

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](#).

CC11: Ymateb gan: | Response from: Alison Butler

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Contact details

Mrs Alison Butler

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I'm 52 yrs old

Submitting as an individual

I have diabetes, Post Covid Vaccine Sequelae, chronic pain & long covid

Some might not be in date order, I'm not quite sure how to explain things so going to set out my experiences and my multi health conditions in a timeline

I had a reaction after my first AstraZeneca covid vaccine

Accessing healthcare was difficult during 2020

Understandable due to covid

However at the time having a change to sensation in my foot was upsetting due to being diabetic

There were other symptoms, neurological and also an increase in my normal previous well controlled pain

I was referred for blood tests, then a wait, my one GP doing what he could to get the tests sooner.

I'd started keeping a symptom diary, I was forgetting things

I then had a relapse of symptoms within hours of my second AstraZeneca

I couldn't get an urgent appointment, I couldn't get a message to my GP

I told the receptionist I had a numb foot, soonest appointment was three weeks away.

I fill in an econsult, due to a numb foot it kept giving me a red screen telling me to contact my GP

My leg gave way a few days later , I managed to get an urgent appointment , on the telephone, it was a different GP. She'd told me my blood tests were fine, that I'd been examined twice and how graded exercises would help me

I tried to explain in tears that before these symptoms started that I'd worked part time and took regular walks with my dog.  
I had to ask in between tears if she was going to help.

She agreed, to check my legs, just to put my mind at rest she said but not any of the other symptoms  
We arrived at the surgery, it was busy with urgent cases

The GP saw me  
Examined my leg, asked me to push up against her arm  
I did, she asked me again, I did.

She then said that I wasn't pushing up, I said I was ( I'd really thought I was)  
She then snapped at me, I snapped back, I managed to move my leg

I expressed my concerns regarding the vaccine, regarding MS due to symptoms of my hand and leg would flick out, that my foot wouldn't lift to go up.

She wasn't concerned, but I was put on sick leave

I had a follow up.. another fit note

I might miss some details but I've kept a timeline of appointments but have kept a symptom diary up until around October 2021

I had an increase in pain , I managed to get a same day appointment through my health online  
I'd explained about a pressing pain in my back that was new, an increase in pins and needles, but it was decided that I'd need to have the ABPI test first, then to see the results first  
I was left in unmanageable pain, no f2f appointment, mental health suffering

Fast forward to another appointment that I'd managed to get , I'd explained to the Dr about the new pain in my back  
He asked about my legs  
I was asked to go straight to the Drs to be examined  
At this appointment I was referred to Orthopaedics and a MRI

There was other times I'd tried getting appointments to be firmly told no, no appointments even though I was crying in pain

October 2021, I enquired about waiting times  
Was told Orthopaedics were seeing urgent 2020, I was routine August 2021

We went private, was referred for another MRI and nerve studies

MRI , they saw me very soon after the referral

We rung nerve study the beginning of December , we were lucky, they a cancellation for the following morning

We then waited, January 2022, contacted NHS orthopaedics, still on the list

End of January 2021 due to the pain, needing to get back to work, also decline in my mental health we went private again to orthopaedics  
I'm diagnosed with chronic multi level degenerative changes

Orthopaedics referred me for a CT scan but also to a Neurologist as I had symptoms that need ruling out

Due to waiting lists, we went private to Neurology

The Neurologist explained how I was the second person he'd seen that morning who'd had problems after the covid vaccine  
Hess explained how he'd refer me for a brain MRI to rule out any demyelination changes eg MS, but also explains how the scan will probably come back as satisfactory like the other patients he's seen with problems after the vaccine

He'd diagnosed UNEXPLAINED NEUROLOGICAL SYMPTOMS IN THE AFTERMATH OF A COVID VACCINE

MRI Brain, we opted to go private

I will not go private for a scan again, I suffer with bad anxiety in closed in spaces. The private staff were no as kind and compassionate as the NHS MRI professionals were with me

The scan came back as satisfactory

My mental health was now really suffering, struggling with the changes to my life, that some were not accepting of the NEUROLOGISTS DIAGNOSIS

Short version I was referred to counselling regarding a lack of a diagnosis that others would accept, was struggling with my disability  
March I contacted covid, the only places I'd been that week was a health care setting

I was struggling with pain trying to walk also suffering with my balance

I asked my GP how to get measured for a walking aid  
I had to refer myself to MSK Physio  
I filled in the online form  
Had a telephone triage  
Was referred as urgent and seen in four weeks and received an elbow crutch

I emailed the Welsh Health Minister asking for help for the problems after the covid vaccine  
8 weeks later I received a reply on her behalf  
That patients receive information prior to the vaccine so that they can make an informed choice , with a link to the current vaccine side effects for June 2022

I'd kept the information leaflets that I'd received March and May 2021  
Much more was known 2022 compared to 2021

I was seen May 2022 by NHS Orthopaedics, was seen by a senior physiotherapist. He explained my scans were fine.  
I'd tried talking about the problems after the vaccine, how some were not accepting of the Neurologist diagnosis  
That I'd been absent on sick leave for nearly a year and was coming close to losing my job.  
He'd told me that as a spinal department, there was nothing they could do for me, that I'd have to challenge the Neurologist about the diagnosis.  
I asked to be referred to pain clinic.

Just as we were leaving the cubicle, he stopped me and said the pain might be coming from my back.

I applied for my medical notes, the clinic report from orthopaedics stated the pain might be coming from my back and that Physio might help

I was seen at another trust

I had given this consultant the same health history/timeline as the other health care professionals that I'd previously seen

I have several tests including a chest X-ray and ecg

I was diagnosed with the following

1: Post Covid Vaccine Sequelae

2: Worsening chronic multi level degenerative spinal changes triggered by 1

3: Long Covid Post Acute infection and 1

At another review they state I have complex pain needs

I dread to think where I'd be if I'd not chased a Diagnosis

I start counselling, but now it's not for having a diagnosis, it's for the way I've not been believed by some in healthcare  
For how the vaccine has ruined my life

I raise a concern with the PUTTING THINGS RIGHT TEAM regarding the Orthopaedics appointment

I then receive a letter from pain clinic, they can't offer an appointment due to information missing

Several weeks later the Concerns manager asks for the information that was missing from my pain clinic referral. It was my current medication tried and current

A couple of months later i explained to my GP about the medication had been missed, that another department had asked if he could send pain clinic the missing information

My GP does and I hear off pain clinic, they will not see me. They offer written advice to my GP

Pain clinic didn't even get my full health history off me, not even a telephone consultation

Not long after I'm invited back to Orthopaedics for a clinic review due to raising a concern about the appointment 6 months previously.

The Concerns manager came with me, to support me. I was quite anxious, because of raising a concern and scared I'd be treated differently.

The consultant snapped at the Concerns manager, asking what she was doing here.

Then he spoke to me different to how he spoke to me at the private clinic. I'd didn't get to discuss my ongoing symptoms and difficulties properly, I'd felt stressed and rushed

Even though the Neurologist that orthopaedics had referred me to, had sent a clinic letter to orthopaedics, orthopaedics did not want to discuss how the vaccine had made my well controlled pain worse  
Not his specialty, knows nothing about the vaccines  
He agrees to refer me back to pain clinic asking for a f2f  
I'd gone to that appointment with hope and came out more upset

I get a letter from pain clinic, they still won't see me, the written information still stands even though they don't have my full history  
How this pain was well controlled

I then get covid again, the only place I'd been again was to health care settings  
This time there's no track and trace  
We contact the different healthcare settings, to warn them that I might have been infected  
One hospital ward, they say not to worry as they are testing patients every so many days as there are patients with covid on the ward

This second infection leaves me needing inhalers

During this time, I'm needing help with ADLS  
My husband becomes my carer

I can't shower with out help

I'm advised to refer myself to Occupational Therapist, I get loaned a bathboard, bath step, they install a grab rail

I still need help to get my leg into the bath and off the board

I'm offered a loan of an electric bath chair. But I'd still need help to get my leg over the bath, but also every time I need a shower, my husband would need to fix the chair in place

I'm told by Occupational Therapist that it's what the council can provide to meet my needs, not what I want

But I don't call having a shower about every 4 weeks with the occasional flannel wash by the sink as meeting my needs

We've been advised as my husband works full time we won't meet the criteria for the disability grant to fund a walk in shower

I just want some independence, to be clean, to have some dignity  
I'm also not entitled to ESA because my husband works

So we are not entitled to several things because my husband works full time but he also then has to help me

It's been advised that I'm referred for counselling for loss and adjustment for the disability I'm now having to deal with but I can't start until my work situation and the concern I'd raised to the putting things right team is finalised

I'd raised the concern August 2022, I last had contact January 2023. Even though I've emailed twice since I've still not had a reply

2023 accessing GP care has become a bit easier, my one GP has been supportive, I can ask for him as I have complex needs

I've been in a really dark place, due to what we've been through

This is what I'm up against, chasing appointments, being sometimes passed back and fro. Not my speciality, can't help, discharge. Instead of I can't help you but I know I can refer you to another department.

I've recently been awarded ill health retirement  
The IRMP states that my numerous health conditions have been significantly exacerbated by the covid vaccines



So I have been dismissed from my job  
I'd worked in a school with children, I'm diabetic, was told I was vulnerable,  
had the covid vaccines. It didn't keep me safe

I use a crutch around the house , a wheelchair when out . I have a blue  
badge.

There's no joined up care  
There's no support with help with information, support for benefits

So many are still dismissive in healthcare of the post covid vaccine sequelae  
diagnoses that I take my clinic reports to each appointment that I now  
attend

Forget to add May 2022 I was referred to secondary care Diabetes  
department, May 2023 I was seen

I've missed quite a bit out, but I do have a timeline of appointments, emails,  
conversations, clinic reports to support everything that I have written here

Regards  
Alison Butler