Experiences of Living with Long-term Health Issues in Wales

FTWW
DrawingOut
Cardiff University
Prifysgol Caerdydd
Women's Health Research Wales
Ymchwil Iechyd Menywod Cymru
ROSA
The UK Fund for Women and Girls
Cronfa Gymunedol
Community Fund

Introduction

This booklet has been developed as part of the *DrawingOut Long-Term Health Issues in Wales* project.

The project was undertaken by FTWW: Fair Treatment for the Women of Wales, in partnership with Cardiff University & Women's Health Research Wales, and supported by the Rosa Fund and National Lottery.

The project used the participatory DrawingOut methodology to gather drawings and stories based on the lived experiences of women and people assigned female at birth living with chronic and long-term health conditions across Wales.

Project Team

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Booklet Design marcheatleydesign.com

What is this booklet about?

The content

The experiences of living with various long-term health issues in Wales, described by women and people assigned female at birth, using their own words and artwork.

Those involved

In total, there were 20 participants in the *DrawingOut Long-Term Health Issues in Wales* workshops. Nine of these attended a workshop held in Cardiff, south Wales, and 11 attended a workshop in Conwy, north Wales. All have lived experience of at least one long-term health issue or chronic condition. Most identified as disabled and spoke about their own health issues, with two speaking about their children's experiences. All participants are members of FTWW: Fair Treatment for the Women of Wales.

The workshop activities

We carried out several drawing exercises designed to encourage participants to share their experiences of living with long-term health issues:

- Draw yourself thinking or talking about your health issue
- If your health issue was an object, creature or animal, place or situation, what would it be?
- How would you draw your relationship with healthcare staff
- Do a final drawing to express whatever you like about your disease experience. You can focus on a positive aspect of your disease experience.

The main conclusions

Participants talked about:

- difficulties accessing healthcare and differences in the services available across Wales
- how symptoms are often not taken seriously
- how biases can have a negative influence on how people are treated
- how long-term health conditions can have a negative impact on many aspects of life, including mental wellbeing, physical wellbeing, and financial security
- how having a long-term health condition can also affect people’s families and carers
- needing to develop their own ways to cope and manage their health
- the importance of the support they receive from others living with long-term health issues
- how being part of a community group can be empowering.

Our chronic conditions impact all parts of our lives

"It feels like you're hyper vigilant, waiting for that next attack of your condition, or what's going to come and attack you next"

"So, there's a physical and a mental side, and I can't quite get to that point of managing both of them"

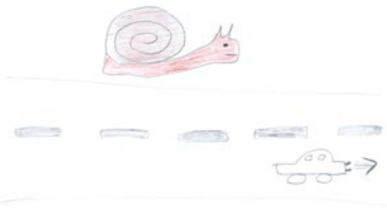
"I literally can't move house for that reason because I would lose the care that I get"

"I feel that I'm shackled by the lack of energy."

"God, this is a nightmare. When's it going to stop?"

"It's kind of the small things that people take for granted, like I can't drive anymore, so then that makes life loads more difficult."

"Sometimes is just overwhelming, trying to exist"



"Being ill has held me back professionally"

"I'm just treading water all the time. That's how I feel with my illnesses. And its effect it has on my like, personal life and everyone around me."

"Just not being able to manage time, and all these professional things, all these adult things you think you should be able to do."

"I'm a cake decorator, and I can't really do that anymore because I can't stand up for long enough and it takes too much energy."

"I'm off work because of burnout because I've been trying to manage all these physical health symptoms and still be everything to everybody"

"It isn't just a painful period. It affects all parts of you, all parts of your body or parts of your life."

The physical impact: we feel pain and discomfort

‘It took all my energy to get out, to get up today, that just my head hurts so much, still, even with medication.”

“We would like just one day where we wake up feel rested and have no pain. That’s all I want. Just one day will do me.”

“I don’t remember a point from puberty where I wasn’t battling pain and sort of periods and trying to sort of get on with it because that’s what we’re told to do”

“I feel it’s like a dragon or a crocodile licking its lips ready to cause a lot of pain and blood”

“I’m in pain all the time, constantly”

“You just feel like you can’t exist anymore in a room or outdoors in a particular temperature, and your body’s just kind of dying on the inside, and you’re sweating like mad. It’s usually humid, so the sweat isn’t helping at all. It’s just making you uncomfortable.”

The physical impact: we feel exhaustion

“It’s like a glacier of fatigue, so I’m stuck in it, and I feel frozen. There’s lots of things, like everything’s happening outside and it’s all colourful and sunny, and there are things I want to do, and I am so tired.”

“But if I could just wake up feeling rested once. I sleep, and then in the morning I wake up, I take my medication, my husband brings me breakfast, I eat that, drink my coffee, and then I go back to sleep so that my meds can kick in. Oh, and it’s just exhausting. And then I wake up, and I’m still tired. Go through my day and I get some stuff done, but I’m still tired. So, then I go to bed at night. I’m tired.”

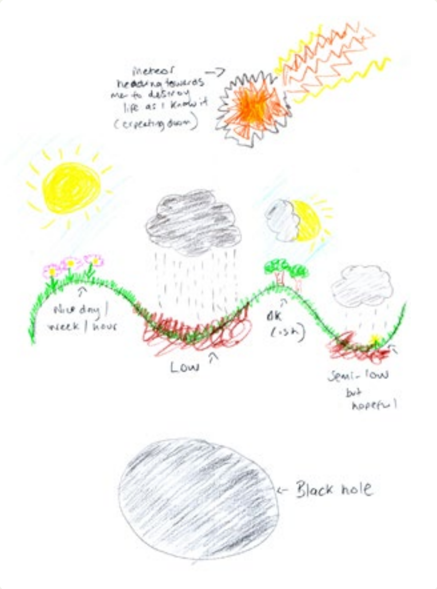
“So surely, the tiredness is the worst thing, and sleeping all the time, I can’t do anything, I can’t make any plans because, you know, I’m exhausted”

“And I’m always fecking tired. Always tired”

The emotional impact:
we feel hopelessness and fear

“I did the question mark because we don’t know what, if the gun is going to go off and the bullets say different things. So, it’s life, death, hope, loss, but it’s got a lot of fear on the gun that’s always there.”

“But then this is the meteor coming towards me at all times to destroy life as I know it, and the constant expecting doom, you know, thinking what's going to be next.”



“Some days I don’t want to be here.”

“The black is the hopelessness. I realised that despite the pain, despite the anger, it is the hopelessness that affects me more because when you’re fighting all the time and you’re running against the wall, you think, what is the point? What am I going to do? And no one listens. That’s the hard one.”

The emotional impact: we often feel alone

"It's a desert island where it's raining. Your boat's broken, the oar is broken. You can't get off it. There's nothing there to help keep you going. So you feel a bit deserted."

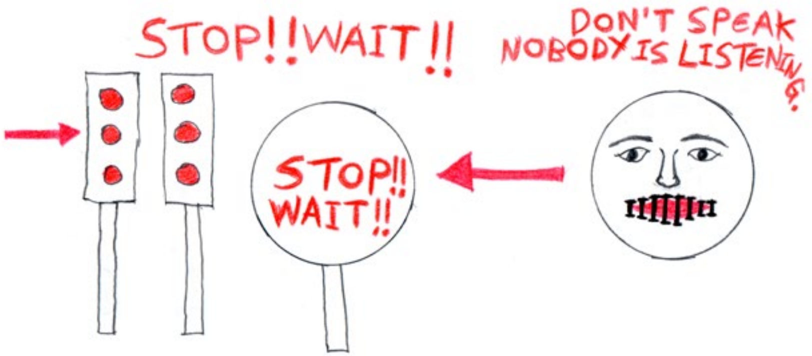
"I lost a lot of my friends... so there's just like this big bubble of isolation, and then just like this tiny little drawbridge with loads of spikes. Because it's like, I feel like people have to really work to get close to me"

"Then we've got a social situation, probably mostly with neurotypical and they're all over there, and they're all in a group and chit chatting and multi way conversation. And I'm stuck on my own, and I feel like I'm surrounded by barbed wire because I can't say the right thing, [it's] difficult to find how you can feel so alone in a group"

Others often don’t understand what we’re going through...

“One of my colleagues said, just have a baby and the endometriosis will go away. This was a senior male colleague”

“Sometimes people are just committed to not getting it, and they will still always have those ableist judgments of us”



“It’s just a bad period. We all have periods. That was a sister in the hospital and HR”

“One of my colleagues called me a wuss about period pain”

“I feel like everyone just sees me as lazy, but, you know, shattered, you know, got to have a few naps in the day, still be absolutely, it’s a different type of tired”

…so, we mask our struggles

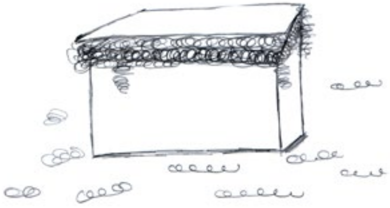
“Makeup is my war paint. But a lot of people, they just see the makeup. They see you all together, see you’re happy, smiling, I’ll smile even if I’ve got pain”

“So to me, I’d look in the mirror and I look sick, but to my friends, they just say, it’s the face that I put on when I go with them for an hour.”

“I go through all the fakery of putting my makeup on, doing my hair, getting my nails done, to sort of give this mask of competence and the mask of having it all together.”

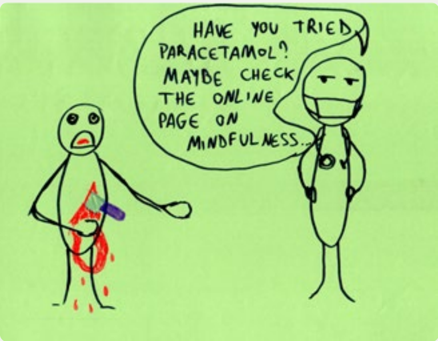
“So one side, happy. Got makeup on, carry on smile. The other side, I’ve got a list of conditions”

“So it’s kind of like how I feel with my health, is that I’m trying to put a lid on it and keep it all concealed so no one else can see what’s going on, but it’s still trying to come out.”



Our healthcare experiences: we have to battle to be heard

"And then that led to that where I was like a piece of meat, basically, like I feel like the medical system treats you like a body, and that's it. It just meat without any feelings."



"The pain through endometriosis, so been stabbed and my bowels are hanging out, and so doctor asked, well, have you tried Paracetamol? Maybe check the online page for mindfulness"

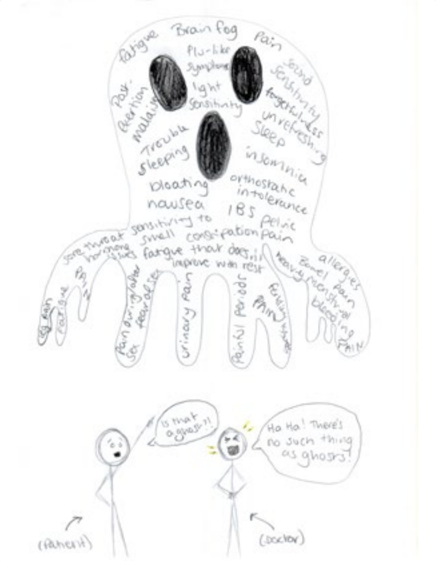
"Yeah, that's me, and that's the doctor with his hands on his hips and his stethoscope, just to make sure that he's a doctor, I said, made to feel small and insignificant and washed up"

"I was gaslighted, you know, I didn't know what I was talking about, even when I was talking about my own body."

"That's a patient, going, is that a ghost? And the doctors just pissing themselves laughing, saying, Ah, there's no such thing as ghosts"

"So they just dismiss your symptoms, and you get gas lit and told there's nothing wrong."

"I can't turn on the TV any more, which has been suggested as undiagnosed ADHD (Attention Deficit Hyperactivity Disorder), but nobody listens"



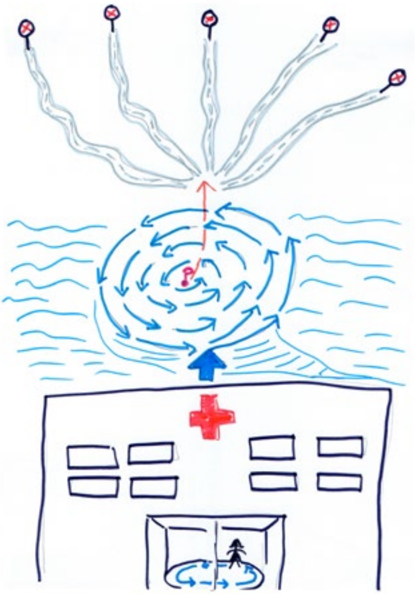
"It's because you're a woman"

"Your test results are normal. Your thing was normal. There's no sign of illness, seeking problems that don't exist"

"Not heard, not believed. I know I don't look ill, but I have, and there's, you know, a whole list of conditions."

"Because I'm a woman, I feel as though I've been ignored. And I'm an old woman, which makes it twice as bad."

Our healthcare experiences: we encounter delays and confusion



“For one of my diagnoses, it took 23 years, and I went through the NHS system multiple times being told there’s nothing wrong with you”

“I feel that the separate departments they don’t communicate with each other.”

“So, I’ve still got my uterus. I’ve been waiting for a long time to have it removed”

“I think it brings around the holistic, you know, everything’s in the box, mental health, physical health. Nobody like, joins the dot.”

“I became very ill at 22 with what is suspected to be endometriosis, but I’m only 26 because so of course, they haven’t diagnosed it yet”

“It’s not holistic health care, is it? It’s very fragmented.”

“And that’s having to wait all the time, feeling like you’re not getting anywhere, yeah, feeling as though you’re not really getting anywhere with the health service, having to wait all the time for everything”

Our healthcare experiences: sometimes we're caused harm

"And after the operation, I was, like, so stressed and overwhelmed and tired that I couldn't speak about, like, non-verbal and I was so tired, I couldn't move, and they moved the pain and the call button out of my reach, where they knew I couldn't reach it"

"And they still kept ignoring it, and it's getting bigger and bigger. And in the end, she had to pay to go private. And the surgeon said, if it was left any longer, she'd have lost a kidney. They just kept ignoring her throughout that period. She was having x-rays; it was getting bigger."

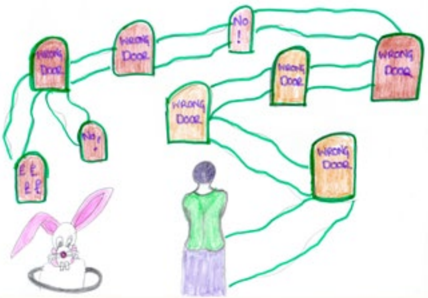
"I felt butchered because this was in the context of having had surgery outside of my consent, which has had life-changing consequences for me, and being told they did it because I was a woman of a certain age who didn't need all those other bits and pieces. And I was told, literally by the doctor, basically, we castrated you. That was the language they used."

Our healthcare experiences: we face barriers to accessing support

"One of the things that you find once you get an autism diagnosis is that becomes the overriding thing. My arm could fall off, and I'd walk into a GP, and they would say it's because I'm autistic. So, it creates a great big barrier to healthcare."

"That's got pound notes on it. Yeah, there's always the option to go private, isn't there?"

"I can't afford to go private anymore"



"We're just so behind in South Wales, you know, it's scary, really, and it's sad that we have to pay and go somewhere else to get the answers that we want."

"I've been told since that they probably won't prescribe it for me anyway because I haven't actually got COPD (Chronic Obstructive Pulmonary Disease) and you've got to be really, really desperate, and yet you can go and buy your way into an oxygen tank. Isn't there somewhere in Chester?"

Our healthcare experiences: we value the commitment of individual professionals

"When it's right, it's really good, and it sort of reinstates your trust a little bit in the system, which is great"

"He just sat with me and held my hand, literally just sat, and then he left with a hug, saying, we're going to be fine. We're going to do this, and I've got you, and I will be looking after you"

"Okay, so I'm one these rare, rare creatures where my GP is absolutely amazing. I know. I know. I know. I ring her up, and she will give me a call back. We have a chat on the phone. She diagnosed my fibro on the phone because she believed me when I told her"

"His whole ethos was about empowerment and patient strength and all of that kind of stuff."

I told my (young, female) GP I'd had back pain & bad periods & my mother had endometriosis. She actually didn't dismiss me! And sent me for a scan where they found a cyst the size of a large grapefruit.

"I tried to reflect that I don't think it's all bad because I think it's really easy to bash the NHS, but there are people there that are doing the best that they can with what they can, and I do see that."

"We had kindness and warmth and empathy from some individuals."

We are a community and we support each other

"Finding community. So even though I've lost a lot of friendships and things like that because a lot of my old friends didn't understand what I was going through, I found a lot of new friends, people going through similar experiences."

"When I was heading doing that journey of, oh, I might have to get a wheelchair, oh, I might have to get scooter. Listen, you kept me safe. No, thank you because without you, I'd have just locked myself away. And the thing that has been the positive is community. Croeso. So yeah, the welcome I've had from communities"

"It's a bit like therapy, getting stuff off your chest and talking to people that understand."

"So, community and activism and the love, even like all these people I've not met before today, there's been so much love in this."

"I did talk to myself as if I was the worst person on earth until I found other disabled people"

"FTWW, here for me."

"I was unwell, I was alone, I was struggling, and I was unheard. And then I found FTWW"

"And then someone I work with saw about FTWW, and I came to watch the video, and it was lifeline. So that was meant to be like a dinghy or something. So, the positive, there are people I can navigate, that help navigate the health system and support you on this fight, jumping through hoops. You're not alone because I did feel very alone."

"And then through FTWW, like you feel like you're the only one, before I met everyone, that you're the only one who's got like, loads of health problems, and that has a massive impact on your life. But sadly, there's a lot of people in the same boat, which is not nice, but it does, it's a good thing to know that you're not alone like that. So, support from other people, you know, who understand."

We are resilient and are adapting to life with our health conditions

“So, this is me, like, trying to fit, trying to, like, find a new path, and trying to fit all the new jigsaw piece puzzles back into what I think it should be. I don’t how to explain it, but it’s like trying to find, trying to find the right path to go on, so trying to find the right jigsaw pieces to go in the puzzle.”

So, you have to just keep finding those glimmers of hope and light, don't you?”

“So, I’ve had to accept these things are part of who I am now, and I can’t change that, so don’t fight it.”

“And then I feel like I’ve got a bit of a shield around myself, and also it makes you, makes me care less about some things that, you know, not in a bad way, but just hopefully the small things.

“I found a lot of inner strength. So even though I’m not strong physically, there’s a lot of things that I am strong at.”

Creating change has become our purpose

“Recognising actually that I have a voice. I think, as women, a lot of the time, we’re silenced, whether that be through shame or whether it be through the closed doors, we are silenced because people don’t want to hear”

“I’m teaching, I’m explaining, I’m enlightening.”

“So, I thought, like, I need to help others.”

“I’m contributing again. Might only be a little bit, but I actually do feel like I’m contributing, and I can make a difference. And the way that’s boosted up my self-esteem, which had been on rock bottom it’s really important”

“My niece is the same, you know, I’m doing it for them because I don’t want them to see them have to go through what I’ve been through.”

“And then through FTWW, again, I’ve done volunteering and advocacy things to help other people.”

Who created these drawings?

All of those who took part in the DrawingOut Long-Term Health Issues in Wales project described often difficult and challenging experiences, no matter what the symptoms or diagnosis. However, each of them is much more than a person living or supporting someone with a long-term health issue.

They are an avid reader. They are happiest with a cup of tea and good book in hand. They love to cook, to craft, and to wear the most colourful clothes they can find. They are an artist, a poet, an activist. They are a human who is just trying to make things better while eating ribs. They used to be a nurse helping patients. They are incredibly passionate about politics and equity for all. They love eating satsumas. They are a genealogist and social historian. They immerse themselves in stories of people from the past. They enjoy walking and exploring new places. They are a sequins and jewellery fan. They're owned by two furry monkeys that like to bark. They give their sister hope by breaking old behavioural patterns. They've been their family's liberator by confronting issues head-on. They are a writer. They are a cat and dog person.

They love all things Star Wars. They've experienced many highs and lows over 30 years of being a Liverpool Football Club fan. They are a family-oriented person who cherishes the simple moments spent with their granddaughter. They love gardening, cooking, and travel. They are an advocate for intersectionality. They spend time with their cat. They love a long walk in nature and the smell of freshly baked cookies. They enjoy connecting people and building community. They love to spend time with their son. They are passionate about the arts. They enjoy going to the theatre and the cinema. They play PokémonGo and practise Qigong. They are a keen baker. They are a human rights campaigner. They are mummy, holding little hands in theirs. They are a wife, a daughter and a friend. They are a runner and a hiker, and a professional who loves to be creative in any free time. They are learning to accept this new life.

Further information and support

FTWW, Fair Treatment for the Women of Wales

FTWW is a pan-Wales charity and disabled people's organisation focused on health equity for women and people assigned female at birth. It offers peer-support and resources to help people advocate for the healthcare and services they need. FTWW also offers opportunities to get involved in activities which can improve wellbeing, and influence health policy and practice.

ftww.org.uk

Women's Health Research Wales

Women's Health Research Wales is an all-Wales research centre dedicated to women's health, funded by Health and Care Research Wales. Its mission is to eliminate inequalities in the health and wellbeing of girls, women, and people who were assigned female at birth.

whrw.uk

Welsh Government and NHS Wales Women's Health Plan and Website

Launched in December 2024, the Women's Health Plan for Wales sets out a ten-year vision that outlines an NHS Wales approach to improving the health outcomes for all women in Wales.

www.nhs.wales/womens-health/womens-health-plan-for-wales
womenshealth.nhs.wales

National Health Service (NHS) Wales

NHS Wales provides information about health services near you. Its 111 Health A-Z pages detail symptoms, causes, management and treatment options for patients affected by health issues and conditions.

nhs.wales
www.111.wales.nhs.uk

Llais

Llais is the national, independent body set up by the Welsh Government to give the people of Wales a stronger voice in their health and social care services. They provide support to make complaints.

llaiswales.org

National Institute for Health and Care Excellence (NICE)

NICE produces evidence-based recommendations that guide decisions in health, public health, and social care in the UK. Its guidance is useable for patients, service-users, NHS and care-providers.

nice.org.uk

This booklet presents people's experiences of long-term health issues in Wales using their own artwork and words.