:

if you are feeling dismissed:

- Could there be anything else causing these symptoms?
- What other tests can we do to investigate this more?
- Can you explain why you think I do not need follow up treatment/ referral/tests?

if you are being offered treatment or medication, and are feeling unclear:

- What are the benefits and risks of my treatment/medication?
- Are there any alternative treatments/medication I can try?
- What if I choose not to go with this treatment/medication?

if you are feeling like you are not being taken seriously:

- I know my body, and I know this is not normal for me.
- I appreciate your expertise but I would like to be referred to a specialist.
- This is really impacting my quality of life, I need some clear next steps before I go.

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if you leave your appointment feeling like you haven't been heard or understood, you have the right to choice, to ask to see a different GP or for a second opinion.

- I would like to get a second opinion/speak to someone else about my condition/treatment.
- I believe that getting a second opinion would help me make a more informed decision about my treatment options and give me peace of mind.
- I am going to see a different doctor because I don't feel like this appointment has helped me in the way I hoped.

if you feel like the diagnosis or explanation for your symptoms doesn't feel right, you can ask for a 'differential diagnosis'. This means your healthcare practitioner should tell you what the other possible causes are for your symptoms.

- Can you tell me your differential diagnosis?
- Can you tell me what else could be wrong?
- Can you tell me some other reasons I might be experiencing these symptoms?

You have a right to access safe and timely healthcare, if you feel really unhappy with your interaction with a healthcare practitioner, this page on the NHS website tells you how to make a complaint. There is also Patient Advice and Support Services, which supports anyone who uses the NHS to understand their rights and responsibilities as a patient in Scotland, raise concerns, give feedback or comments, or make a complaint about NHS treatment in Scotland.

SUPPORT

Feeling supported is so important, especially when you are experiencing ongoing struggles with your health. Support groups can be really helpful. These groups provide a space to listen and share, and they can help you feel less alone. You might learn helpful information about what you are experiencing, like how to deal with it and what to expect. It can be a bit like having a team to support you in your health journey, both emotionally and with practical advice. Young women have told us being part of a support group has been the most impactful experience for them to understand their own bodies and how to access the best care for them.

If you would like to join a support group, you can do a quick google search for your condition, area and support group. Here are some to get you started:

- Endometriosis UK has groups in Ayrshire, Dundee, Edinburgh, Fife, Forth Valley, Glasgow, Grampian
- North Highland Women's
 Wellbeing Hub. Support groups
 in Highland related to specific
 conditions, and also general
 women's health.
- LGBT Health and Wellbeing. <u>LGBT</u> and Autism Group who meet in Glasgow.

Advocating for yourself in a healthcare setting can be tiring, stressful, and emotionally draining. It is important to talk to people that you trust about how you are feeling. We hope that in the future, young women will not need to push so hard to access the healthcare they need and deserve, but until then, don't give up! You deserve to feel heard, respected, cared for and understood by healthcare practitioners.

FURTHER READING, RESOURCES AND SIGNPOSTING

There are many helpful resources and supports out there when it comes to accessing healthcare. We have gathered a few more that might be helpful for you here.

GENERAL HEALTH:

- Young Scot. There are lots
 of helpful resources and
 information on Young Scot's
 website about different health
 conditions.
- The Mix. resources and information to support people under the age of 25 to understand mental health.
- NHS resources on puberty, sexual health, mental health, vaccines, women's heart health.
- BEAT. If you are struggling with disordered eating, this resource is to support you when you are going to the doctors for the first time.
- Women's health resources, graphics, recorded webinars, and further signposting.

MENSTRUAL AND SEXUAL HEALTH:

- Brook. Confidential sexual health and wellbeing experts. Self support services offered too, e.g. STI kit delivered to you confidentially.
- Endometriosis UK. Website with lots of resources, information and support for people who might have endometriosis, adenomyosis, or PCOS, or have a diagnosis.
- The Vaginismus Network.
 supporting women living with vaginismus, supporting them with a community of other women going through what they are and providing resources for self-advocating and self-management
- <u>Vulval Pain Society.</u> Resources, practical advice and information for people living with vulval pain.
- Sexual Health and Sexuality.
 A pack to help young people understand sexual identity and health.
- Sexpression. Peer independent UK charity with the goal of empowering young people to make decisions about relationships and sex.

MAMMAM SELF-ADVOCACY, SUPPORT AND **SELF-MANAGEMENT** My Self Management. provides resources to support people with self-management and selfadvocacy. Medical Herstory. feminist health organisation Medical Herstory stories and support in relation to medical mysogyny. The Luna Project. Supports and raises awareness of young people with chronic illnesses, disabilities, and long-term health conditions. North Highland Women's Wellbeing Hub. Signposting and resources about women's health. **GriefSick.** A newsletter that explores and bears witness to chronic illness and the emotions that come with having one.

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About this resource
This resource was created by a
group of young women aged 16-30
living across Scotland, facilitated by
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THE YOUNG
WOMEN'S
MOVEMENT