

Cyflwynwyd yr ymateb i ymgynghoriad y [Pwyllgor Iechyd a Gofal Cymdeithasol](#) ar [Cefnogi pobl sydd â chyflyrau cronig](#)

This response was submitted to the [Health and Social Care Committee](#) consultation on [supporting people with chronic conditions](#).

CC41: Ymateb gan: | Response from: Dee Montague-Coast



- **The readiness of local NHS and social care services to treat people with chronic conditions within the community.**

I am someone living with four chronic health conditions and trying to establish diagnosis for a fifth. My experiences since being diagnosed with ME and fibromyalgia have been incredibly poor; I would go as far as saying I have had NO treatment from the NHS and have actively had referrals to Occupational Therapy and specialist pain services refused.

Conditions are treated in silos with no patient-centred care and no shared decision making (the latter in breach of NICE guidelines, which clinicians then defend as not applicable to Wales). I have been given advice for one condition with no recognition that if I follow it, it might make other conditions worse.

I have had to pay for all of my mobility and disability living aids.

Too many people – myself included, are having to turn to charities to get the advice and support they need. These charities are often micro-charities and poorly resourced, and aren't respected by the systems that patients have to navigate. I now work for Fair Treatment for the Women of Wales (FTWW), the charity that saved my life; I had battled with my health, with decades of dismissals by healthcare professionals. I learned about pathways available to me through FTWW members, not the health boards whose systems I was trying to navigate. Information that should be readily available is actively withheld from patients, contributing to long diagnostic delays and a lack of appropriate help and support to treat conditions in the community.

- **Access to essential services and ongoing treatment, and any barriers faced by certain groups, including women, people from ethnic minority backgrounds and disabled people.**

I am a disabled woman. Using the telephone is inaccessible for me and it takes me around two hours to get up and be coherent due to the symptoms of my impairments. Yet the only way I can get an urgent GP appointment is to join telephone roulette at 8am and sit on hold for about 30 minutes, usually to be told that the appointments have gone. Appointments are either in-person (which causes me additional pain and fatigue and means my husband has to take time off work to take me to them) or over the phone. Healthcare professionals no longer mask in appointments (even when patients are), putting patients at additional risk. In 2023, especially after the global pandemic where the world moved online, you would

think it possible to have more medical appointments over video calls and a basic respect for public health measures to keep us safe would exist.

We do not receive medical letters and referrals about us as standard, so we are not kept in the loop on decisions made about us. I only found out my occupational therapy referral had been refused because I contacted the service to see how much longer I would have to wait to see someone. No one ever gave me a reason why, despite me making an official complaint. Communication – particularly around waiting times – is kept from us. Letters inviting us to book appointments are often unclear and have strict criteria; appointments must be booked by phone, in limited working hours (for example between 1:30 and 4:30), and there is a deadline to book by or you are removed from the waiting list. The lines are often engaged, and letters often arrive beyond the deadline or don't arrive at all, meaning patients are removed from the waiting list.

Waiting lists themselves are a huge issue. I am experiencing debilitating menopause symptoms, but I had to wait for 10 months for my appointment with specialist services. The follow up appointment was scheduled for five months later. I can expect to wait 2-3 years for a neurodivergence assessment, which I feel I need in order to be able to access medication to improve my quality of life and help me complete my PhD.

Twelve months before the pandemic, I experienced a loss of sensation in my left leg, with it collapsing under me often. I had to go private for any support in establishing the cause of this; a GP told me I was stressed and ordered me to clench my fists repeatedly before asking, "Better?!" . How on earth anyone could deem that acceptable care I have no idea.

I changed GPs and found a fantastic team with one GP in particular who was knowledgeable and helpful. I haven't been able to see her since before the pandemic, and during that time my mobility has decreased so much that for the vast majority of the time I cannot walk outside of home without at least a stick, but usually need a wheelchair. I can no longer drive because of the pain and loss of strength in my leg. There is no urgency from any NHS healthcare professionals I see to establish a cause or offer robust help and support, let alone recovery pathways. I believe I am seen as attention seeking, potentially hypochondriac.

With the numbness in my leg, loss of mobility and increasing uncontrollable spinal pain – and no NHS support - I went private to see a specialist rheumatologist who requested an x-ray on the NHS (due to how cheap it would be, apparently without delay). This was refused by my GP for twelve months - no shared care agreement could be established even though my GP had agreed to refer me to the consultant in the first place. When I finally had the x-ray, I was in and out of the room within two minutes. Twelve months of battling, just for that. The x-ray (and the rheumatologist) has suggested a condition called Bertolotti's Syndrome but needs an MRI to confirm and establish potential treatment pathways. My GP

informed me they are not allowed to book an MRI and had to refer me to physio to get the MRI referral. The physio service has so far refused the MRI, but now – about another year later – the specialist physio has agreed to see me. I don't hold out hope that I will get the MRI, as the specialist has already refused it twice. I believe cost is the only reason for this.

I have endometriosis and experienced a diagnostic delay of over two decades. I was forced to pay privately for diagnosis – NHS consultants who performed laparoscopies were not appropriately trained and told me nothing was wrong with me, suggesting that I had IBS. A specialist team is based less than ten miles away from the hospital in which I had my second failed NHS laparoscopy, yet I was refused any referral to them – despite my symptoms fitting the pathways according to NICE guidelines. A consultant shouted at me in an appointment telling me “WE are the specialists.” Over £10,000 later I have had two surgeries on my stage 4 endometriosis. The diagnostic delay caused my ME and fibromyalgia, bladder issues and permanent damage to my bowels – I have to do bowel irrigation every day to be able to go to the toilet. Block funding causes barriers to care rather than empowering services and patients, and there is no urgency to amend this, causing so much additional harm to patients.

Only very occasionally do I allow myself to think about / discuss the very fact that if I had received the optimum care I needed when I was in my late teens, I very likely would not have the impairments and mobility issues I am having now. I would be able to work full-time, enjoy hobbies, still play sport, ride my bike. I would be able to have full independence and not rely on disability benefits, I would not be leaving the house almost entirely for medical appointments (that are still ableist in their nature in that so many insist on being in person). I would not have to rely on my husband to help me and drive me everywhere as I can no longer drive myself. I would not have folders full of medical admin to keep on top of. I likely would not have been in abusive relationships (disabled women are twice at risk of domestic abuse), I would not be estranged from family members who (among other issues) thought I was making all of this up for attention because other relatives are disabled. I would not have been bullied and discriminated against in workplaces where employers were fixated on diagnosis / medical model of disability and refused me reasonable adjustments because of the failure to diagnose me twice...I cannot put into words how traumatic it is to return to work after a surgery to tell people who already don't believe you that: “They said there is nothing wrong with me”. I would not have medical PTSD (I haven't even bothered trying to get that diagnosed but tick all of the boxes) because of my experiences, in particular a violent internal examination from a consultant who was angry at my persistence that something was wrong with me, as a nurse who told me I was being brave as she held my shoulder down as I screamed and sobbed. I would not have two suicide attempts behind me. If I allow myself to think about all of this, I am scared I will spiral into a mental health spiral that will lead to my successfully taking my own life. I am

sharing this with this consultation with the desperate hope that something radical will change and no one else has to experience what I have.

- **Support available to enable effective self-management where appropriate, including mental health support.**

Let's start with the positives: pelvic physiotherapy has been hugely beneficial for my endometriosis management (including post-surgery scarring/adhesions) and bladder and bowel issues. My endometriosis nurse referred me to that service, as well as the bowel specialist nurse, which has been so helpful. I was declined pain management support initially because the locum GP I spoke to failed to cite endometriosis as well as fibromyalgia as a source of pain on the referral. Pain specialists won't see fibro patients despite the agony we live in – they claim primary care can support us, but GPs are often fearful of prescribing complex or high dose medication. Luckily my endo nurse did a referral too. The pain specialists increased my medication dosage which has been mildly helpful. They then wanted to discuss mental health. I have done CBT courses and practice good mental health myself through implementing CBT practices and mindfulness – I talked them through all I have done and do, and there were notable delays on the call (it was over the phone – despite that being inaccessible for me; I would like video appointments) as they were at a loss as to what else to suggest, despite my obvious neurodivergence and medical PTSD.

In terms of pain management, I am eligible to join medicinal cannabis trials and am willing to pay the private costs needed at this time, such is my desperation. My GP practice is delaying this process and hasn't sent basic paperwork to the clinic. [REDACTED]

[REDACTED]

[REDACTED]

[REDACTED] I hope that being prescribed an appropriate strain and amount will improve my quality of life, as well as feed into the vital research in this area.

The only advice I am getting from the NHS is to do CBT and exercise. Exercise is potentially dangerous for people with ME and – despite the NICE guidance removing exercise and CBT as treatment methods for ME due to that danger, as well as efforts by Physios for ME to educate colleagues on post-exertional malaise,¹ I keep being asked about exercise. Just today I was asked by a physio: “What do you mean, dangerous?” and “Couldn't you do low level activities?”. I have had to put in a complaint to the health board.

¹ Post Exertional Malaise <https://www.physiosforme.com/pem>

I keep being told about the National Exercise Referral Scheme (I worked in Leisure on and off for years, I know it inside out) – none of the classes are accessible in terms of activity or time of day (sick and disabled people do work too!). The only support service locally that I thought might be helpful has been inaccessible so far due to time of day – sessions are all during working hours.

There is a real danger at the moment that NHS services are obsessed with exercise / obesity and have no idea what else to suggest to patients who cannot safely exercise or lose weight, seeing our behaviours and lifestyles as the problem instead.

It is ludicrous that wheelchair services in Wales will only pay for basic models, meaning that so many have to stump up the cost or fundraise for the mobility aids that will help them keep their independence and – in many cases – allow them to do more of the things that keep them well, for example exercise, getting outdoors, working, accessing education, and socialising. It is seen as radical to believe that anyone who needs equipment should receive exactly what they need at no cost to them.

So many people in Wales living with chronic conditions have no idea that under the social model, they are fully entitled to call themselves disabled and therefore access support available to them. Systems need to be joined up so as GPs and other healthcare professionals are linking in with social services and making people aware of other support available – even discounted arts tickets, rail and travel cards et cetera. All of these things empower people to live a better quality of life, and help with the additional costs of being disabled – something that is poorly understood by non-disabled people who have been misled by the ‘scrounger’ narrative.

The Disability Benefits system should be devolved in Wales as it is in Scotland; the UK Government’s running of that section within the DWP has been known for years to be causing more harm than good, with the process of even applying being traumatic. So many of us – myself included – had to go all the way to tribunal to get what we are entitled to, and even then the award falls short of what is actually needed. The system is so traumatic and harmful, that recipients often talk about how triggering even receiving a DWP-labelled brown envelope can be. If the Welsh Government truly is committed to being socialist and implementing the social model of disability, they cannot continue to allow the UK government to inflict so much harm on disabled people.

Multiple conditions

- **The ability of NHS and social care providers to respond to individuals with multimorbidity rather than focusing on single conditions in isolation.**

This ability does not exist for me outside of my endometriosis specialist nurse appointments. As a result of my experiences, I genuinely believe that I have been seen as too complicated, so healthcare professionals would rather ignore me than try and help me find an accessible path to a better quality of life.

- **The interaction between mental health conditions and long-term physical health conditions.**

Take endometriosis as an example; we are told it's all in our heads, yet often never referred to mental health services. "It's ok to not be ok" seems to only apply if you feel a bit down – the advice then becomes exercise focused; "Go for a walk / run". We are told to get into nature, as if it is the most accessible thing to do and green spaces haven't been taken away from us. There is no appropriate care for people with severe and complex mental health conditions.

The isolation that comes from living with chronic health conditions is poorly understood, but it has a catastrophic impact on our mental health.

Six weeks of counselling / CBT seems to be the only option for us. There is no joined-up thinking or person-centred care.

Impact of additional factors

- **The impact of the pandemic on quality of care across chronic conditions.**

I haven't been able to see my preferred GP since February 2020. Waiting lists are out of control. My health has declined so much and there seems to be no way of improving it. Services were broken before the pandemic, Covid has had a catastrophic impact on them.

- **The impact of the rising cost of living on people with chronic conditions in terms of their health and wellbeing.**

I used to have massage treatments every two weeks which were hugely beneficial – I can now only afford these every 4-6 weeks. The costs of my supplements have increased. I have been advised to try acupuncture and can't afford to. I was having private mental health therapy every two weeks and can no longer afford it. When my health allows, I would like to try and swim every week (that is one exercise I can occasionally do) but I am worried about the costs – that's a very cheap activity traditionally, but has increased and getting there isn't always easy. I worry about the cost of electricity as I need it to charge my wheelchair batteries. I have to have regular baths and showers and worry about heating costs even as we go into warmer weather. Food costs are rising and that is starting to have an impact on my ability to eat healthily consistently.

- **The extent to which services will have the capacity to meet future demand with an ageing population.**

Services can't meet demand of chronically ill and disabled people. We are getting older, and our health will continue to decline with a severe lack of social care – I don't have any confidence in this at all.

Prevention and lifestyle

- **Action to improve prevention and early intervention (to stop people's health and wellbeing deteriorating).**

As someone whose mobility has been allowed to decline with absolutely no concern from healthcare professionals, as someone whose pain levels have been allowed to become completely unmanageable, this point made me laugh bitterly. Before my health deteriorated, I had always assumed that healthcare professionals would fall over themselves to treat, cure or help me manage my symptoms. Covid proved that this would not be the case, with 68% of deaths in Wales made up of disabled people.

There needs to be radical approaches to treatment of many symptoms. Things like medicinal cannabis could be revolutionary. People – especially women and marginalised groups – need early interventions and to have their health issues taken seriously from the outset.

Education in schools can do so much more. Young people, particularly girls, aren't learning enough about the benefits of healthy activity, food, social skills and relationships. So many still worry about what their body looks like over what it can do for them, so don't eat enough; many young women I speak to don't understand nutrition at all, nor do they understand the changes their bodies experience due to puberty. Girls drop out of sport at a higher level than boys, often because of menstruating and/or to focus on academic subjects ahead of exams, and so many develop eating disorders and a poor relationship with food. A more holistic approach needs to be implemented in schools to address all of these issues and help young people to understand what they can do to protect and improve their health. BUT, there must be acknowledgement that not all children will be able to participate due to impairments or other factors, and they must not be left behind.

- **Effectiveness of current measures to tackle lifestyle/behavioural factors (obesity, smoking etc); and to address inequalities and barriers faced by certain groups**

The onus is placed entirely upon the patient; eat a perfect diet, exercise often, lose weight, don't smoke, drink, or take drugs. Many patients living in severe pain or with other debilitating symptoms, on long waiting lists, will self-medicate – especially when the NHS is not radical or proactive in helping to prevent or intervene with severe pain or symptoms. If we fail in these activities, we are seen as undeserving of treatment and care.

If the NHS can't recognise the barriers faced by disabled people to manage their health through diet, weight, exercise, not smoking/drinking/taking drugs, what hope for people who aren't facing additional barriers?

The BMI scale was never intended to be a measure of health, and certainly doesn't accommodate for female bodies, especially those from global majority ethnic groups. I once had a health check where the first thing the nurse did was calculate my BMI. I was told I should consider doing some exercise to lose some weight – at that time I was playing roller derby and training 4-5 times a week at my club and in the gym. I was in the best shape I'd ever been (still living with chronic health conditions), but was told I was borderline obese so should rethink my activities. What if that had triggered the disordered eating I experienced in my teens?

Healthcare professionals should already have the information and resources they need; they should be able to treat illnesses, and medications can already be dosed appropriately for patients taking weight into consideration. If they need to educate patients on the benefits of a healthier lifestyle, they already have those resources. BMI is not an appropriate tool for female health, and should not be the first consideration – and often the first reason for dismissal of women's symptoms.

There are real dangers with the NHS and politicians' approaches to current measures; diet and exercise are too often seen as treatments and cures, and sick and disabled people are judged unfairly when they can't 'control' their symptoms through activity and food.

The Welsh Government's commitment to implementing the social model of disability must be actioned swiftly and with excellent communication to professionals and wider society. Us patients need to stop being treated as if we are the problem and to blame for our health issues, and the systemic barriers must be addressed. Our society is systemically ableist and this is felt acutely by disabled people accessing health services. There is racism, gender bias and medical misogyny in our health services – we need a brave and radically different approach that recognises these issues and works hard to eradicate them instead of skirting around the issues or pretending they don't exist.

Submitted by Dee Montague-Coast, as an individual

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