

Ask How I Am

Supporting emotional health
among people living with
long-term conditions

 National
Voices

Centre for
Mental Health



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Summary

Mental and physical health are closely related. People who live with long-term physical conditions are twice as likely to have poor mental health as those who do not. Before the COVID-19 pandemic, one-third of people with a long-term condition also had a mental health problem, and for people with multiple long-term conditions the chances of having poor mental health are greater still. It is highly likely that this has increased further during the COVID-19 pandemic. Many of the people who have been classed as clinically vulnerable or extremely clinically vulnerable during the crisis have long-term conditions. The day-to-day realities of shielding have had a profound effect on people's home, social and work lives – disrupting their medical care and access to support while creating new health-related anxieties. And once again, people and communities with the least resources and greatest adversities have seen the biggest impacts on their mental and physical health.

During the pandemic, we spoke with people living with long-term conditions, their family members and the healthcare professionals who work with them, to understand the relationships between having a long-term illness and people's emotional and mental wellbeing, and to identify ways of improving people's experiences and outcomes. We found that:

Having a long-term condition affects people's mental health in a number of ways, including coming to terms with the illness and its effects; living with it day-to-day, and for many years; the burden of having to go through repeated appointments, treatments and procedures; and the effects on people's relationships.

People's experiences varied according to a number of factors. There was as much difference between people living with the same conditions as there was between different types of illness. Key factors included age; racial discrimination; poverty and financial difficulty; and fluctuating and progressive conditions, which mean people's experiences and needs change over time.

Aspects of people's physical healthcare either helped or undermined their emotional wellbeing. Key aspects of care for a long-term condition that people found helpful (or would have liked) for their mental health included: continuity of care over time; being given information and treated as a partner in their care; support and advice being given between appointments; and small gestures of care from healthcare professionals, such as asking people how they are feeling during a consultation.

People had accessed a range of forms of support for their emotional health, from informal help from friends and family to treatment from health and care services. No one form of support was universally helpful. There is no 'one size fits all' solution. More important than the form of support was whether the person providing it had insight (either from professional training or personal experience) into what it was like to live with a long-term condition.

Key elements of an effective system of support for people's emotional wellbeing and mental health included: making emotional support a standard part of care for their long-term condition; psychological interventions; joined-up mental and physical healthcare; a holistic, whole-person approach; being offered help proactively, not having to search for support; peer support; opportunities to give support to others; help for carers and family members.

Numerous barriers stood in the way of accessing mental health support. People told us about a lack of opportunities to disclose distress, both during and in between medical appointments; strained relationships with healthcare professionals; poor communication about the support that is available; a belief that the NHS and its staff are already over-burdened; mental health stigma and discrimination; and previous bad experiences of getting mental health support.

As a result of these findings, this report has one overarching call to action: **Ask How I Am**. That means all healthcare practitioners and services working with people living with long-term physical conditions to show care and compassion in all their interactions and to take every opportunity to ask about emotional wellbeing.

This can begin now. In some places, it happens already. We know that many healthcare practitioners already provide compassionate care to people with long-term conditions. We also know that the pressures of working in health and care services often make this difficult; and never more so than during and in the aftermath of the pandemic. Many healthcare practitioners are currently exhausted and overstretched. Some are traumatised and experiencing their own mental health challenges. Short appointment times, inadequate training and patchy availability of mental health services make it more difficult to support people's emotional wellbeing.

But we need to ensure compassion is universal. This is the business of all healthcare practitioners, no matter what their role, speciality or client group. And service providers have a special duty of care to those living with long-term conditions who are dealing with the particularly difficult ongoing and after-effects of the pandemic.

To improve emotional support will require significant system change. It is crucial to ensure improved mental health literacy among healthcare professionals working with people with long-term conditions; longer appointment times and regular holistic health checks to allow routine enquiry about people's emotional wellbeing; and access to a wider range of support for people's mental health as a standard element of care, including signposting to voluntary and community organisations providing advice, peer support and advocacy. It also means recognising how the social and economic determinants of health affect people living with long-term conditions.

As part of the NHS' commitment to 'build back better' in the wake of the pandemic, we emphasise the urgent need to build a system where anyone living with a long-term condition is supported with their emotional health at every stage of their journey. To make that a reality, we set out recommendations for system change, both nationally and locally, which we believe will enable significant improvements to be made:

1. NHS England, Health Education England, health professional bodies and education providers must ensure that all health and care workers who work with people with long-term conditions have a sound basic knowledge and understanding of mental health, and of the emotional impacts of having a long-term illness. This should be included in basic training for all relevant health and medical professionals. And it should be included within continuing professional development (CPD) for existing staff working in primary, acute, community and mental health services.
2. NHS England and the British Medical Association should consider whether general practices should receive funding as part of the GP contract to provide an annual holistic health and wellbeing check for people living with long-term conditions. This would include routine enquiry about the person's emotional wellbeing alongside other issues they are facing, beyond but connected to their clinical condition – for example relating to personal finances and relationships. Where needs are identified, practitioners would offer signposting and onward referral to relevant support. Where annual health checks for people living with long-term conditions are already carried out, those designing and delivering them should ensure that emotional and other issues are now included alongside clinical considerations.
3. NHS England should explore options for increasing appointment times for specialist long-term conditions consultations and providing improved access to specialist advice and help between appointments. This will require an increase in capacity, but it is likely to be cost-effective by improving outcomes and reducing later costs.
4. NHS England should review the IAPT Programme for long-term conditions to determine whether its current approach and structure is able to meet people's needs adequately, how easily accessible it is for people with the full range of long-term conditions, and what modifications may be needed to achieve these aims during the implementation phase of the NHS Long Term Plan.
5. The Government should ensure that the implementation of the COVID-19 Mental Health Recovery Action Plan addresses the mental health needs of people with long-term health conditions, with funding allocated to support for those with unmet needs resulting from the pandemic.
6. The Department of Health and Social Care should use the Health and Care Bill to ensure Integrated Care Systems will be held to account for providing adequate levels of mental health support to people with all long-term conditions. This should be regarded as an integral element of population health management, and systems should have to account for how they identify and address the needs of their communities.
7. NHS England should ensure that there is equality of access to effective emotional support for people with long-term conditions across all protected characteristics, and especially for people from racialised communities. The Advancing Mental Health Equalities strategy (NHS England, 2020) could facilitate this. The strategy aims to bring about system change to improve the experiences and outcomes in mental health services of people with all protected characteristics.
8. Integrated Care Systems should secure adequate provision of mental health support to people with the full range of long-term conditions as an integral element of their responsibility for population health management. This should include support at every level of need, from prevention, information and advice to specialist psychological services, and for all age groups, including children and those in later life. This should be supported with routine data to enable system partners to identify gaps and inequalities in access, experience and outcomes.

9. Acute and community health service providers should ensure that all specialist care for people living with long-term conditions includes at least one mental health practitioner as a member of their multidisciplinary teams. Where this is not possible – for example in very small teams with limited caseloads – a liaison model would provide access to on-call advice and support when it is required. Mental health practitioners in such roles need to have knowledge and insight into the specific conditions people are living with, and the impact this may have on their emotional wellbeing.
10. Primary Care Networks should take the opportunity to offer mental health support close to home to people with long-term conditions. From 2021, they will have access for the first time to mental health practitioners through the Additional Roles Reimbursement Scheme (ARRS), to be employed by local mental health trusts (NHS England, 2021). This can bolster emotional support within primary care.



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Introduction

Our mental and physical health are not separate, and cannot be kept apart. How we feel physically affects our emotional wellbeing, and our emotional state, in turn, affects our body's health. This is especially true when an illness lasts a long time.

When someone receives a diagnosis of a chronic condition, whether it's at birth or later in life, their future changes. Having a long-term physical illness can affect every aspect of your life: your relationships, your education, your work, and more. It means having to navigate health and social care systems, which can often be maze-like and unresponsive. It can restrict freedom, take away life chances and choices, and impose chronic pain.

Across the UK, approximately 38% of people aged 16 or older are living with a health problem expected to last one year or more (ONS, 2020a). We know that, from first symptoms and diagnosis onwards, experiencing sustained periods of illness can take a major toll on psychological wellbeing and poor psychological wellbeing can, in turn, worsen physical symptoms (Moussavi et al., 2007). Yet the emotional needs of people with long-term conditions frequently go unmet.

Before the COVID-19 pandemic, one-third of people with a long-term condition also had a mental health problem (Naylor et al., 2012), and for people with multiple long-term conditions the chances of having poor mental health are greater still. It is highly likely that this increased further during the COVID-19 pandemic. Many of the people who have been classed as clinically vulnerable or extremely clinically vulnerable during the crisis have long-term conditions. The day-to-day realities of shielding has had a profound effect on people's home, social and work lives; it has disrupted their medical care and access to support; and it has created new health-related anxieties.

In July 2020, for example, 37% of people who were shielding said their mental health had got worse since the start of the lockdown (ONS, 2020b). And once again, it is people and communities with the least resources and greatest adversities who have seen the biggest impacts on their mental and physical health (Independent Sage, 2020).

Research and lived experience both point to the circular relationship between mental and physical health among people living with long-term conditions. Just as physical illness, chronic pain and disability undermine mental health, so poor mental health takes its toll on physical health.

Yet poor emotional wellbeing isn't an **inevitable** consequence of chronic illness: it should be possible to live a happy and fulfilled life with a long-term condition (Robinson, 2017; Kralik et al., 2006; Maguire et al., 2019). This leads to the question, what do we need to do to make this a reality? What can be done to reduce the risk of poor mental health among people with long-term conditions, and what help should be offered to prevent difficulties from escalating?

Our research set out to develop a clearer picture of the emotional needs of people living with long-term conditions. We wanted to explore the impact of long-term illness on people's psychological wellbeing. We wanted to understand what would make the most difference, in terms of reducing this impact. And we sought to address the barriers to providing and accessing effective support.

Definition of terms

- 'Emotional impact' refers to a wide range of experiences and feelings, from everyday ups and downs in mood to diagnosable common mental health problems, especially depression and anxiety. For the purposes of this project, it generally doesn't refer to severe mental illnesses such as schizophrenia or bipolar disorder, though similar issues may apply to people living with these conditions alongside a physical illness.
- For the purposes of this report, 'mental health' refers to the emotional and psychological impacts of living with a long-term condition. The terms we use reflect where possible those used by the people we spoke to.
- 'Long-term physical health conditions' refers to any condition that can be managed but often not cured. This includes conditions such as arthritis, diabetes and heart disease, as well as those that are at the physical/mental health borderline, including Alzheimer's, Parkinson's and other neurodegenerative conditions.

Methodology

The priority for our research was to learn from people with long term physical health conditions what it was like to live with their illness – its impact on their emotional wellbeing and mental health, the support that was available to them and the support they needed.

We spent three months talking to people who were living with long-term conditions, their family members and the health and social care professionals supporting them. By the end of this consultation, we had carried out more than 40 hours of one-to-one interviews and more than 300 people completed our online surveys. We offered participants a small payment in recognition of the time and experience they were sharing with us to participate in this project.

The people who took part in the research had a wide range of diagnoses, with approximately 40% living with more than one long-term condition. Diagnoses included:

- Autoimmune conditions
- Blood disorders
- Cancer
- Cardiovascular conditions
- Chronic pain
- Diabetes
- Hormonal conditions
- Kidney conditions
- Metabolic conditions
- Musculoskeletal conditions
- Neurodegenerative conditions
- Rheumatological conditions
- Sleep disorders

Some people had only just received a diagnosis; others had been living with their condition all their lives. Some were only experiencing mild symptoms; others were in the final stages of their illness. And many were somewhere in between. People also came from a range of backgrounds and differed in their levels of social support.

We heard from people across the UK aged 18 to 80, with a majority of people aged between 55 and 75. Approximately 70% of people who participated were women. One in ten respondents self-identified as coming from a diverse range of racialised communities.

The launch of the project coincided with the first COVID-19 national lockdown. As a result, recruitment was mainly through email newsletters and social media. This came at the risk of missing people who don't have access to or don't use digital technology.

We know that a majority of the people who responded were members of organisations for people with long-term conditions. This suggests that they might be more likely than average to find it helpful to be in touch with peers and to be kept informed about their condition because they'd actively sought out and joined an organisation that would allow them to do this.

We also spoke to family members and partners of people with long-term conditions – a group of people who have emotional needs in their own right, as well as being an important part of the support network of people living with long-term conditions.

The research was overseen by a steering group of people from organisations supporting the project.

Throughout the research, we were struck by people's willingness to talk openly and in detail about their experiences. It was also noticeable that similar experiences and concerns came up across different diagnoses and age groups. This enabled us to build a consistent and coherent picture from the diverse experiences people shared – a picture that is similar to other literature on this topic.



1. The emotional impact of living with a long-term condition

The term 'long-term physical health condition' covers a very wide range of chronic disorders, from sickle cell anaemia to epilepsy, from polycystic ovary syndrome to Parkinson's disease. Yet, even when the only thing two conditions share is that they are likely to last a long time, this results in common ground. Unlike for someone with an acute illness, having a long-term condition means that interactions with health professionals, visits to hospitals, treatments and procedures, become a permanent and regular feature of your life. We identified four overlapping domains in which having a long-term illness has an impact on people's emotional wellbeing:

- Coming to terms with the illness and its effects
- Living with it: day-to-day, and for many years
- The burden of repeated appointments, treatments and procedures
- The effects on people's relationships.

Coming to terms with it

"You gradually come to realise that this is forever"

Some people are born with long-term conditions, others receive diagnoses later in life. For all, there is a point at which they become conscious of the impact their condition has on their lives.

'Coming to terms' with a long term condition is rarely a one-off event, instead it is an ongoing process. For most of the people we spoke to, this process began at diagnosis and became more prominent at times of change, for example when they experienced a worsening of their symptoms. People spoke about their fears for the future, and loss of a sense of meaning and purpose in life: Will I be able to continue doing my job? What will happen if I lose my independence? Will I see my children grow up? Some described this process as being similar to a bereavement, expressing a profound sense of what they had lost.

"There were times when you just feel completely overwhelmed by it, particularly at the start."

"When you get diagnosed with a chronic illness, you do experience a loss. It's a bereavement."

"The shock of having my future stolen was the overwhelming issue, at 59 years old to approach retirement with a life sentence from Parkinson's. I have come to terms with living for the day since then, and although physically worse, I have come to terms with the loss."

Some participants talked about unhelpful experiences with health professionals when they were diagnosed which made coming to terms with it even more difficult.

"[The nurse] said, 'Well, you'll have to lose weight,' and she then threw hundreds of leaflets at me, taught me how to prick my finger so I could test my blood and that was it, and I think I cried all the way home."

"I got into the taxi [after leaving hospital] and I burst into tears, and he [the taxi driver] said, 'Has somebody died?', and I said, 'No, I've just been told I've got something wrong with me and I don't know what it is, so I've got to go home and look it up myself.'"

Coming to terms with a long-term condition isn't a one-off event, however. It is something people may have to do many times in their life, for example as they go through stages of illness and various different treatments for it. For example, people with chronic kidney disease spoke about feeling more and more ill and coming to terms with death, only to receive a transplant and to come to terms with life again; and then, further down the line, for the transplant to begin to fail, and so on.

Coming to terms with a long-term illness can be linked not only to changes in illness and wellness but also to life stages. For example, some of the people who had grown up with a long-term condition said that they felt like they only really faced the reality of their illness in their late teens and early twenties, when their peers left home and became much more independent than they were able to be.

"I'm still coming to terms with my condition itself. I struggle to still think in terms of trying to understand the fact that...this condition...doesn't define me as a whole."

"Worrying about the course of the disease, worrying about dying early, worrying about leaving my husband a widower and how he will cope, watching every day for changes in my physical health (is this another step down?) is very draining..."

"I have come to realise over time I don't plan for a future because I was never given the opportunity to have one, as I was told I was to die in early adulthood. And now I'm sort of like, having a life in limbo where nobody knows what's going to happen. It's hard. I should save for a retirement but I can't because I hate to be reminded that I'm not like everyone else."

"You gradually come to realise that this is forever. I feel very low when I think about how long it is since I felt really well and not in pain, and that I never will again."

For some people, there was a feeling that they would be unable to be their true selves again: a profound sense of loss, both at the current time and prospectively.

"I miss being me."

Living with it

"You're not your disease, but it's a part of who you are."

With short term conditions, normal life can often be put on hold, then resumed upon recovery. If you are living with a long-term condition, putting life on hold while you're ill for a long time isn't an option: otherwise life would always be on hold.

Many of the people we spoke to were living with pain, fatigue and other symptoms that affected their ability to function day-to-day. These took a significant toll on their energy levels and their mood.

"Stress and emotional distress drain energy which exacerbates my physical symptoms (fatigue, pain, dizziness, weight loss). It's rarely a simple one-way cause/effect in either direction though, much more about just trying to manage my energy levels, which affect and are affected by both emotional/mental and physical factors."

In turn, people described ways in which struggling emotionally made their physical health condition worse.

"Anxiety and stress exacerbate [my] blood pressure, cause physical impact on my heart, reduce my tolerance to pain, which all have an adverse effect on my physical wellbeing."

"My diabetes control is only as good as my mental health."

This phenomenon has been described in previous studies, which have assessed the costs to the NHS of poor mental health among people with long-term conditions, which are estimated to equate to £1 for every £10 of NHS expenditure (Naylor et al., 2012).

Often people were trying to find ways to keep going in spite of the effects of their condition and/or to try to keep their condition hidden from others. However, what a lot of people described was a situation in which they felt damned if they did and damned if they didn't. If they were successful at pushing through their symptoms and carrying on as if things were ok, the people around them, often including healthcare professionals, lost sight of how much they were struggling.

But, during periods when they couldn't push through their symptoms, people described feelings of loss and isolation, of life going by and missed opportunities, not to mention the financial worries of lost income and the relationship worries of 'being a burden' as many people put it.

So while people didn't want to be perceived as 'victims' or to have their identities defined by their illness, one of the things that many people struggled with the most was other people being blind to their suffering.

"You're not your illness. You want normality. But you don't want a big aspect of your life to be invisible."

"My diagnosis is old news to those around me, for me it remains a daily struggle. It's never old news to me, I'll never be used to it."

"Dealing with pain daily is tiring. Initially it would be dealing with the pain but then, by the time I got to the end of the working day I was too tired and sore to go the pub, as an example, with colleagues. Over time, because I was never out, I stopped being asked. Because I was never asked, when I did feel like doing something, I then found it difficult to ask them as I felt like they obviously didn't want my company. Nobody appreciates how tiring pain is until they deal with it."

"You cope with it [cancer] and think, 'I'll just get on with life,' but underlying it, it's always there. I don't really think about it day to day now but it's there...all the time."

"I'm wiped out, absolutely wiped out."

"It's a very unpleasant illness and that's depressing in itself."

People also spoke about their worries for the future and the further concessions they might need to make to illness, such as giving up their jobs or losing their independence.

"My partner is 66 years old and we had serious plans. Financial plans in place with regard to our future. These plans and hopes have been completely dashed. Life is just one long round of medication and hospital visits. He is very depressed, I am very depressed as we see no end to this enforced way of life."

"It's quite difficult to be enthusiastic about things because, quite frankly, you don't feel like doing anything most of the time."

“It was just really, really hard because I couldn’t do anything. You know, at the moment I’m kind of managing well enough to go to work most days, to get out of bed, but you know there are times when it’s not like that, when I can’t do any of those things, when I am literally in bed for days on end. And just feeling like that and feeling there’s nothing on the horizon to resolve the issue...it was just, yeah, it was just too much... I couldn’t see kind of any light at the end of the tunnel, so it had a really massive impact on my mental health.”

Burden of appointments, treatments and procedures

Having a long-term condition means regular and sometimes frequent appointments, treatments and procedures. For many, the fact of having to navigate and be engaged with health and social care systems is a significant strain. Literature refers to the ‘treatment burden’ of a long-term condition, the work involved in attending appointments and sticking to a treatment regimen and the impact this regimen has on people’s wellbeing (Demain et al., 2015). People spoke to us about how vulnerable and powerless they often felt when they were undergoing medical care. Many of their treatments and procedures were intrinsically invasive, painful and risky, causing high levels of distress and, sometimes, leading some to describe feelings related to post-traumatic stress disorder.

“I would describe it as PTSD. My wife is outwardly a positive person but has a long history of poor sleep/night terrors linked to medical experiences.”

“I had PTSD after getting MRSA from an operation scar and having a lot of painful medical procedures done against my will due to my age. For years and years and years I could never sleep with my wrists turned up, otherwise I would feel a needle going into my veins.”

“I think dialysis was probably the most traumatic, lonely experience.”

“They wanted to start me on medication right away, which I did, but I reacted very badly...I just felt awful. I remember I used to sit on the sofa just being in floods of tears all the time.”

Many also spoke about the difficulty of remaining hopeful when no effective treatments were available. People expressed frustration, weariness and anger at the difficulty of navigating health and social care systems. This was especially true for people who were more dependent on these services for support, for example those who were more acutely unwell, and those who had financial difficulties and housing issues.

“I did have a bit of a wobble a few weeks ago because I was told that my six monthly check-up...had been postponed... I was a bit concerned because that would be almost a year until I was checked.”

“Everything about an appointment with a consultant or a hospital doctor is a situation that puts you at a total disadvantage, and that’s wrong. You’re already at a disadvantage because there’s something wrong with you.”

The stress of navigating complex systems was noticeable for family members and carers, too. Some described having to ‘battle’ to get help for a family member, and the emotional toll this took.

“All the time I’m plotting and scheming, how can I get access to one resource or another. Each agency plays a different game and I have to learn the rules of all these games... It’s so wearisome and makes me angry. She’s a human being with genuine needs, I shouldn’t need to play stupid games to get her the help.”

A recurrent theme in the interviews and the survey responses was a lack of alignment between the way the system is organised and the way people experience their long-term condition, especially if they were living with multiple conditions. It isn’t intuitive, it is organised around diagnoses rather than individuals, and the way time and other resources are allocated often doesn’t reflect the priorities of the people the system is there to care for.

“You really do need to work quite hard at working your way round the system because it’s complex.”

“I have to drive to a hospital that’s practically impossible to park at, so I stress about being late, and when I do finally manage to park (usually in a spot the furthest away from the part of the hospital I need to get to), I usually find the clinic is running late and I spend the whole time worrying about whether my parking ticket will run out.”

“You visit one department and they decided another department needs to see you to explore x, y, z, but then there’s a waiting time for each department. Before you know it, two years have gone by and you are still no closer to any significant answers. The whole process is draining and adds to the emotional and mental health impact.”

The burden of recurrent appointments and treatment affects other areas of people’s lives, including relationships, education and employment.

“My employer expects me to make back any time lost including the hour it takes me to travel from work to the hospital and often I am in the waiting room for a while and not seen on time which meant last time I ended up making up three hours overtime after normal work hours in that week. It was exhausting and I felt resentful that others without a condition don’t have to go through this.”

Medical appointments can cause anxiety both before and after – both anticipating the news they might receive and coping with frightening or disappointing results.

“There’s so much emphasis put on to appointments – up to 6 months of waiting for 15 minutes of someone’s time. Appointments can be both inflating and deflating. Most of the time I feel “rocked” afterwards. And frustrated with my body that I’ve had to attend another appointment.”

“Then they found out that I’d got [a rare condition], which resulted in me being in a room full of white coats and scrubs, and people going ‘ooh, look’.”

“How many times do you hope and have your hope dashed and be able to recover from that, pick yourself up and continue?”

“I had to fight. I had to be vigilant as to what tablets I was taking. I had to fight to get home. I had to plead, beg... I had to watch everything. I couldn’t relax for a moment.”

Impact on relationships

People we spoke to discussed the impact of having a long-term condition on the relationships with those who are close to them. We also heard from people’s family members and partners and what was striking was the way in which the emotional impact of long-term conditions ripples out. It affects the person with the diagnosis, but also the people around them, and the relationships between them.

“Sometimes it’s difficult for him [husband] because sometimes he struggles because he’s living his life with a person who’s sick [...] and that can put strain on our relationship.”

“I regret to say I am no longer able to offer much emotional support. I feel very guilty about this but I am having to cope with all financial decisions and plan for somebody else’s future. My life and future is affected through no fault of mine and I have now begun to feel resentful of what lies ahead.”

“I think my daughters felt it greatly and they wished they could’ve talked to someone about me.”

“My parents did very well to hide their fear, but I’d see them both cry a lot.”

“She [mum] needs therapy and support herself because she went through a really traumatic time, but she’s one of these people who’ll never think that therapy is for her, you know what I mean? So it’s always me who’s had to seek that support when I know that really it’s more like family counselling or something like that would be so helpful.”

We also heard about people’s relationships with health and social care professionals. If you have a long-term condition, medical care becomes more relational than transactional. It extends over time, it’s part of your life, it affects your future. You’re being asked to put your trust in others, not just as a one-off, but repeatedly. And, as a result, it really matters that these are people you’ve developed trust in, that you can build a relationship with them, that you aren’t left feeling like you’ve gone back to square one with each appointment.

Yet when it comes to relationships with doctors and nurses, many people talked in terms of a battle, of feeling like they had to be feisty, confrontational, defiant, etc., in order to get their needs met. This dynamic isn’t compatible with an open and trusting relationship in which people would feel safe enough to talk about their emotional health.

“It’s soul destroying. You know, you put your trust in these people.”

“Over the years, I’ve grown quite feisty, to have an armour around me”.

One of the words that came up most frequently in discussions about relationships was ‘burden’. This was a theme among participants of all ages, and for some it may intersect with similar feelings when they reach later life. People were worried about being a burden to family members, and even more so if they spoke about their feelings. This often led them to try to cope with the emotional impact of their long-term condition alone instead of turning to others for support.

“I don’t want to be the person that brings everyone else down, so I often stay quiet. I also don’t want to worry my husband about what the future may hold for me.”



2. Health inequities and variations in experience

“I do think that everyone’s experience of an illness is different.”

The needs and experiences of people with long-term conditions are inevitably diverse. No two people have exactly the same needs, wishes or experiences in life or with their health.

In conducting this research, it was apparent that there is as much diversity of experience among people with the same condition as there is among people with different diagnoses: that diagnosis alone is insufficient to predict someone’s needs for emotional support. People’s experiences vary according to many factors, including their age, their relationships and their economic and social position. And the challenge of living with a long-term condition may be compounded by other issues people face, including poverty, housing or relationship difficulties, racial injustice and discrimination. This means that designing emotional support needs to consider individual circumstances, needs and assets: there is no ‘one size fits all’ solution.

This section explores some of the dimensions of inequality or variability that affect people’s experiences of long-term illness and its emotional impacts.

Age

People’s experiences of having a long-term condition and its emotional impact differ through their lives. We heard from people of all ages about their experiences and how their age played a part in how they were treated by healthcare professionals.

Older people have a complex combination of risk factors for poor mental health: they are more likely to be living with more than one long term condition; they are likely to be taking a combination of medications; they are more likely to be socially isolated. Almost four million people over the age of 65 now live alone in England. Research from Independent Age (2020a) shows that older people are more likely to have depression or anxiety if they have poorer mobility or if they have a caring role (or if they receive care from a family member). Bereavement, especially of a partner, is also a major risk factor for poor mental health in later life.

Some of the older people who participated felt like they were forgotten about by services and their long-term condition was increasingly seen as an inevitable part of the ageing process.

“When I was young I was unusual and ‘interesting’ to doctors and almost felt special. But as you age you get told ‘well everyone has aches and pains after 50’ etc.”

“I feel like quite a lot of doctors [...] don’t really care about us, that we’re sort of expendable.”

“I really do feel, you get to a certain age and you’re written off.”

“What I’ve found very hard is that, when you reach 65, you suddenly become an old person [for the purposes of social services help] and no longer disabled.”

There is also evidence that older people are less likely to be offered mental health treatment than their younger peers (Frost et al., 2019; Commission for Equality, 2020). This is despite evidence that psychological therapy for depression can be highly effective in later life. This is often linked to beliefs that poor mental health is an inevitable and normal part of ageing, and an assumption that it is not worth offering treatment.

At the opposite end of the age spectrum, some of the younger people who participated felt like their symptoms hadn’t been taken as seriously as they should have been because of their age and, as a result, their diagnoses had been delayed. Others described the impact of feeling out of step with other young people, who had more freedom, more opportunity and brighter prospects for their adult lives.

“As I’ve got older, I’ve noticed how much my health is impacting on what I want in the future. I’m getting married next year and have started to think about having children and my friends are having children. It’s only the last year I’ve realised my health may stop me ever having children.”

Racism and discrimination

People from racialised communities in the UK have higher than average rates of some long-term physical conditions, including diabetes and heart disease (The King’s Fund, 2021). For some communities, levels of mental ill health are higher but access to mental health support is poorer and people’s experiences and outcomes are also worse (Commission for Equality in Mental Health, 2020). Likewise, there is evidence in some areas of healthcare that physical health support for people from racialised communities is poorer – for example with less effective pain control and significantly higher mortality rates in maternity services (Knight et al, 2021).

Many of the people we spoke to talked about feeling like they needed to be very assertive in order to get the care they needed for their long-term condition. This is more made more difficult still for people who come from communities that have been stigmatised or marginalised. For example, an interviewee from the Travelling community spoke about feeling like doctors and nurses had a negative stereotype of Travellers. As a result, she felt that if she complained, far from getting her the care she needed, it would be held against her.

“We can’t say nothing because it’ll come back to us.”

“You just know that how you’re being treated is because of who you are.”

Poverty and financial insecurity

The links between poverty, financial insecurity and long-term illness are complex and work in multiple directions. Poverty makes people more likely to have a long-term illness. It also exacerbates the emotional impact of long-term conditions, and for many people having a long-term condition affects their income and financial wellbeing. With fewer resources too often come less power and autonomy. People living in financial hardship felt more dependent on the system recognising and responding to their needs (e.g. receiving Personal Independence Payments) and this, in turn, left them feeling vulnerable and betrayed when the system let them down.

“When I am dealing with any financial stresses, my mental health suffers.”

“I’m only earning half of what I was earning before [the diagnosis].”

“PIP/ESA reassessment makes me feel upset, when I’m feeling ill but look well, people don’t understand.”

The Health Foundation has also noted that people from more deprived communities are not only much more likely to have multiple long-term conditions but that this happens a lot earlier in life than in more affluent areas (Stafford et al., 2018). For example the average age for people to have four or more long-term conditions was 61 in the most deprived areas, combined with 71 in the least deprived.

Impact on Urban Health (2021), meanwhile, have explored the mechanisms by which poverty and inequality in South London interact with health to exacerbate the risks of having multiple long-term conditions. They note that difficulties with money, work and housing, poor living conditions and precarious circumstances create an unequal risk of poor health, especially for women and racialised communities in more deprived neighbourhoods.

Fluctuating and progressive conditions

A number of participants spoke about the impact of conditions that fluctuate, but also the extent to which their emotions changed over time as their illness progresses. For some people, time brings greater acceptance and coping strategies. For others, time increases the emotional toll or creates new challenges – for example when they are ready to start a family or as their condition becomes progressively more painful, life-threatening or life-limiting.

“Many people recover fully from M.E. in a relatively short time, so early on I was focussed on that, struggling/fighting against all the things I wanted to do but couldn’t, but basically impatient to be back to ‘normal’ again. Then I went through almost a grieving process, accepting that wasn’t going to be the case for me and needing to adjust to/accept the long-term impact. Since then it’s just up and down, sometimes it’s easier to live with and other times not so much!”

“As I’ve got older, I think about relationships, starting a family and becoming more independent. I’m more nervous to take steps forward and at times this does affect my mood as I know if I didn’t have the condition it wouldn’t have held me back at all and I would feel more confident in all these areas.”

“Over time I have built up an understanding of how it impacts on me and so I can manage it better. I talk about things more and am more open with others generally about my condition. I am also accepting of it now. I used to get angry about it - now it is part of me and my life.”

“I have had kidney disease for over 25 years. I worried less at first and didn’t think about end stage impact but needed more help with nutrition advice. When I reached stage 4, I really started worrying about my blood results and how fast I was heading for stage 5 and dialysis and the impact this would have on my life. So the worries change with time.”

“I fluctuate between determination to override limitations and succumbing to them.”



3. What helps people living with long-term conditions?

The people we spoke to described aspects of their physical healthcare that either helped or undermined their emotional wellbeing. Key aspects of care for a long-term condition that people found helpful (or would have liked) for their mental health included:

- Continuity of care over time
- Being given information and treated as a partner in their care
- Support and advice being given between appointments
- Small gestures of care from healthcare professionals

Continuity of care

“I’m trying to build up some sort of consistency with one doctor.”

Long-term conditions, by definition, last a long time. People value being able to see the same healthcare professionals from year to year, building relationships that follow them through the various stages of their illness (Independent Age, 2020b). When they trusted their doctor or nurse, people found the continuity of the relationship deeply reassuring.

“It should be a bit more personal if you’ve got a long-term condition.”

“I just say my name and he [my consultant] knows who I am.”

A healthcare professional we spoke to expressed a similar wish to have greater continuity of care with the patients they saw in hospital.

“I am identifying patients once they already have established renal disease. It would be great to work in the community to follow them up and see how some of the measures we put in place work.”

One participant described the sense of continuity they had with a GP they had been seeing for decades. She knew his history and kept an eye on things. But “since she retired, I’ve been passed from pillar to post.”

“It does make such a difference when they [healthcare professionals] know your backstory as well.”

“He [consultant] has been a figure of continuity and, actually, wisdom that’s been enormously helpful in coping with that long-term condition because you just know he’s been there”.

Information and partnership in care

“People are in their own way experts in their own condition.”

The longer people live with their conditions the more they come to understand them and the clearer they are about their own priorities and needs in terms of managing their health. They want to be treated as partners in their care: to be given as much information as possible and to have a voice in the decisions that will affect them.

“Having people in power and authority recognise that most patients have the answers to resolving their own emotional and physical health challenges and they should be listened to and allowed to collaborate for the changes in health services to be made.”

“Learn to be able to implement the changes needed by working with us as partners.”

The importance of having good information about their condition was expressed by many participants, with some noting that this had a direct impact on their mental health.

“I think that becoming better informed about my condition helps with any anxieties I might have.”

“I knew nothing about this condition when I was diagnosed, and felt I was left to get on with it.”

Not being listened to was a frustrating experience for many participants:

“The attitude of some medics is very dismissive, I sometimes don’t feel heard or respected as an individual - more of a ‘patient’ on a conveyor belt being processed with a one size fits all.... My knowledge and expertise is of no interest... No hope is offered.”

“I think sometimes doctors just tell you, ‘You need to go on this’ and that’s it, you need to take their word for it.”

“I felt bullied.”

By contrast, some participants described the recognition they got for the knowledge they had about their condition and what they needed to help them to manage it.

“With my specialist, my consultant, if I don’t do exactly what he’s told me, he trusts that I know my body best.”

“Feeling as if I could control something was important and...discussing things helps and I think it helps them – shares the responsibility.”

“I’m happy to take the medicines, as long as I know why this is happening, as long as I know why I’ve got to do it, why I’ve got to take this medication [...] because they give you some quite hefty medication, and it’s quite nasty stuff, and I just like to know the whys and wherefores before I do it.”

“My consultant, when he put me on [strong medication]...he went through absolutely everything, and let me make the decision... It’s having that time to let you think about it, rather than telling you, ‘You’ve got to do this’.”

At times, some people have decided to take control of their own care, having not been given the opportunity to share decision-making with clinicians. Others described the psychological impact of feeling that they were not understood by healthcare professionals, or that they had a better understanding of their condition than the people treating them.

“I feel like I have to make my own decisions from now on instead of just doing what the doctor says I should do, and I have to keep myself as informed as possible. And that makes me feel better because I feel more in control.”

“When I go into hospital, I am frightened because I know I know more than the people I’m seeing about my disease.”

“The communication was just terrible. Like they didn’t know...they never said what was wrong with me. There was just no communication.”

Support between appointments

A theme in many people’s responses was the importance of being able to get information about their physical condition at any time – not at the timetable set by services. Some spoke of the anxiety caused by long gaps between medical appointments, and the lack of opportunity to ask questions outside these fixed timetables.

“It might sound trivial, but I have just one opportunity a year to talk to my consultant and I usually arrive stressed and then totally forget what I need to speak to her about.”

“With my consultant appointments being some nine months to a year apart, and my Specialist Nurse every six months, I take the opportunity to ask about stuff that has occurred since the last meeting... [It’s] not always easy but if I didn’t ask then, the opportunity is gone...and that would leave me fretting about whatever it is for months.”

“There are a couple of times when I’ve been to an appointment where there’s just had too much to say, and then - I’ve gone with a list – and he’s just taken out the things he could deal with, and I’ve come out thinking, ‘Actually, I wanted to deal with that one.’”

“Day to day, you’re literally on your own.”

“When you’re discharged from hospital...you’ve got to live with this condition that will affect your entire life. And there’s a complete drop off [of care].”

Others gave examples of the kind of support they would like between appointments, or of help they had received that met that need – for example someone who understood their condition that they could call at any time.

“A specialist nurse attached to you would be useful, someone you could phone for advice and support.”

“They [the Parkinson’s nurses] were almost better than the doctors because you could ring them up at any time and they’re terribly knowledgeable because they just deal with Parkinson’s.”

“Make it clear your door is always open, and keep in regular contact particularly at the beginning until you both feel comfortable with how often you contact each other.”

Small gestures of care

“Just simply Ask How I Am feeling/coping with my mental health on a regular basis – to know someone cares means a great deal and can be immensely supportive.”

“People will forget what you said. People will forget what you did. But people will never forget how you made them feel.” (Maya Angelou)

In *Labours of Love*, her investigation into the 'crisis of care' in the UK, Madeleine Bunting refers to the importance of small gestures of care – things as simple as a smile from a doctor or a less formal 'How are you doing?' at the start of an appointment. They might not have prevented the long-term condition from having an emotional impact, but they did help people get through the day, especially when they were unwell. Many of the people we spoke to reflected this view, and they noticed when clinicians made (and didn't make) small gestures of care.

"The consultant I've got now is far more personable. He'll open the conversation with, 'How are you getting on?'"

"If I see a clinician who listens to my concerns, offers suggestions and enquires about how I am coping, then I feel supported and positive. Sadly, this has not always been my experience and then I feel frustrated and let down."

"It's important that people feel that they're heard and, you know, just get some validation that someone's taken them seriously."

"I think a lot of it is time. I know that they haven't got an awful lot of time to go through everything, but some medical people are better at it than others. Some will listen to you and make you feel valued for doing that, and others just almost talk over you and do what they have to do... That's really frustrating. You know, they make you feel quite small."

"The ones that really stood out really just like took the time, even if it wasn't a lot of time, took that little bit of time to explain something or, you know, express some understanding of what I was experiencing. And obviously there was a lot of... discussions 'should we do this, that or the other and what are the consequences and implications of going down those various routes', and just taking the time to talk some of those things through... Just being given time and understanding and it just really seemed like they cared."

"The consultant who operated on me happened to be there and just made time to see me and literally spent, I don't know, half an hour or 45 minutes with me even though... I wasn't scheduled to see him or anything like that. Stuff like that was just amazing."



4. Emotional health support for people living with long-term conditions

The people we spoke to had accessed a range of forms of support for their emotional health, from informal help from friends and family to treatment from health and care services. The most frequently reported types of formal support were talking therapies and medication. Others had received help from community mental health services, inpatient care, support groups, alternative therapies and from their GP. Many people reported a combination of informal and formal support. During the pandemic, informal support has included being part of a family 'bubble' and the use of digital technology to stay in touch with both personal, community and service contacts.

No one form of support was universally helpful. Likewise, none was universally unhelpful: once again, pointing to the conclusion that there is no 'one size fits all' solution. More important than the form of support was whether the person providing it had insight into what it was like to live with a long-term condition. Several people drew a connection between this insight and their more helpful (or unhelpful) experiences of receiving emotional support.

"A strong marriage, a daughter who's formed a bubble, online communities on Zoom, church and family, Arthritis Action."

"I found the more you talk about it and acknowledge it, the easier it is to control and to have as part of your life alongside what you're doing."

Commonly cited elements of what an effective system of support for people's emotional wellbeing and mental health included:

- Making emotional support a standard part of care for their long-term condition
- Psychological interventions
- Joined-up mental and physical healthcare
- A holistic, whole-person approach
- Being offered help proactively, not having to search for support
- Peer support
- Opportunities to give support to others
- Help for carers and family members
- Making emotional support a standard part of care

Many participants emphasised the importance of integrating emotional support with long-term condition care – as an intrinsic and standard feature of the service rather than an add-on or something they would have to look for elsewhere.

The support people found most helpful was that which came from a peer or professional who understood their specific long-term conditions and the challenges these presented.

A strong call from the people we spoke to was for health and care professionals to ask them about how they are feeling as a routine enquiry. Rather than waiting for them to disclose distress, they wanted to be asked on a regular basis as a normal part of the care they receive for their condition.

"I feel it would make a huge difference to a consultation if a consultant said to me or a registrar, you know, 'How are you feeling? How does it affect you emotionally?' Well, I mean obviously there's nothing they can do about that, but...as soon as someone asks you how you're feeling, how you're doing emotionally, you close a gap."

One participant noticed that their doctor started asking them 'how are you?' when they had a consultation. At first, they did not understand why, but they grew over time to appreciate the question.

Participants felt that routine enquiry should occur at all stages of a person's journey, not just early on when they are receiving a diagnosis. Some felt this should be formalised, while others felt it should happen within appointments with physical healthcare professionals.

"We should all get a regular six monthly/annual appointment to discuss any [mental health] issues we have. If we have an urgent need that appointment should be something that we can bring forward. It's a massively neglected area of physical health conditions."

Some noted that this remained important throughout a person's life, including towards the end: that, just because someone's coming to the end of their life, either through old age or because of a condition deterioration, doesn't mean that emotional health should be ignored.

A common theme among many participants was the importance of emotional support from someone who understood their condition, and the effects this might have on their mental as well as physical health.

“There were a few times when I thought I’d love to just speak to one of the nurses. I’d love to get some support from somebody in [department specialising in my condition] who could just understand to some extent physically what I was experiencing and then also have some appreciation of the impact that was having mentally and why, and that would have been a lot more helpful than the crisis team saying, you know, ‘Oh try and do something that you enjoy.’”

“But when I do get to see one of the [specialist] nurses, the one that I see is actually very good and she’s probably actually the first person who recognised the link between having anxiety and having the illness, and I was able to talk to her about that.”

Psychological interventions

Academic research has shown that talking therapies, and particularly CBT, can improve the symptoms of depression in people with long-term conditions (Dickens et al., 2013; Chilcot & Hudson, 2018).

The NHS in England has recognised this and in recent years it has expanded the Improving Access to Psychological Therapies (IAPT) programme to more people with long-term conditions through an adapted ‘pathway’ (NHS England, 2018).

Approximately 50% of the people we spoke to had accessed support specifically for their emotional wellbeing. Views about how helpful these had been were mixed.

“Before transplant, I did see a counsellor. She was a help, but I still struggled. Going to see a counsellor on a certain day when I was poleaxed with kidney failure was impossible at times when I was so cripplingly tired.”

Some participants described long waiting times to get access to talking therapy.

“Referred through IAPT 12 months ago and still waiting for initial appointment for CBT.”

“CBT was its name I think. Referred May last year. Phone conversation, questions, etc (July 2019). Told that in a matter of months I would be contacted [in] February 2020 but lockdown loomed. I had eight phone conversations, moderately helpful.”

Some participants described going private for therapy, either as an alternative to NHS provision or because there was nothing else available.

“I have pursued counselling over the years, but it has always been private and therefore limited by cost.”

“Psychoanalyst, privately funded. This is the only real and effective help I’ve received on emotional/mental health issues.”

Discussing access to mental health support also brought up potential issues with (and for) family members. One participant, for example, wanted to be able to access talking therapies without their family knowing:

“Having a counsellor I could talk to privately, without immediate family knowing. I don’t want to worry / upset them by knowing I struggle sometimes.”

And a carer we spoke to talked about wishing they had some talking therapy skills themselves:

“It’s just hard to know if I am approaching things the right way. I feel I need a crash course in counselling!”

Not all offers of help were for psychological therapies, however. Some participants described getting help directly from their GP for their mental health.

“Regular mental health checks with my GP which is very useful. I have sometimes been prescribed anti-depressants which have worked for me”.

A small number of people spoke about having contact with specialist mental health services, including crisis teams. One participant described asking for a referral to a psychiatrist. She had a single appointment in which she was given a prescription for Valium, which she returned to her GP. By contrast, this participant described finding meditation and CBT helpful, but noted that she had had to find them for herself.

“Renal counselling through hospital...was completely unhelpful. After two sessions, I realised it was a waste of time as the counsellor had no knowledge of renal issues.”

Joined-up care

“We’ve got very good services, but they’re not integrated.”

Nearly ten years ago, a government policy paper noted that “[p]atients universally say they want to be treated as a whole person and for the NHS to act as one team” (Department of Health, 2012). This is nothing new. Yet the experience for too many people is still of services that are fragmented.

Tiredness, anger and despair came across strongly in people's narratives when they described the problems they had in navigating the healthcare system. This was especially true for people who were living with more than one long-term condition who, as a result, experienced discontinuity of care, not only between their mental and physical health, but also across their different physical health conditions. Mental and physical healthcare are usually provided by separate services that are rarely co-ordinated. What they wanted was support that was co-ordinated across primary, secondary, community and social care.

"You've got the GP surgery, you've got the mental [health] unit or professional psychiatrists, and then you've got the [physical health] specialists in the hospital, and they all work beautifully separately but...there's no continuity, they are like dissociated units."

"The lack of knowledge and lack of joined up care leads to frustration and despair at times."

"There was no continuity in care [...] everything was in bits."

This is a view that was shared by some healthcare professionals, one of whom told us: "I feel that it is important to have the social/psychological staff embedded in the long-term conditions teams. Referring to outside agencies who have a different focus and criteria often leads to people not receiving the support they need."

Holistic/personalised approach

The people we spoke to felt the traditional medical model, in which body and mind are seen as separate, was unhelpful. Many felt like their mental health had a very limited place in their interactions with the doctors and nurses supporting them; and, equally and oppositely, they felt mental health professionals generally didn't understand the ways in which their emotional health interacted with their physical health.

More holistic models of care were preferred. This is especially true for people who are living with more than one long-term condition and who, as a result, experience discontinuity of care, not only between their mental and physical health, but also between their different physical health conditions.

"I'm the only person looking at me as a whole."

"I have had mental health problems since before my long-term physical conditions developed. It is difficult to separate the fluctuation intrinsic to my mental health problems from the effect of my physical health on my mental health."

"if the clinician sees the problem only within the context of his discipline, they don't see the whole me, living with lots of conditions."

"The interaction that goes on between my mind and body is two-way. So, for me, I very much enjoy working with practitioners who take a more holistic approach."

"I've been told in hospital, 'That's a different problem, we don't deal with that.'"

Being offered support instead of having to go out and find it. There was a view from many participants that the health system is increasingly expecting the patient to be proactive in help-seeking, especially for their mental health.

People felt that, if they did want extra support, they would need to ask for it proactively, and this was a barrier to disclosing distress. Often the times when people felt like they most needed emotional support, they were too ill or exhausted to go looking for it, especially when they perceived that they would have to fight for anything more than what they were already receiving.

"Ask me how I am mentally at every medical appointment and check-up... 'Can we get you any help, advice, guidance?' It should be routine. Then I might feel comfortable saying that, yes, I could do with having a chat with someone or attending a group session with other people. I have good family & friends but it's hard for them to understand all of the time."

"All these things are out there, but at the moment, you have to go and find it yourself. Better signposting is needed so that patients get the support they need when they need it at diagnosis. More acknowledgment of the mental health aspects of living with a progressive condition."

Some spoke of the need for advocacy support for when they were less able to seek help but may need it most acutely.

"I'm fearful for the day when I can't advocate for myself, when I can't cope, can't be mentally as strong as I have learned to be."



Peer support

“Coming into that room with people who’d had similar experiences just meant so much.”

Peer support has been referred to as “one of the most highly valued sources of help to people with physical and mental health conditions” (NHS Confederation, 2019). There is strong evidence of its benefits to the wellbeing of both the person giving and the person receiving support (National Voices, 2021; Embuldeniya et al., 2013; Galdas et al., 2015; Nesta/National Voices, 2015). Previous research has identified several factors that are associated with these benefits. These include: the opportunity to talk to someone who ‘gets it’; being able to find meaning in illness; and the more ‘equal’ nature of the interaction, in contrast to the power imbalance that is often seen in medical settings (Embuldeniya et al., 2013; Clark, MacCrosain, Ward & Jones, 2020).

These themes were echoed strongly in our findings. People spoke of feeling isolated when no one understood what they had been through:

“I feel very much with other people that they don’t understand and it’s caused me to...feel very different from other people anyway because I don’t know anyone else who’s got my illnesses [...] and the people that I do meet are fit and healthy, so you feel different anyway because you can’t relate to that any more.”

For many, the most powerful antidote to this loneliness was being in touch with others who had the same condition or who had had similar experiences. One participant summed up his feelings about peer support saying, “You’re not the only one, that’s the key thing.”

Participants spoke about a sense of connection and belonging when they were in touch with others with the same condition:

“We all were in the same boat – that was so reassuring. That was the most comforting thing.”

“You feel less alone...and you realise that there are other people living with it.”

Some had made their own contacts through digital technology and social media.

“In the days of social media, it’s quite easy to find others with similar conditions.”

Another aspect of peer support that people often found positive was seeing people who had gone through treatments and procedures and come out the other side, or people who had a more advanced form of their condition. Sometimes this gave hope for the future. For example, one person spoke about the benefits of going to a Parkinson’s dance class: “I can see that they’re a bit further on than me but they’re still coping all right, and good fun and enjoying life so, you know, that’s encouraging.”

“[The] most beneficial support is talking to a friend who had a heart transplant and talking normally.”

“[The] physiotherapist put me in touch with another Parkinson’s patient of a similar age, which was most useful as my wife could meet his wife and discuss their experiences of the disease.”

“If I had been able to talk to someone post-transplant I think the past few years would have been easier to cope with.”

“So much of my knowledge about diabetes has come from the community, the other people with diabetes.”

Some participants, by contrast, spoke about the lack of understanding among people not living with their condition, despite the best of intentions.

“Not everyone has to deal with having a chronic illness and, especially with my family and my friends, they were really, really supportive...and understanding – but I think that, after a while, they didn’t understand that it still affects me now... They were like, ‘Well, you’ve had your surgery already, so surely you should be better?’, and I find that quite frustrating because I feel in those kind of situations people don’t really understand the long-term implications.”

“A lot of it [counselling] was kind of helpful and transferable but felt quite vague, and there was a part of me I think that was kind of like, ‘Ok, this is good, this is informative but I don’t think they can ever truly understand’ because...there’s not very much known about transplants [...] and even then it’s so different for everyone’s personal experience... I should really seek out a community of transplant recipients that I can like, ‘Oh yeah, I experience that too,’ or, ‘What do you do with this?’, very specific support in that sense.”

Opportunities to give

“The other thing that helps me is to help other people”

Many people who took part in the research volunteered their time to help others. This included involvement in patient advocacy, running support groups and contributing to medical research. While allowing for sample bias (people who value having opportunities to be helpful are also more likely to take part in surveys and interviews), this was a strong theme.

One participant described “a really horrible reliance on people” that had resulted from her illness. When she was at her most unwell, she felt passive and disempowered. Being in the helping role, in contrast, was an opportunity to “hold my head up high and show that I have an ounce of something to give”. Similarly, someone who ran a support group said, “I am usually the leader of a group rather than receiver. [I] feel the group is essential to my wellbeing though, I feel useful and not isolated.”

For others, the value of their helping role was the feeling that they were transforming their bad experiences into something good.

“I would like to be able to take an active role in how healthcare is delivered to patients, I want to limit what happened to me to other people. But I'd like to be paid for it. If I'm an expert in my experience I expect to be paid like a consultant. That would help my mental health as I'd be told that my expertise is worthy.”

Support for families and carers

Participants spoke about the importance of offering emotional support to families and informal carers as well as the person living with the long-term condition.

“Offer my husband help too. It's not just about me.”

“It's very hard to have a sick child knowing that they won't get better. To be honest we didn't even realise to begin with that kidney transplants aren't for life and that actually there is no life long cure for this illness. We have found most people don't understand this or the illness and as such feel very isolated. I lost my job with associated financial implications and my other child had to move schools multiple times.”

“He has very bad anxiety from the four months I spent in hospital in London and then when I disappeared to hospital in the middle of the night for the following year. It puts a lot of strain on our family.”



5. Barriers to mental health support

We asked participants what stood in the way of accessing mental health support. Among the widely cited barriers to getting emotional health support were:

- A lack of opportunities to disclose distress
- Strained relationships with healthcare professionals
- Poor communication about the support that is available
- A belief that the NHS and its staff are already overburdened
- Mental health stigma and discrimination
- Previous bad experiences of getting mental health support.

Lack of opportunities to disclose distress

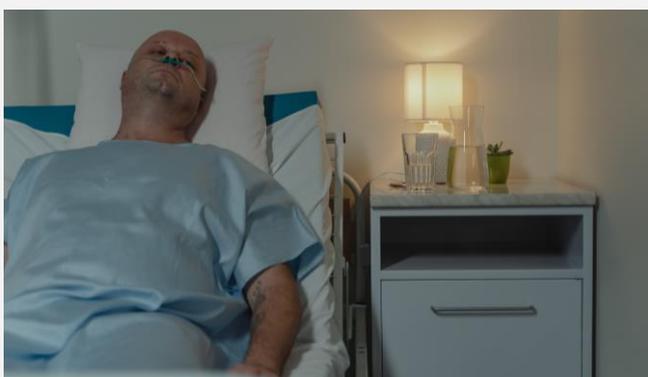
Some people said they would raise their feelings in an appointment if they had the opportunity to do so. However, because they were not in regular contact with services, or because their appointments were perfunctory and far apart in time, the opportunity didn't present itself.

"Nobody asks you, 'Have you got any concerns?' They haven't got the time to talk to you really."

"I raised concerns around mental health, depression & anxiety pre transplant & my consultant at the time hardly acknowledged it which shocked me. He seemed busy & preoccupied but could & should have referred me on for support. I ended up having to deal with it through my family."

One participant said they would not disclose distress to a healthcare professional for fear that their only response would be to offer medication.

"I would never approach my GP saying I had mental challenges as I believe their first response would be a prescription for medication."



Strained relationships with healthcare professionals

People with long-term conditions have often had a correspondingly long-term relationship with healthcare services. Many spoke of feeling like the only way to get anything done was to be strong-willed and defiant. This didn't leave much space for being emotionally open and vulnerable with healthcare professionals.

"Over the years, I've grown quite feisty, to have an armour around me."

"Consultant is intimidating. [I'm] always anxious before seeing him, and usually cross after I have seen him."

"I started to hate myself, and felt like I was not worth the time and money spent on me. NHS policy reflects this. I still do hate myself, but now my anger is directed more at the NHS than myself, although hating myself is still pretty strong."

Some also lacked trust in the system, especially if they had had an experience of something going wrong with their care.

"In order to get anything done, you have to complain or you have to be angry."

"The thing it's developed in my character is the feeling of being a persistent moaner, rather than being someone who's bringing things to their attention."

"I think her [doctor's] attitude came down to, 'You've had the surgery, you've still got problems, you're just going to have to get on with it really.'"

Other breaches of trust and care were also very common among the people we spoke to. Many had had at least one experience of being let down by healthcare professionals during their years of living with a long-term condition. Such incidents had an emotional impact in their own right and, again, also had an impact on the willingness of people to talk openly to healthcare professionals. And as a result, their relationships with healthcare services were marked with distrust, wariness and scepticism.

"People are afraid to be too vocal because it is absolutely something that could be held against you."

"Everything about an appointment with a consultant or a hospital doctor is a situation that puts you at a total disadvantage, and that's wrong. You're already at a disadvantage because there's something wrong with you."

“Clinicians...think they know how patients think and they know what’s important to patients. But they get a snapshot because there are so many things we don’t tell them and so many things that we don’t mention because our experiences are there’s no point in telling them about these things and there’s no point in mentioning these things, like pain, fatigue, that impact on your mental health, or whatever, because they are unable or unwilling to do anything about them.”

“We have to battle and beg for everything.”

Poor communication of what is available

A major barrier to getting mental health support was not knowing that it was available, or how to access it. People felt that, if they did want extra support, they would need to proactively ask for it, instead of it being an intrinsic part of their care. Often the times when people felt like they most needed emotional support, they were too ill or exhausted to go looking for it, especially when they perceived that they would have to fight for anything more than what they were already receiving.

“I know I should be talking to people from time to time about how I’m feeling and I’m coping but I don’t. I don’t want to cause a fuss & I don’t know who to access help from.”

Access to mental health support may also be limited by a lack of information, even about services that are available.

“I only found out after my transplant that a counsellor had been available if I’d wanted to talk to them.”

“I think it would have been helpful if they’d pointed me in the direction of some emotional support.”

An overburdened healthcare system

Many people perceive the NHS to be overburdened. As a result, although they might have appreciated the opportunity to talk about their concerns, they didn’t want to bother people who were perceived to be tired and overworked. This resulted in a situation in which people felt like they were having to look after the NHS as much as the NHS was looking after them.

“I just assume you have to be in and out as fast as you can and take up the least time possible, so that’s what I do.”

“[I’d like] longer appointment times with my consultant to be able to discuss the emotional impact of my condition. But she has a huge waiting list and only 10-minute appointment slots.”

“I would’ve appreciated more psychological support... The nurses were so busy, you couldn’t just go off and chat to them and I think this is where possibly they’re understaffed... There was never an opportunity to sit in a room with a nurse [to talk through your concerns].”

“My experience was that it was understaffed generally, and I felt for the nurses because they were absolutely exhausted, you know, and they just didn’t have enough staff basically.”

Some of the healthcare professionals we spoke to reflected similarly that pressures on staff and a lack of knowledge made it difficult for them to have conversations with patients about their mental health.

“If it’s recognised, no one knows what to say or do, so it’s easier not to acknowledge it.”

“Having enough time to spend with individuals to discuss issues can be difficult. Also need to keep staff consistent to build up rapport so patients trust them to discuss difficult issues.”



Mental health stigma and discrimination

Some people were worried that, if they spoke to a healthcare professional about their emotional wellbeing, they might be labelled as a 'mental health patient' and, as a result, their physical health symptoms might not be taken seriously. This fear was especially strong for those who, before receiving a physical illness diagnosis, had been told that their condition was psychological rather than physical in nature.

One participant with a rare condition had her diagnosis missed by healthcare practitioners for many years for this reason. The feeling of being disbelieved led her to feel depressed but she didn't want to talk to anyone about her feelings in case this meant her doctors focused only on her mental health and overlooked her physical health.

Other people spoke about similar wariness when it came to talking to doctors about their feelings in case this distracted or detracted from how seriously their physical health was taken.

"I used to cry in every appointment. But tears of anger and frustration are indistinguishable from tears of depression so I had to toughen up."

"It's made me very reluctant to talk about my mental health with healthcare professionals or to seek any help when I'm struggling a bit because of fear ...because someone's going to come along and take away my diagnosis and my access to treatment away from me."

"Why would I talk about my fears with anybody? Why would I talk about the things that are worrying me? Because my experience has been that people don't get it and it can be used as further evidence of the fact that things are all in my head."

"One man [doctor] said to me, 'You don't look like you're in pain.'"

"As a young person...if you complain about chest pains or say, 'Oh I think I have a heart problem', a lot of the time they might say, 'Well maybe you have anxiety, maybe you have other problems...maybe you're just stressed.'"

One participant described that she had had a nervous breakdown in the past, and because this was in her medical record, when she presented with knee pain, this was put down to emotional causes until tests were done: "The nurse at the hospital said that they had been treating me as if I was suffering from depression."

"You do start to believe...you know, 'is it me, am I imagining things?'"

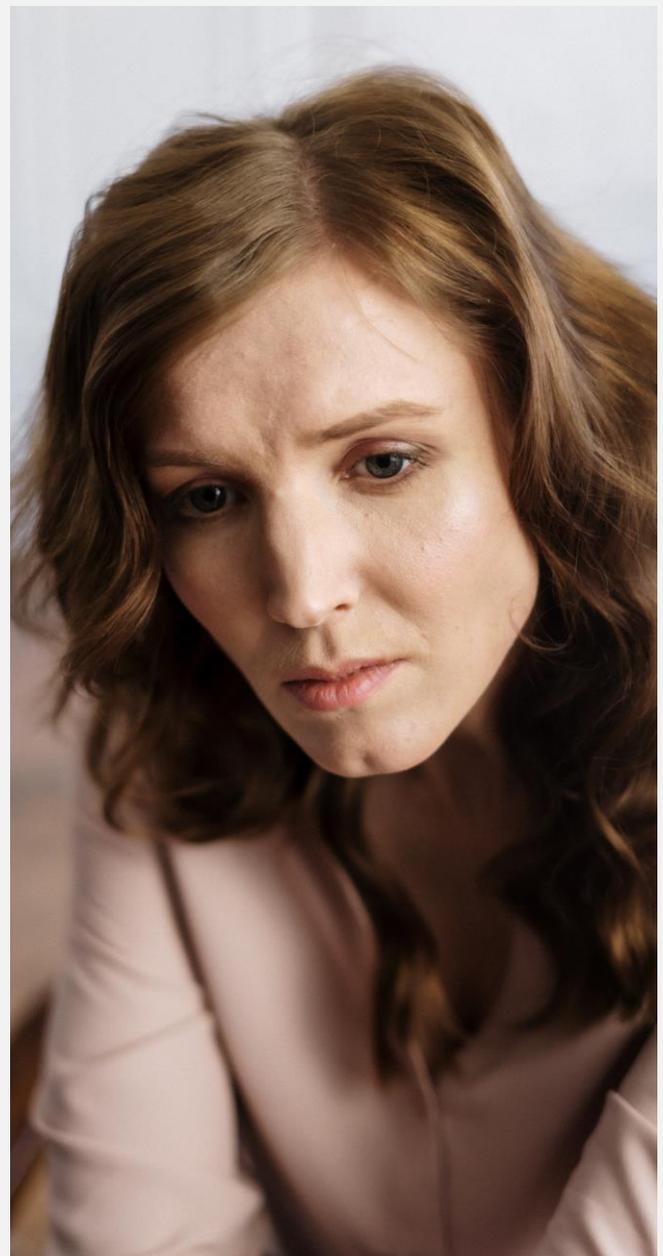
"Because I didn't respond to treatment in the way that they thought that I should have...they thought for some time that the illness could be psychological."

Unhelpful mental health support

A small number of participants spoke about their experiences of getting support from mental health services that they found unhelpful. They described "ill-fitting support from generic mental health teams" who did not understand their physical health needs, who were unable to offer more than 'platitudes', or who advised them to get their physical illness under control before seeking mental health support.

"Support from somebody with more understanding of the actual condition I was living with would have been much more helpful."

"The level of knowledge and understanding that would come from having somebody who has more...or just has more knowledge about the actual physical health condition, I think that could just be so much more meaningful."



6. The impact of COVID-19 on people living with long-term conditions

Many people mentioned that the COVID-19 pandemic had made them feel more vulnerable, bringing their health and their mortality to the forefront of their minds and leaving them in a constant state of anxiety.

"Covid has destroyed me completely... I am really struggling with my mental health."

"I am petrified."

"To begin with, I thought [lockdown] was wonderful. It sort of simplified life... As time's gone on, I've felt rather overwhelmed by things."

"[The pandemic] has made me much more emotional. I have felt worried and confused, especially at the start when I received a lot of mixed messages about my risk and shielding. Being less active also meant that my flare ups once again became more regular, which also had an impact on my emotional health."

"It has affected my mental health because I am at high risk, and it has made me feel very vulnerable and feel weak mentally, exposed."

"Right at the beginning, it was dreadful. For about three weeks...I was almost constantly crying."

"I feel like my whole life is on hold."

A number of people talked about appointments, treatments and procedures (for both physical and mental health) that had been cancelled or postponed, and the negative effects this was having on their quality of life.

"I was planning for a living donor kidney transplant. As transplants are deferred due to Covid and there will be huge backlog/lack of availability of testing when hospitals reopen as well as backlog of transplant patients, it means I have missed my 'window' for a pre-emptive living donor transplant and will have to go on dialysis first (this route lowers my life expectancy)... Mentally, I am having to adjust to the goalposts moving every month or so. I have also had to sit in hospital for four weeks waiting for surgery availability due to Covid taking primary time in the NHS. [It] feels like other illnesses have been pushed to one side. Phone appointments rather than in person appointments are not enough especially when you are going through critical stages of your disease, you crave talking to your consultant to get the empathy and face to face experience, it is hard to share your feelings and worries down a phone to an overstretched consultant. Covid has totally changed my life plans."

"I had my second appointment with a new neurologist cancelled and treatment stopped. Lost hope."

"I have had very little access to my psychologist [as] she has been redeployed. I [also] have very little access to my GP."

"My cardiologist is too busy. I have no appointment for six months nor can I contact him if there are problems."

Others said that they had become more hesitant about seeking help for their long-term condition during the pandemic, despite the risks this posed. The reasons for not seeking help included fears about the safety of visiting health service premises, worries about being a burden (exacerbating an existing worry for many) or concerns that they may not get support.

"I am staying at home when perhaps I should go into hospital when my angina becomes unstable."

Several respondents described ways in which the pandemic had impeded or undermined their coping strategies for dealing with their long-term condition or maintaining their mental health. That includes access to physical activity and a range of talking and complementary therapies.

"I haven't been able to have counselling at work as I am not allowed into the building. Also, the complementary therapies which I have accessed at work have ceased. This has led me to become much more emotional and tearful."

"At first I was coping well, but as the situation has dragged on, I have felt a bit depressed at times. I am still shielding when others are going out, and I am unable to do the things which normally cheer me up, like singing in a choir. I normally try to make the most of each day. I now feel that the time when I am reasonably well may be limited and I am wasting it by being stuck indoors, especially as I live alone."

"It has made things worse. I usually have acupuncture to ease the pain and to calm my emotions but my practitioner wasn't allowed to work. I usually swim when strong enough as the only low impact exercise I can do but the pools are closed. My poor consultant was off for 12 weeks with Covid so my appointment was cancelled. I felt I had nowhere to turn."

And there was anger about the lack of clear communication, both from government and from local health services.

"Yes, I'm alright, but that's not the point. I would've thought someone would've come along and said, 'How are you?'"

"I knew I was high risk, but I had to wait [for a shielding letter], I had to be so passive, I had to wait until someone identified me as being at risk."

7. What needs to change

In this section of the report, we reflect on what needs to change in order to facilitate improved emotional support for people living with long-term conditions. We draw on both the findings of the research and a virtual roundtable with charities, patient organisations, professional bodies and experts by experience that was held following the interviews and focus groups.

We know that changing people's experiences will be challenging for a health system that has inherited a Westernised model of health that separates out mind and body, that is coping with growing demand for healthcare, and that is yet to recover from the COVID-19 pandemic. But it is clear that system change will be necessary to enable services and professionals to meet the needs of people living with long-term conditions effectively in the future. Key elements of the system change that is necessary to enable improvements include:

- Mental health awareness and literacy
- Prevention and promotion
- Routine enquiry
- Longer consultation times
- Continuity of care
- Individualised, coproduced care
- A wider range of support for mental health
- Addressing health inequalities
- Clearer pathways through the system
- Multidisciplinary approach
- Greater clarity over accountability

Mental health awareness and literacy

Awareness about mental health has grown significantly over the last decade. But it is a work in progress. And it is clear from the interviews conducted for this report that many people struggled to have their needs recognised. Some professionals do not realise how common it is for long-term conditions to have an emotional impact and, moreover, how debilitating this can be. This suggests a role for raising awareness and building literacy among healthcare professionals.

This needs to start with how healthcare professionals are trained in the first place: education and training needs to equip every health professional with enough knowledge and skill to show an understanding of people's mental health and offer basic help and compassionate support.

But it also needs to build up the knowledge and skill of the existing long-term conditions workforce. A major challenge for health and care services working with people with long-term conditions will be to ensure that all of their staff are aware of the potential emotional impact and that everyone is able to take ownership for being alert to the signs and for taking swift action to offer help when a need is apparent.

There is an important place for patient education too. Research among older people, for example, has shown that some struggle to identify with the clinical language used to talk about mental health, with many choosing to use terms such as feeling 'low', 'blue' or 'sad' or having 'bad days'. Others hint at their mood or mental health problems using euphemisms (Independent Age, 2020b). Letting people know that having a long-term condition can have an emotional impact throughout their life might enable them to be:

- More mindful of their own emotional wellbeing, taking proactive steps to improve and maintain it, and being alert to early signs of problems
- Able to see psychological issues they might experience as an understandable and normal response to living with a long-term condition, rather than as an individual failing or weakness
- More prepared to be asked about their emotional wellbeing by the healthcare professionals who support them with their long-term condition
- More proactive in raising issues relating to their emotional wellbeing and seeking the help they're entitled to.

This, alongside other system changes, would help to shift the balance of power between patients and professionals, creating a more equal relationship and more responsive services.

Prevention and promotion

We shouldn't wait until people start to experience problems before offering help. It's important that, right from the outset, people are made aware of the fact that having a long-term condition may have a negative impact on their emotional wellbeing, and that they are supported to maintain or improve their mental health. Social prescribing activities – for example that support physical activity, social connection and opportunities to give – could form a part of this offer (National Voices, 2020).

Routine enquiry

One way to boost awareness and improve access to effective support would be for healthcare professionals to routinely enquire about emotional wellbeing during all medical appointments (in general practice, hospital and community settings) and make people aware of the emotional support they could access if needed. This would go some way towards making both patients and professionals more vigilant for early warning signs and more aware of the different forms of help that are available.

Longer consultation times

To enable conversations about mental health to take place routinely, services may need to offer longer appointments. Research on other aspects of mental health in primary care (for example maternal mental health and suicide prevention) have found that short appointment times are a major barrier to disclosure and help-seeking. This came out strongly in our interviews, with many people giving examples of rushed consultations that stopped them from asking for emotional support. Short appointments are of course a function of a system working under pressure, with high demand and limited resources. But they may also be a false economy: missing opportunities for longer conversations that might ultimately enable people to manage their health better between consultations. One option to address this would be to offer routine holistic health checks to people living with long-term conditions that would include a psychological element.

Continuity of care

There needs to be more recognition of the importance of relationships to effective mental health support to people with long-term conditions. Continuity of care makes a big difference to people with long-term conditions: having a relationship with a professional you trust with information about how you are feeling, knowing you won't have to tell your story repeatedly to different people, and knowing that there will be an offer of help at the end of it.

For some of the people we spoke to, having someone to contact in-between fixed appointments, when they needed some advice or support, who understood their needs, made (or would have made) a big difference.



Individualised, coproduced care

Many of the people we spoke to expressed a wish to be partners in their care – to have their knowledge of their condition recognised and to have an equal say in their treatment, for both their physical and mental health. National health policy documents have long advocated services that are personalised, responsive and (more recently) coproduced. But the reality has not yet caught up with the rhetoric. Too many people's experiences are of getting scant information (unless they looked for it themselves), of not being listened to when decisions are made, and of feeling anxious and angry after appointments. The future for long-term conditions services lies in higher levels of coproduction, in which the expertise of people using services is given equal value and voice. Services are designed jointly, contributions from lived and professional expertise are equally valued, and peer support is embedded within the clinical offer.

A wider range of support

Different people respond better to different types of support for their mental health: there is no 'one size fits all'. So emotional support for people with long-term conditions must offer a range of approaches, not a single model that can be applied to everyone. The most widely used therapy within Improving Access to Psychological Therapies (IAPT) services is CBT. This is because it is highly effective for many people, and it should be available universally and quickly.

But not everyone benefits from CBT. For some people, other therapies may be appropriate, especially where they have complex traumas, or those who need longer term support to help them to manage a fluctuating condition. Others need emotional support of a different kind – for example from peers, or from practitioners who understand the emotional impact of their long-term condition. And Western models of psychological therapy may not be appropriate or acceptable for everyone.

Data from the IAPT programme demonstrates that a number of groups of people, including racialised communities and those from more deprived neighbourhoods have higher than average attrition rates (ie. they are referred but do not complete therapy) and poorer recovery rates (Commission for Equality in Mental Health, 2020). It is important to understand what is driving this phenomenon in order to identify how IAPT can better meet the needs of people who are not benefiting as much as others from this programme.

Over time, many people with long-term conditions become expert in managing their condition, and this may apply as much to their mental health as their physical illness(es). This means that support needs to be 'on tap' long term, available for people to draw on when they need it.

Address health inequalities

Access to mental health support is about more than physical accessibility and proximity: for many groups of people, poor access derives from the services that exist not being relevant to their needs, not being trusted, and not being offered proactively (Commission for Equality in Mental Health, 2020).

To some extent, this report shows that this is the case for people with long-term conditions as a whole. But some groups, including people from racialised communities, people whose first language isn't English, and people with hearing or communication difficulties, will face greater barriers still to accessing emotional support. In both physical and mental healthcare, levels of trust in mainstream health services are lower among many racialised communities (Impact on Urban Health, 2021). Understanding the particular challenges faced by people from specific communities in greater depth would help to address their needs more effectively.

Poor access to support exacerbates inequalities in the determinants of mental health and also leads to poorer experiences and outcomes (CQC, 2019).

This is likely to have been heightened over the last year. As many mental health services, including talking therapies, moved to remote working during the first lockdown in 2020, digital exclusion left a number of groups of people – including those on lower incomes and those in later life – with an even more limited offer than others (Allwood and Bell, 2020). National Voices' recent insight report on digital exclusion, [Unlocking the Digital Front Door: Keys to inclusive healthcare](#), explores how the move to remote service models has impacted people, and how the Voluntary, Community and Social Enterprise sector (VCSE) has led innovative ways to deliver healthcare and support people during the COVID-19 pandemic.

An equitable system would enable access for groups of people who do not find existing services easy to access, trustworthy or relevant to their needs. This might, for example, mean peer support from people with similar backgrounds or characteristics, which a digital offer may make much more practical for some groups. Co-production and co-design approaches could also help to close the gap by working in partnership with groups that are poorly helped to develop alternatives that are welcoming and meet their needs.

Clearer care pathways

It is clear from our interviews and focus groups that people's mental health is undermined not just by having a long-term condition but by the struggles they describe navigating the health and care system and the interactions they have with it. This makes the already stressful experience of having a long-term condition even more difficult, especially for those living with multiple conditions. Many find themselves in conflict with health and care services – battling for support, caught in confrontational relationships with staff and feeling unable to show their vulnerability. This is doubly difficult for anyone seeking support for their mental as well as physical health.

In some local areas, care navigators have been employed to help people chart a path through the system and to ensure that people are aware of what support is available to them and to access it. Care navigators, employed within primary care networks, for example, could span mental health, physical health, social care and more, ensuring people get the support they're entitled to.

Multidisciplinary approach: mental and physical health 'side by side'

Mental health and physical health expertise need to exist side by side. Healthcare for long-term conditions needs to be psychologically-informed, and emotional support for people with long-term conditions needs to be informed by an understanding of their specific needs and challenges. For this to happen, we would need to see some significant shifts in the ways long-term conditions services work – from general practice to acute and community services:

Training: All healthcare professionals should be emotionally literate, competent to identify signs of distress, to understand the concept of trauma and how it can affect people with long-term conditions, and to have a conversation with a person about their emotional wellbeing. They should regard it as their responsibility to enquire routinely about a person's mental health and know how to have that conversation in a helpful and compassionate way.

Teams: Multidisciplinary teams should always include mental health professionals. In larger teams, this may mean including dedicated staff who can provide psychological support, advice and intervention. In others, it might mean having access to mental health expertise 'on call', for example through a liaison model.

Technology: COVID-19 has accelerated the adoption of remote consultation platforms. There is still work to be done in terms of improving the compatibility of the different digital systems that are in use across the NHS (interoperability). But, in theory, technology could begin to break down the practical barriers to multidisciplinary appointments enabling patients to talk to their GP and their secondary care doctors, including psychological support, in a single conversation: pending action to address inequalities in access to digital technology.

Greater clarity over accountability

Where does responsibility for the emotional wellbeing of people with long-term conditions lie? Because this agenda spans between primary and secondary care, between hospital and community services, between mental and physical healthcare, and between the NHS, social care and public health, it risks being both everyone's job and nobody's.

This creates an accountability gap. While waiting lists and times are relentlessly measured for individual services, the experiences of people who need support for their physical and mental health are invisible. And without routine data, transparency and accountability have little foundation to build upon.

There are no simple quick fixes to this. But with the arrival of integrated care systems, provider collaboratives and primary care networks in the NHS, there is an opportunity now to build a system that supports and encourages improvement. Bringing separate organisations together to plan and deliver services may help to foster greater collaboration, and it could engender a more holistic approach to healthcare.



Conclusion

“I kind of feel a bit let down when I look back.”

The emotional impact of having a long-term condition has been ignored, downplayed and side-lined for too long. While not everyone who has a long-term condition experiences mental ill health as a direct result, there is a clear and significant risk to people’s mental health. Having just one long-term condition doubles a person’s risk of having poor mental health, and having multiple conditions increases it further.

This is partly a direct result of having a long-term condition: from living with chronic pain or reduced mobility, from having a shorter life expectancy, from having to undergo invasive treatment or repeated hospital appointments. It can also result from the indirect effects – for example from missing school or having money worries because of reduced income and negative interactions with the social security system.

It is also evident that, for some people at least, avoidable negative experiences of being treated for a long-term condition can cause or exacerbate emotional difficulties. Poor communication from healthcare professionals and rushed appointments, for example, can increase people’s anxieties about their illness, undermining their mental and physical health and reinforcing distrust in health services. Not getting information, not feeling listened to, and having long gaps between appointments were especially problematic for the people we spoke to.

For some groups of people, these experiences may be heightened. People from communities with poorer experiences of health and care services (for example on the grounds of race, neurodiversity or identity) may find it even harder to be heard by professionals and to have their needs met and wishes respected.

It is notable that about half the people we spoke to had received some support for their mental health. That may be a reflection of the people we were able to reach (predominantly via long-term conditions charities) and their interest in the topic. Their experiences were wide-ranging: some talked about emotional or psychological support that they had found helpful, while others reported very little benefit from what they had been offered. This offers an important reminder that there can be no one-size-fits-all solution here. There is no single intervention that works for everyone.

The one constant was that emotional support was better if it came from someone with knowledge or insight about the condition a person is living with. This has significant implications for the way emotional support is provided for people with long-term conditions. And it underlines the need to develop a workforce that is equally comfortable supporting people with their mental and physical health, free of the constraints of the past that kept the two separate and anything but equal.

The offer of mental health support for people with long-term conditions needs to come with an understanding of the challenges people face. For some, being offered emotional support can feel like a denial of their physical illness. But many don’t even get to the point of being offered help, for example because they don’t feel comfortable disclosing distress or they have a difficult relationship with healthcare professionals. And for many, the feeling that the NHS is already overburdened is a deterrent to help-seeking – especially now in the aftermath of COVID-19.

Again, it is likely that access to mental health support is made harder still for people who are more marginalised: through poverty, racism and other forms of discrimination in society. Offers of mental health support need to come with an understanding of the ways long-term illness intersects with economic and social inequality, and an offer that is relevant, trustworthy and culturally appropriate.

Pockets of good practice do exist in the provision of emotional support to people with long-term conditions. We heard of examples in some people’s experiences of getting effective help that made a big difference to them. But most of these are linked to particular conditions or localities. This means that access to support is a lottery, of what condition (or conditions) you have, and where you live.

The challenge now is to build a universal offer for anyone living with a long-term condition that meets their needs holistically, flexibly, empathically and effectively, from first diagnosis to the end of life, and from small gestures of care to specialist treatment.

We have developed a model of 'whole person care' for people living with long-term physical health conditions (Figure 1). The model identifies three dimensions of care and support that should be offered universally, no matter what conditions people are living with. They are:

- **UNIVERSAL:** continuity of care, information and partnership, routine enquiry about mental health, an annual holistic wellbeing check, and support for carers. These elements should be a feature of all long-term conditions services for everyone.

- **HOLISTIC:** practical help (for example with money and work), mental health self-help resources, social prescribing and peer support. These should always be available freely when and where they are needed, offered proactively and equitably, adapted to people's needs and wishes.
- **SPECIALIST:** a range of psychological therapies and interventions, mental health practitioners located within long-term conditions services and emotional support for carers. These should be 'on hand' to offer specialist support when it's required.

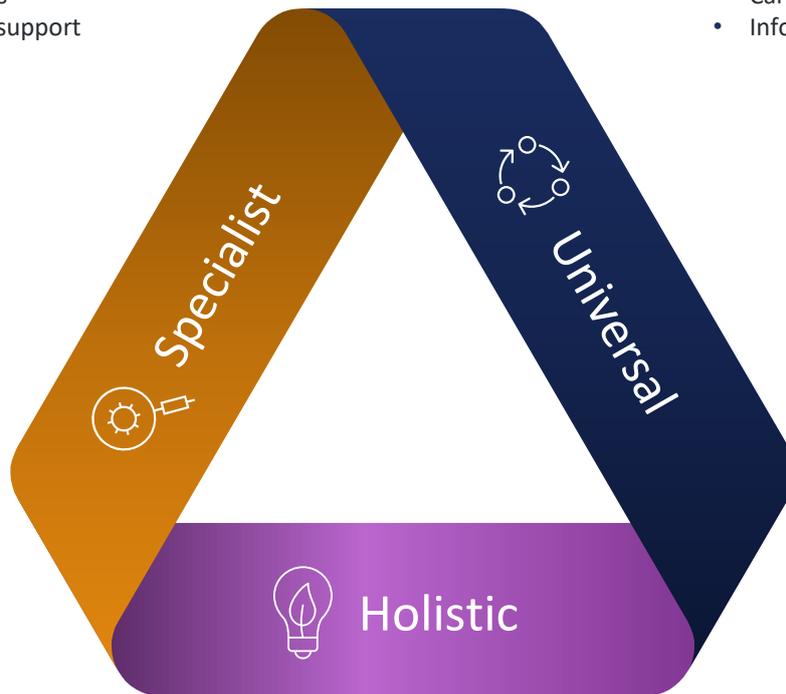
Figure 1

SPECIALIST

- Psychological therapies
- Collaborative care
- Mental health staff in long term condition teams
- Carer mental health support

UNIVERSAL

- Continuity of care
- Annual wellbeing check
- Routine enquiry
- Carer support
- Information and partnership



HOLISTIC

- Self-help resources
- Practical support
- Social prescribing
- Peer support

Recommendations

“Ask How I Am.”

This report has one overarching call to action. It is for all healthcare practitioners and services working with people living with long-term physical conditions to show care and compassion in all their interactions and to take every opportunity to ask about emotional wellbeing.

This can begin now. In some places, it happens already. But it is nowhere near universal. This is the business of all healthcare practitioners, no matter what their role, speciality or client group. We have set out six practical tips for healthcare workers to help them to do this routinely.

We know, however, that this needs to be facilitated by significant system change. Short appointment times, inadequate training and patchy availability of mental health services make it more difficult to support people’s emotional wellbeing. So below we set out recommendations for system change, both nationally and locally, which we believe will enable significant improvements to be made.

System change recommendations for the Department of Health and Social Care, NHS England and other Arm's Length Bodies

1. NHS England, Health Education England, health professional bodies and education providers must ensure that **all health and care workers who work with people with long-term conditions have a sound basic knowledge and understanding of mental health**, and of the emotional impacts of having a long-term illness. This should be included in basic training for all relevant health and medical professionals. And it should be included within continuing professional development (CPD) for existing staff working in primary, acute, community and mental health services.
2. NHS England and the British Medical Association should consider whether general practices should receive funding as part of the GP contract to provide **an annual holistic health and wellbeing check for people living with long-term conditions**. This would include routine enquiry about the person's emotional wellbeing alongside other issues they are facing, beyond but connected to their clinical condition – for example relating to personal finances and relationships. Where needs are identified, practitioners would offer signposting and onward referral to relevant support. Where annual health checks for people living with long-term conditions are already carried out, those designing and delivering them should ensure that emotional and other issues are now included alongside clinical considerations.
3. NHS England should **explore options for increasing appointment times** for specialist long-term conditions consultations and providing improved access to specialist advice and help between appointments. This will require an increase in capacity, but it is likely to be cost-effective by improving outcomes and reducing later costs.
4. NHS England should **review the IAPT Programme for long-term conditions** to determine whether its current approach and structure is able to meet people's needs adequately, how easily accessible it is for people with the full range of long-term conditions, and what modifications may be needed to achieve these aims during the implementation phase of the NHS Long Term Plan.
5. The Government should ensure that the implementation of the COVID-19 Mental Health Recovery Action Plan addresses the mental health needs of people with long-term health conditions, with funding allocated to support for those with unmet needs resulting from the pandemic.
6. The Department of Health and Social Care should use the Health and Care Bill to **ensure Integrated Care Systems will be held to account for providing adequate levels of mental health support** to people with all long-term conditions. This should be regarded as an integral element of population health management, and systems should have to account for how they identify and address the needs of their communities.
7. NHS England should **ensure that there is equality of access to effective emotional support for people with long-term conditions** across all protected characteristics, and especially for people from racialised communities. The Advancing Mental Health Equalities strategy (NHS England, 2020) could facilitate this. The strategy aims to bring about system change to improve the experiences and outcomes in mental health services of people with all protected characteristics.

Recommendations for healthcare systems and service providers:

8. **Integrated Care Systems** should secure adequate provision of mental health support to people with the full range of long-term conditions as an integral element of their responsibility for population health management. This should include **support at every level of need, from prevention, information and advice to specialist psychological services**, and for all age groups, including children and those in later life. This should be supported with routine data to enable system partners to identify gaps and inequalities in access, experience and outcomes.
9. **Acute and community health service providers** should ensure that all specialist care for people living with long-term conditions includes **at least one mental health practitioner as a member of their multidisciplinary teams**. Where this is not possible – for example in very small teams with limited caseloads – a liaison model would provide access to on-call advice and support when it is required. Mental health practitioners in such roles need to have knowledge and insight into the specific conditions people are living with, and the impact this may have on their emotional wellbeing.
10. **Primary Care Networks** should take the opportunity to offer mental health support close to home to people with long-term conditions. From 2021, they will have access for the first time to mental health practitioners through the Additional Roles Reimbursement Scheme (ARRS), to be employed by local mental health trusts (NHS England, 2021). This can bolster emotional support within primary care.

Top tips for practitioners

From the insights we have gathered in the creation of this report, we have identified these top tips for people working with people with long-term conditions.

We know that many healthcare practitioners already provide compassionate care to people with long-term conditions. We also know that the pressures of working in health and care services often make this difficult; and never more so than during and in the aftermath of the pandemic. Many healthcare practitioners are currently exhausted and overstretched. Some are traumatised and experiencing their own mental health challenges.

So these tips are offered as simple and practical ideas, drawn from the experiences of the people we spoke to, to offer practitioners a starting point to work from:



1. Ask patients how they are at every opportunity. Sometimes people just want to be asked how they are feeling. Creating a space for them to express how they are feeling can be a vital first step to getting the right support.

“Listen, believe, and ask me what is important.”



2. Be aware of what help is available to people using your service for their emotional health. This could be how to get access to talking therapies, peer support, voluntary and community sector services, online help or advice, or referrals for specialist mental health support.

“I think it would have been helpful if they’d pointed me in the direction of some emotional support.”



3. Give information and advice to help people to manage their condition, and be available when people need help with this. Where possible share decisions and acknowledge how much people have to cope with in living with a long-term illness.

“Make it clear your door is always open.”



4. Reassure people that it’s ok to seek emotional support at any time while living with a long-term condition. Acknowledge that it can be difficult and that looking after your mental health is an important part of living with a long-term condition.

“Ask me how I am mentally at every medical appointment and check-up.”



5. Show compassion: small gestures of care can help people who are struggling with their mental or physical health.

“I just want someone to understand.”



6. Challenge inequality: be aware that for people from marginalised and excluded communities there are additional barriers to support and low levels of trust that need to be rebuilt.

“You just know that how you’re being treated is because of who you are.”

Information for people with long-term conditions

Your mental health matters: Living with a long-term condition can put pressure on your mental health, but you don't have to 'put up with it'. Looking after your mental health can help you to manage your condition and to enjoy better overall wellbeing.

You have a right to be supported with your emotional wellbeing: Asking for help is not a sign of weakness or a lack of resilience. And help with your mental health can be as important as caring for your physical health. You can ask for general help and advice from your healthcare providers, as well as access to talking therapies, online help or advice, or referrals for specialist support.

Asking for support can make a difference: Getting help early can prevent emotional difficulties escalating into more serious problems, but there is no wrong time to seek help for your mental health. If you have internet access, advice, self-help resources and information online can be helpful. Many long-term condition charities also have helplines which may offer advice and support on emotional health.

Information about looking after your mental health and supporting others is available from the NHS Every Mind Matters website <https://www.nhs.uk/every-mind-matters/> and information about a range of mental health conditions and how they are treated can be found at <https://www.nhs.uk/mental-health/>.



If you are in a crisis or immediate danger, please call 999



Call NHS 111 if you need help but are not in immediate danger



Contact your GP and ask for an emergency appointment



Contact the Samaritans who are available 24 hours a day, by phone (free for UK and Ireland) 116 123 or email jo@samaritans.org.



For more advice and helplines please visit the Helpline Partnership



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