

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](#).

CC72: Ymateb gan: | Response from: Barbara Chidgey



Supporting people with chronic conditions

My name is Barbara Chidgey. I am submitting these views as an **individual** and confirm that I am aged 18+ years.

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Brief medical background: I have coeliac disease, one of the first people ever to be diagnosed in 1951. Very severely ill and anaemic in my early 20s. Pregnancy, birth (C-section) and other complications. I had major back surgery in 1993. I developed fibromyalgia in 2001 and lupus (after multiple acute medical crises) was diagnosed in 2018. I live daily with highly significant levels of chronic pain, and fatigue.

In addition, I have APS and multiple other AI conditions. I am immunosuppressed. I have numerous monitoring and treatment consultations. These generate from lupus attacking my body and organs. I have contact with many clinical specialities including Cardiology, Rheumatology, Nephrology, Bone Treatment Clinic, CAVOC (lupus has also attacked tendons in both hands), Gastroenterology, ENT, Maxillofacial, occasional Clinical Psychology support from the Pain Management Clinic at Velindre. I lurch from acute crisis to crisis; my last in-hospital experience was October 2022 when a perfect storm of bacterial infections including rhino virus, upper respiratory infection, E.coli, a UTI then led to a bladder infection, to a kidney issue and sepsis. You will realise I have had a lot of engagement too with paramedics, A&E, assessment unit. And of course primary care, phlebotomy, and with pharmacies.

I am a very highly activated patient and have developed a very high level of 'knowledge, skills, and confidence' to self-manage my health and illnesses. I am extremely well informed and articulate. I am very determined and able to navigate my way round the NHS system (or have found ways to bypass it).

I am very well networked across various patient and NHS bodies and systems, and hence even better informed by listening to the experiences of others.

As a result of my intense personal experiences I founded the charity called [Daring to Dream](#) (1190590), whose mission is to support the emotional health and wellbeing of adults in Wales living with physical illness. This has extended my knowledge and understanding enormously as I meet more and more adults living with physical illness and different clinical teams who care for them.

Fundamental to supporting people with chronic conditions is understanding that we all experience illness both physically and emotionally.

The primary focus of clinicians and their teams (at both primary and secondary care) is on the biomedical aspects of care, responding to and addressing the clinical and physical needs in response to illness. The emotional aspects of living with illness are not usually considered within the context of medical care. (Hence the need for Daring to Dream to complement the work of the NHS.)

With careful self-management of my conditions, I can manage my pain and fatigue for a few hours most days enough to function in ways that matter to me. I have been divorced many years and have no family in Wales.

It is very difficult indeed living with reduced social activity, loss of career, hobbies, activities, friendships, and lots more. This is the reality of living with chronic illness.

NHS and social care services

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

Sadly, there is no readiness for this at all in the local community. At my personal GP practice, there is little chance of accessing a GP, minimal chance of accessing a nurse. In both cases, appointments are for at least 4 weeks in advance. There is no access to services such as physio, pain management, dietician, COPD clinic etc Access to blood tests at the GP surgery is a battle I have given up on. It is a regular struggle to access repeat prescriptions – even via myhealthonline! The practice has insufficient GP coverage and depends on paramedic support; the paramedic team are a good team and far more engaged (and solution focused) with the patients than the GPs are.

The practice is very badly managed and led. The practice leadership needs to be driven forward by the clinical leadership needs (not by the management needs) and must put the needs of the patients front and centre of decision-making and the needs of the clinical teams that support them close behind.

Instead, the administrative 'tail' is in charge and 'wags the dog', dictating processes and blocking patients from appropriate support. This is a very, very serious, and common issue across Wales. I hear this over and over from across my pan Wales patient networks. Yes, there are pockets of good practice, but they are very few and far between.

In an acute scenario, in my experience primary as well as secondary care overall respond well. Acute crises need 'transactional' responses and actions. That is what the NHS is focused on.

However, supporting people with chronic conditions needs to be about working in equal partnership with patients and their families or carers in a planned and proactive manner. Genuine co-production.

Currently this is simply a 'wish' or even worse 'tokenism' and not common practice.

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

As a woman at primary care level, and at times in secondary care, it is likely that I frequently won't be listened to. This is my regular and oft repeated experience.

For instance, I had a major heart attack in early 2016. My heart attack did not present as a man presents with a heart attack, so I had no reason to recognise the symptoms. I experienced the so-called 'silent' heart attack, common for so many women, I now realise. I just knew I felt very, very ill and by the next day, when I went to the surgery's 'walk-in' clinic, my ankles and legs were already so swollen and I already struggled to breathe.

I sought medical support and was sent away with a prescription for anti-depressants. That saga ended many weeks later (even though I had repeatedly visited the GP surgery seeking assistance) with me having just arrived on a cardiology ward (via a private cardiac appointment when I was finally given a diagnosis of acute heart

failure). On admission to the cardiac ward, I almost immediately had a spontaneous pulmonary oedema. If I hadn't been on that ward, I would have died.

I regularly have different conversations in the GP surgery where I feel not listened to. I have frequently been told that I am 'above their pay scale'.

Recently I am convinced that I had another mild cardiac episode. I did manage to be checked over by a locum GP a few hours later. He did not listen to me, had never met me before, knew nothing about my context. He decided I had vertigo and sent me away with a prescription to deal with labyrinthitis. Totally ridiculous.

For me to access essential services, I now mostly bypass primary care. I have my own co-created trusted relationships with key clinicians, email them directly for relevant assistance, interventions, and referrals. Primary care refuse to prescribe my immunosuppressants; so these prescriptions are dealt with by secondary care, posted to me together with my monthly blood test monitoring forms. I take my blood forms and drop in at phlebotomy at UHL as it suits me – and avoid battling with Primary Care admin telling me they have no appointments for blood tests – even though I know that the UHB fund some of their phlebotomy hours!

I have learnt to bypass the system to reduce stress on me.

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

In reality, there is minimal support or interest in supporting people to self-manage effectively. I am well aware of the EPP programmes (because of my involvement in patient networks). No one has ever suggested I join in with one. Neither am I convinced in the level of change they provoke.

Emotional health is continually confused with mental health:

I must speak up strongly to say that most people living with chronic conditions may well **NOT** need mental health support; first and foremost they need acknowledgement of their emotional health and conversations with trusted health professionals when they can simply say how they feel and not be subjected to merely transactional content.

If we are 'given the 'space' and permission to also talk about how we feel as well as what symptoms are worrying us, that would have a huge impact in helping us name

the emotions we are experiencing related to living with chronic illness. The permission to do this within our conversations with health professionals helps us to then express those emotions appropriately.

This really could help avoid so much escalation into mental health.

Addressing emotional health is the essential first step and is currently overlooked since the various medical staff are focused on being transactional and ticking that patient off on some list as 'job done'.

Training health professionals to discuss emotional responses to illness with patients and their relatives and help them come to terms with their emotions would have a huge impact. It actually could save the NHS vast amounts of time and resources, and importantly help patients live their lives as well as possible whilst living with chronic illness.

A lot of mental illness that arises from those living with long term physical illness can indeed be prevented by a stronger focus on emotional health. Health professionals must accept that discussing emotions is an essential part of their patient / HCP relationships and conversations. Instead they turn away, shut you down as a patient and send you away with nonsensical prescriptions.

Mental health services and support are needed for those with psychological issues such as clinical depression, schizophrenia, addictions to alcohol, drugs, eating disorders, suicidal thoughts, and suicide attempts. Lets ensure that we don't refer the wrong people to those services and stop those that really need them from accessing them.

It is essential to separate emotional health from mental health.

Multiple conditions

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

Non-existent! It is appalling – everyone is in a silo: 'I only do hearts, you will have to speak to nephrology', 'I only do kidneys, you will have to speak to orthopaedics', 'that's not my expertise' 'I can refer you to Z?' (i.e. if I refer you, my job is done and I can tick you off my list)

I don't want any more referrals or tests, I need one person who is my 'medical mentor' who works with me (in equal partnership) in a trusted relationship, helping me navigate the system, join up specialties into shared opinions and treatments, chase up appointments and letters and ensure I get my copy, and treat me as one person with one body – not as a load of 'bits' with one bit in cardiology, one bit in nephrology, one bit in Llandough, one bit in Primary care etc.

It feels that no one knows who I really am. It feels that no one actually cares. Just get me in, tick me off their list and send me out purely transactional and certainly not leadership in any shape or form.

Sometimes I feel I want to fall on the floor in the concourse at UHW and shout out 'I am not a number, I am a person' (Actually I have had clinicians tell me they feel the same.)

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

What interaction? I am well aware that mental health conditions often arise from long term physical conditions because no attention has been paid to the patients' emotional responses to their illness. I repeat again, what I said up above. It is essential to separate emotional from mental health and clearly identify which is which and then respond accordingly.

Training health professionals to discuss emotional responses with patients and their relatives and help them come to terms with their emotions would have a huge impact. There needs to be an expectation on the health professionals to be open to doing this. It is not complicated. It does not take a lot of time. It is about being a human being and really listening to another human being.

If the step above takes place, then it will assist health professionals to better identify those who are at risk of or who already do have a mental illness. Just because a patient is tearful doesn't mean they are depressed – they may well be sad, suffering grief and loss, all of which are some of the basic emotions that arise for those living with long term physical illness.

Mental health services and support are needed for those with psychological issues such as clinical depression, schizophrenia, addictions to alcohol, drugs, eating

disorders, suicidal thoughts, and suicide attempts. Let's ensure we allocate those essential services to those who really need them.

I repeat that it is essential to separate emotional health from mental health. Health professionals across all disciplines, not just oncology for instance, must acknowledge the emotional impact of living with physical illness, allow patients to talk about their emotions, express empathy and understanding – instead they say: 'I can refer you for counselling', 'I can refer you for mental health support' or 'I can write a prescription for anti-depressants'..... no, as an individual patient you first need an empathetic listener with whom (in the clinical context) you can discuss and express your emotional response to the illness and its treatment.

Impact of additional factors

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

Of course the pandemic increased pressure on the staff. The operational challenges are still severe and are adding to the unrelenting pressures on them.

For all of us living with chronic conditions, the pandemic increased pressure on us. Services have been withdrawn, never to be replaced. And we still live with our longstanding illnesses, the pain, the fatigue and all the unrelenting pressures of living with chronic illness.

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

I am not really able to comment on this. I am past caring; I simply spend what I need to spend and draw on my savings. When they are gone, they will be gone.

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

The answer is simple – they will not have the capacity and they don't have it now. It is essential we work together in proper co-production and enable all the population to better self-manage their own health and ill health when it happens.

Prevention and lifestyle

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

No 'body' can stop an individual's health and wellbeing deteriorating. The issues of poverty, demographic groups, ethnicity, employment / unemployment, genetic diseases and illnesses and factors, lifestyle and more – together they represent about 80% of the causes of illness that are beyond the scope of NHS systems or personnel to 'stop'.

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

As human beings we are all responsible for our own behaviours. We learn well from those we trust and respect within conversations.

Siting health services in primary schools and utilising the trusted relationships to develop 'knowledge, skills and confidence' to manage our lifestyle, health and ill health would be very beneficial. Children are great too at influencing changes in their parents' lifestyle, exercise, food etc

Co-production must be at the centre of change, not lip service to co-production but actual 'working with' the community to create change together. Less of (a) and (b) and lots more of (c):

- a) 'doing to' i.e. telling people not to smoke, telling people to exercise etc
- b) 'doing for' providing information (leaflets etc which usually focus on risk), creating focus groups maybe to include participation
- c) Co-production needs to become real and to shift into properly 'doing with' and 'working with'. Treating the public, patients, their families and/or carers as **equal partners**.

- 3. You are welcome to comment generally or specifically about a certain condition.

Pages 9, 10 and 11 are my personal notes re: emotional health.

1. The context of living with physical illness:

We all experience illness both physically and emotionally. The primary focus of clinicians and their teams is on the biomedical aspects of care, responding to and addressing the clinical and physical needs in response to illness. The emotional aspects of living with illness are not usually considered within the context of medical care.

Our emotions arise in response to being faced with any situations that we consider personally significant. Dealing with acute or chronic illness is certainly a situation that is personally significant to all of us. It is essential we acknowledge our emotional responses to illness and identify which emotions we are dealing with to find ways to cope with those responses. That then give us the 'headspace' and capacity to focus on practical solutions to living as well as possible with our illness or condition.

Fear and anxiety: A serious illness, acute or chronic, creates lots of uncertainty across much of our life. That uncertainty can feel very scary and frightening, for the patient and for her/his family. It feels frightening because it can take quite a bit of time to gain knowledge and understanding of the impact of the diagnosis, the illness, and its treatments. It takes time to 'get our head around it all.' Illness also leads to a great deal of concern and worry. The worry can feel more like fear and anxiety.

Anger and irritability: Living with the illness often leads to a feeling of being lonely, isolated, and on our own. This is a feeling that can come and go. The distress caused by illness in turn creates an emotional response of anger or feeling irritable. It is also possible to feel resentful at times when living with or alongside illness when other people around us are perfectly well; seemingly getting on with their lives OK.

Sadness and grief are very common emotions resulting from illness. A huge amount of loss arises from illness – of careers, income, lifestyle, friendships, independence, social activities, of hobbies we enjoy, and lots more. Sadness may come and go or may be present most of the time. There is no time limit on grief or sadness.

We are not in control, in the way that we were pre-illness, of what is happening to us, our bodies, or our lives. We all feel more secure when we have a sense of control, able to plan things we want to do and enjoy the things that we do.

2. What are emotions?



Emotions are short-lived and intense; usually they have an identifiable cause. **Feelings** result from specific emotions, influenced by, for example, beliefs and memories. Emotions are about how people deal with situations that they consider personally significant. Illness is a situation that we will consider personally significant.

The 6 basic emotions:

1. **Happiness:** is about enjoying life and living it to the fullest, characterized by feelings of joy, contentment, satisfaction, [gratification](#), and well-being.
2. **Sadness:** plays a vital role in signalling one's need for help or comfort characterised by feelings of disinterest, hopelessness, grief, disappointment, and low mood.
3. **Fear:** serves a vital role by activating the fight-or-flight response and keeping us safe. Fear is triggered by a real or imagined threat or danger.
4. **Disgust:** signals us to get away from or eliminate something offensive, toxic, or contaminating. Disgust response can be triggered by such things as blood, infection, poor hygiene, rot, and death.
5. **Anger can be helpful when it is expressed constructively**, and it can lead to actions that can help find solutions to challenging problems. Anger is characterised by feelings of agitation, hostility, antagonism towards other people, and frustration.
6. **Surprise:** a very brief emotion and is characterised by a physiological reaction to something unexpected. This emotion quickly gives way to anger, happiness, fear, or disgust, depending on what provoked it.

Sources:

Paul Ekman <https://www.paulekman.com/universal-emotions/>

[6 Types of Basic Emotions and Their Effect on Human Behavior \(calmerry.com\)](#)

3. What is emotional health?

Often the terms mental health and emotional health are used interchangeably. However, mental, and emotional health have very different meanings and it is important to differentiate between the two.

Mental health influences our thoughts and actions, and it covers three main types of well-being:

- **Psychological**
- **Social**
- **Emotional**

The World Health Organization defines mental health as: “Mental health is a state of well-being in which an individual realizes his or her own abilities, can cope with the normal stresses of life, can work productively, and is able to make a contribution to his or her community.” There are a wide range of symptoms associated with mental health problems, including severe changes in mood, feeling a lack of energy, overeating or under-eating, insomnia, excessive sleeping, and increased use of drugs and alcohol.

Emotional health is about being emotionally self-aware and being able to express our emotions appropriately.

And it is emotional health & wellbeing that the charity Daring to Dream is focused on supporting.

Why does this matter?

It matters because we experience illness (and the impact of its treatments and interventions) physically and emotionally. The clinical teams who treat us provide great medical expertise and care, but it is essential we also address our own emotional responses too in order to live as well as possible with physical illness.

There is a growing evidence that patients who are physically and emotionally robust, or can be supported to be so, make better recoveries. Some patients, who are living with chronic illness, without a doubt have to face the increasing fear factor of having to come back into hospital repeatedly at times when maybe they want to study more, develop their career, develop their independence, or start a family ... so to do that with a long term health condition requires an increasing focus on emotional health and wellbeing.