Specialised Healthcare Alliance
FOR EVERYONE WITH RARE AND COMPLEX CONDITIONS

Are you okay?

Rare diseases and mental health – A case study report

Overview

Mental health is an integral part of living well with a rare condition – yet it remains under-supported and inconsistently prioritised across the rare disease pathway. This report shares real experiences from individuals and organisations representing the rare disease community to show the urgent need for action. It builds on the Specialised Healthcare Alliance's (SHCA's) 2024 survey findings and subsequent report *SHCA survey: unmet mental health needs of people living with a rare or complex condition*, and reinforces our calls for mental health support that is timely, equitable, and fully embedded in the rare disease care pathway.

The SHCA is calling for mental health support to be:

1. Accessible in a timely and equitable way
2. Integrated into wider care
3. Available through peer support networks
4. Offered to family and carers
5. Provided in collaboration with charities

Introduction

Around 3.5 million people in the UK live with a rare condition.[1] Behind each diagnosis is a person – often a family – navigating not only clinical uncertainty but a wider, more complex reality that affects every aspect of daily life. Mental health challenges are a common part of this journey. For many, the rare disease experience is marked by periods of isolation, anxiety, and stress, as well as an ongoing struggle to find appropriate care and support.[2]

Mental health issues frequently arise as a direct or indirect consequence of a rare condition. The uncertainty of diagnosis, limited treatment options, fragmented care, and social stigma all compound to affect mental wellbeing.[3] These pressures can occur at any stage in someone's rare disease journey and affect not only individuals living with rare diseases, but also those who care for them. Rare diseases often put strain on families, disrupt friendships, and lead to relationship breakdowns.[4] Rare Minds, one of our member organisations, found that 85% of people[5] said that having or caring for someone with a rare condition had negatively impacted their mental health or emotional wellbeing. At the same time, poor mental health can have a knock-on effect on physical health – limiting people's ability to manage their condition, advocate for their needs, and access care.[6]

Despite this, services are not keeping pace with need. Of SHCA members surveyed in 2024:

Only 12% described current mental health provision for the rare disease community as good

62% described it as poor

72% said mental health support is poorly integrated into the wider care pathway[7]

There is increasing recognition of the intrinsic link between mental and physical health,[8] and the rare disease community is beginning to see this reflected in policy. In 2024, England's and Scotland's Rare Disease Action Plans identified mental health as a key area for improvement, demonstrating the growing consensus across both the health system and policymakers for parity of esteem. The evidence is clear: physical health problems significantly increase our risk of developing mental health problems, and vice versa.[9]

The current political landscape presents uncertainty for both rare disease and mental health policy. The UK Rare Diseases Framework, which underpins the national action plans, is due to end in January 2026. Many in the community, including the SHCA and its members, are concerned about what will happen to ongoing initiatives.

Adding to this uncertainty is the ongoing reintegration of NHS England into the Department of Health and Social Care (DHSC). While details remain limited, the implications for people affected by rare, genetic and undiagnosed conditions could be significant, as outlined in our joint open letter with Genetic Alliance UK and the Neurological Alliance to Secretary of State for Health and Social Care Wes Streeting and Chief Executive of NHS England Sir Jim Mackey.

At the same time, the wider landscape for mental health support is increasingly strained. NHS mental health services are under immense pressure, with long waiting lists and stretched nationwide.[10] Third sector organisations – including many charities supporting people with rare or complex conditions – are stepping in to fill the gap. However, this shift is not sustainable. Our 2024 survey found that 91% of charities supporting people with rare or complex conditions are under increased strain since the COVID-19 pandemic, with 48% describing this pressure as *"unsustainable"*.[11] Many are being asked to provide emotional and psychological support that should fall under NHS provision, including for individuals with complex needs.

About this report

The SHCA is a coalition of over 140 charities and corporate supporters working to improve services for people with rare and complex conditions. Our members have shared their concerns that the mental health needs of those living with, or caring for someone with, a rare condition are being overlooked – and that the emotional and psychological toll of rare conditions is under-recognised and under-prioritised across the rare disease pathway. In 2024, we conducted a survey of our members to better understand how mental health needs are being met or not. The results highlighted widespread concern about the lack of support available and an urgent need for more integrated care.

This case study report builds on that foundation. It brings the statistics to life by sharing the voices and lived experiences behind them – people affected by rare conditions, their families, and those who support them through charity and community services. These accounts offer new insights into how mental health challenges unfold over time, what support has made a difference, and where current systems are falling short.

To develop this report, the SHCA invited its charity members to either:

- Share personal reflections from staff or volunteers supporting those affected by rare conditions and mental health issues; or
- Connect us with individuals or families willing to share their lived experience.

In total, eight interviews were conducted that reflected a range of conditions, experiences, and perspectives. All participants took part voluntarily and gave informed consent. Given the sensitivity of the topic, all names and specific conditions have been anonymised, ensuring the focus remains on the experiences themselves, rather than the identities of those who shared them.

Disclaimer: *Some of the case study content included in this report may feel upsetting. If you need someone to speak with someone about your mental health, the Samaritans can be contacted at any time, via https://www.samaritans.org or on 116 123 for free.*

The case studies

Person A: A mother caring for her young child with a rare condition

"Nobody says, 'let me help you'."

Person A is a journalist and mother of two. Her second child was diagnosed with a rare condition at just three months old. The experience of reaching that diagnosis, managing her child's care whilst handling a lack of recognition and support from healthcare professionals involved in their care, and ongoing uncertainties since diagnosis, have all combined to have a significant and lasting impact on her mental health.

Despite her child receiving a diagnosis quickly, Person A described the time leading to her diagnosis and the weeks following as incredibly isolating. When the diagnosis came, it was delivered without much context or empathy. She and her partner were not told about the wide spectrum of severity associated with the condition – something that caused additional stress as even post diagnosis they still didn't know the extent to which their child was affected.

"Your brain goes straight to the worst-case scenario. Are we going to need to make the house wheelchair friendly? What adjustments will we have to make?"

She also spoke about the layered emotional toll of receiving life-changing news while adjusting to a new baby.

"I was dealing with all of the emotions that come with a new baby and giving birth, as well as the diagnosis."

At no stage was Person A referred to mental health support by the healthcare professionals involved in her child's care, nor did they acknowledge the impact on her mental health a diagnosis can have.

"Nobody says, 'Let me help you.' I had to ask at every step of the way."

Person A felt that healthcare professionals lacked both the time, understanding and desire to talk about the emotional toll her child's diagnosis was having on her.

"They say 'I'm sorry,' but they don't seem to recognise that you're grieving the life you thought you were going to have. There's no buffer. You're in shock, and you know you'll have questions in a few hours – but the session ends, and your world is collapsing."

To access mental health support she spoke with her GP, who told her to contact her local council. However, Person A found the process of finding and being referred to a local mental health service overcomplicated and stressful.

"There were so many hoops to jump through. In the end, I gave up and found a therapist privately."

Person A explored various support groups, both in-person and online, but found that virtual support lacked the personal connection she needed. Person A accessed and found all of the support groups herself.

"What I needed was human contact – someone in front of me, someone to talk to."

She told us that local council-run in person groups were mixed in value.

“Rare means rare – you’re unlikely to meet someone whose child has the same condition. And even when you do, the children can present so differently.”

Managing her child’s care has reshaped every part of Person A’s life. She spoke about the long-term mental health impact of carrying that responsibility:

“It’s a full-time job. I can’t miss an appointment – each one is a piece of the puzzle. It’s affected how I view my job, how I manage stress, how I live my life.”

Person A believes that emotional and psychological support should be built into the care pathway for all rare diseases from the outset. She suggested that following a diagnosis, parents should be taken into a separate room and offered a space to process the information with a mental health professional.

“If the neurologists don’t have the soft skills to deliver sensitive and upsetting information, there should be someone else in the room who does.”

Person B: An independent Chartered Psychologist

“Listening is an intervention in itself – and costs nothing.”

Person B is an independent Chartered Psychologist with a professional focus on the connection between physical and mental health. Alongside her private practice, she lectures at universities and has conducted research on the psychological needs of patients with rare conditions, as well as providing support to people living with rare conditions through collaboration with a rare disease charity.

Person B told us that many people affected by rare conditions – whether patients or their families – face profound psychological challenges, especially around the time of diagnosis.

“There’s shock and trauma – especially in how people find out about the condition.”

She has observed that while the person with the rare condition may sometimes have little memory of the diagnosis due to its traumatic nature, for family members and carers it can be an ongoing and deeply traumatising experience. However, this trauma often goes unrecognised by the people who have experienced it, and the healthcare professionals involved in diagnosing or consulting on rare diseases are often not aware of the signs of trauma.

“People need to know they may have experienced something really significant – and to look out for the signs of trauma.”

Given the widespread rhetoric of ‘patient-centred care’, Person B feels that families and carers are routinely left out.

“The impact caring for someone with a rare condition can have on family and carers’ mental health is ignored – they don’t get acknowledged or supported. Everything is focused on the patient.”

She has observed that families often experience burnout without even recognising it themselves, due to the widespread belief that what they're doing is 'normal'. Many reach a point of emotional shutdown, unable to identify or express how they feel – a phenomenon known as alexithymia. This emotional numbness is often accompanied by guilt, shame, and a sense of failure, all of which are compounded by the lack of an offer of referral to emotional support from healthcare professionals involved in their loved one's care.

In some cases, caring for someone can lead to what Person B describes as inanition – a psychological state associated with, and underpinning, depression and/or anxiety. From Person B's experience of supporting families of those with rare conditions, isolation and suicidal thoughts are not uncommon.

"It's a loss of energy and purpose – like you're being starved of the things that give life meaning."

Person B firmly believes one of the biggest flaws in rare disease care is the absence of integrated mental health support. This gap can leave patients and families to navigate profound psychological impacts without the tools or acknowledgement they need, with mental health feeling secondary to physical health.

"There's no psychological check-in, no mental health support built in. It's completely missing."

Even when individuals with rare conditions or their families seek mental health support independently, outside of the rare disease pathway, Person B has concerns about the relevance and effectiveness of what's typically offered. In particular, she critiques the widespread reliance on cognitive behavioural therapy (CBT). For people living with a rare condition, the emotional distress often stems from unique challenges specific to their condition, and generic forms of therapy such as CBT don't address their specific needs.

"CBT reinforces the idea that the problem is how you're thinking – not what's happening. It doesn't make it better."

Instead, Person B advocates for what she calls ***"third wave"*** approaches – therapies that acknowledge suffering and build emotional resilience without denying the legitimacy of someone's experience.

"It's not about 'what's wrong with you' but 'what's happened to you.' That shift changes everything."

Yet even with different therapy options, Person B cautions that integrating mental health into rare disease care is not only about referrals or providing extra services – but that it starts with the way health professionals speak and listen. For Person B, it's about changing the culture of clinical consultation.

"We need to move away from rigid scripts. Listening is an intervention in itself."

She describes the need for a more holistic approach that acknowledges the connection between mental and physical health, and encourages open, human dialogue.

"Ask one question: 'What's troubling you?' You don't have to solve it, just asking changes the dynamic."

In her view, fear holds many health professionals back – a fear of ***"opening the can of worms"*** when asking about mental health. But she insists that it doesn't take longer. It simply takes willingness.

"Most healthcare professionals don't have training in mental health. But that doesn't mean they can't be part of the support."

Person C and D: Individuals representing a patient organisation

“People need to know mental health support is there – and that it’s there to stay.”

Person C and D are part of an organisation offering practical, emotional, and peer support to everyone living with or impacted by a specific rare condition. Person D also lives with a rare condition.

The organisation provides a range of support including psychological services, helplines, support groups, and has a lived experience advisory committee. While these services existed before the COVID-19 pandemic, demand escalated during and after. The team is now exploring options to expand their psychological support, including developing a therapy group for up to 15 people.

The organisation provides both volunteer- and nurse-led helplines, and mental health comes up in many of the calls they receive, often by regular callers who initially tried going to their GP but found they needed rare disease-specific support. Person C and D described several key mental health challenges regularly faced by those affected by rare diseases. Panic and anxiety often stem from the fear of needing to go to A&E, where staff may not understand the condition. The mental health impact is particularly acute at the time of diagnosis, when people often feel overwhelmed by the unknown. The invasiveness of tests and operations also carries psychological consequences – not just for the patient, but for their family members too.

Through their organisations work, Person C and D often hear that the treatments required, and side effects of life sustaining drugs which some individuals with a rare condition need to take can create a sense of dread that interferes with their daily life activities like school, university, or employment. They’ve been told that, even after a successful operation or a period of feeling well, people often experience anxiety about future deterioration.

“Am I going to get sick again?”

Person C and D feel there is not suitable mental health support available for people living with or caring for someone with a rare condition, with generic services not always suitable due to the often complex and unique nature of someone’s rare disease journey. Through their organisation’s work, Person C and D hear from individuals that the mental health support available from the NHS is simply not accessible. They state that the thought of a long waiting list, and the ongoing narrative around overstretched and underfunded services, puts them off accessing support through the NHS.

In terms of what could help, Person C and D pointed to automatic mental health referrals – similar to what is offered in cancer pathways – as a model to explore. They also stressed the importance of the health professionals involved in the care of an individual with a rare condition revisiting the topic of mental health continually over time, not just at the point of diagnosis.

In their professional and personal experience, peer support groups – in person or online – are especially valuable. These groups offer a space to connect, particularly for those who are newly diagnosed, and could be integrated more closely into healthcare settings within the NHS.

While they see their organisation as playing a vital role in bridging gaps, Person C and D are clear that charities and organisations cannot replace specialist NHS mental health services.

“It’s a scale of who can we help? Because some people do need more than what organisations and charities like us can provide.”

Person E: A young man living with a rare condition and neurodiversity

> ***“There’s always light at the end of the tunnel.”***

Person E is a young man living with a rare condition and is also neurodivergent. Both have shaped his mental health in different ways. While he now feels he is coping well – thanks to support from charities, community groups and private mental health care – this hasn’t always been the case.

> ***“Throughout my school life, my mental health was good, likewise with going into COVID. It was around 2022/2023 when I was in the Merchant Navy where my mental health was badly affected. When I returned to Reading College in the 23/24 academic year, I compartmentalised these issues, which all came out last November, a few months into my current apprenticeship.”***

When Person E decided to seek support for his mental health, he contacted NHS 111 and was referred to NHS Talking Therapies. However, the long waiting list was discouraging. Knowing that he needed tailored support, Person E chose to access private therapy instead – specifically seeking a therapist who understood both trauma and neurodiverse needs.

This, he says, highlights a critical gap: while talking therapies can be helpful for many, they are not always designed for people with rare diseases or neurodivergence. The one-size-fits-all approach, combined with long waits, leaves some people without accessible or appropriate options.

In addition to accessing private mental health support, for Person E’s specific condition, mental health support is included within the care pathway. His clinical team included a psychologist, and they did raise mental health with him, particularly during a review when he was 20. At that time, he was offered genetic counselling, where he learned more about his genetic profile, including an increased risk of mental health difficulties. He appreciated this acknowledgement and the information, though it came relatively late in his care.

For Person E, it’s important to recognise that people with a rare condition are not immune to facing additional health challenges or life events – and that support needs to reflect the whole person, not just their diagnosis. His rare condition significantly affects his motivation and mood, which in turn shapes his ability to work, pursue hobbies, and engage with daily life. Some days are better than others, but the ongoing emotional toll can be unpredictable.

Beyond the healthcare system, Person E has also found meaningful support through charities, a local orchestra, and a walking group. These sources of community have been important in helping him process how he feels and stay connected to others.

He would like to see healthcare professionals show more empathy towards the mental health challenges that can accompany rare conditions – not only at diagnosis or in crisis, but as an ongoing part of care. He also believes self-referral options for mental health services should be made simpler and more accessible, especially for people who are neurodiverse. Clearer signposting and formats designed with accessibility in mind would have made his own journey to support far easier.

Person F: Living with two rare conditions and medical trauma

"I feel like a healthcare professional's nightmare."

Person F lives with two rare conditions and has a diagnosis of medical trauma related to her experiences since childhood. She says she has ***"always struggled with mental health"*** due to her condition – but that it took years to understand the root of it.

At school, she often felt ***"othered"*** because of her condition. People called her ***"resilient,"*** which only reinforced a sense that she had to appear fine on the outside, even when she wasn't.

"You appear unscathed, and it reinforces you to keep it in."

Living with a rare condition has felt deeply isolating for Person F. Until recently, she only knew of one other person with the same condition in her region of the UK. The lack of shared experience made it difficult to feel seen or understood.

"We have nothing in common apart from the name of the syndrome."

Her trauma responses stem not only from living with a rare condition, but from the procedures she's required over the years – some of them at a very young age. She recalls being restrained for a medical injection as a child, one of many frightening experiences that left a lasting impact. In 2018, years of unprocessed trauma came to a head. Person F reached crisis point and was unable to function, hypervigilant, and easily startled. She referred herself to local mental health services and was diagnosed with complex PTSD stemming from medical trauma; a set of psychological and physiological responses to pain, injury, serious illness, medical procedures and frightening treatment experiences.

In light of this trauma, admission to a psychiatric ward would have been highly distressing, so Person F was supported by nurses to access home-based treatment for nine months instead. Afterward, she was referred for ongoing mental health support, which – due to the pandemic – was delivered over the phone.

Since then, she has received mental health support through the NHS. Still, she stresses that the support on offer ***"doesn't touch the sides."***

Despite ongoing mental health needs, she says no healthcare professional involved in her care has ever raised the subject of mental health with her, not even after her medical trauma diagnosis.

"They treat you like you're rare."

Person F has advocated strongly for her mental health needs to be recorded in order to receive the correct support – asking that her medical trauma be explicitly noted in her health records. At its best, this has helped: a dentist made changes to her care, including a note on the door to avoid loud noises. But in other settings, her requests have been dismissed or met with eye rolls from healthcare professionals and not been addressed by those involved in her regular care.

Her trauma also affects her ability to access care for her rare conditions. Appointments themselves can be triggering – especially enclosed spaces or long waits behind closed doors. Sometimes, even attending one appointment will affect her mental health significantly.

"If my mental health is bad, I can't go, it wipes me out."

Today, she continues to live with the long-term impact of medical trauma while navigating her rare conditions. She was diagnosed with a second rare condition around five years ago and is currently supporting her daughter through a possible diagnosis.

For Person F, taking part in research has become an important outlet for her.

"It's really good for my mental health, it helps me feel like I'm making a difference."

Person G: Part of a rare disease mental health organisation

"We only exist because there's a gap in support."

Person G works at an organisation that advocates for, and provides, specialist mental health support for the rare disease community. The organisation offers telephone and online counselling, training and awareness sessions, and a range of wellbeing resources.

When the organisation was first founded, there was an assumption that people would mostly seek support within the first year or so post-diagnosis. While that's true to some extent, they've since found people may seek help at any point in the rare disease journey – sometimes five or even ten years after diagnosis. The delay can be due to a shift in physical health, a turning point like surgery or progression, or simply the emotional readiness to face it. For others, mental health challenges arise around moments such as recovery, palliative care, or bereavement. Some groups experience specific peaks in need by age or condition.

Person G emphasises that mental health needs don't follow a fixed timeline and support shouldn't either. Emotional toll can take years to surface, especially when people are preoccupied with managing the physical aspects of their condition. Many reach out only when they're ready, not necessarily when a healthcare professional or family member suggests it.

This is why Person G's organisation calls for rare disease care to normalise mental health as part of the whole journey, not just something raised at diagnosis.

"Asking how someone is shouldn't be a checklist question at one appointment – it should be part of ongoing care."

The organisation uses an integrative counselling model, where therapists draw on a range of approaches and adapt them to the individual. Sessions are patient-led rather than technique-led. They also offer a serial model of therapy (usually 6-12 sessions) with flexibility to return later – acknowledging that rare conditions are ever-changing and mental health needs can resurface over time. The aim is to maintain continuity, pairing people with the same therapist if they return.

This differs from NHS statutory mental health services, which are often limited in duration, use a fixed assessment model, and are typically only available to the individual, not carers or family members.

> *“In statutory services, a person with a rare condition might present as anxious and be funnelled into a generic anxiety management course – but what they really need is help to process the underlying experience of living with a rare condition. The anxiety is a byproduct.”*

The organisation also offers couples therapy for parents of children with complex rare conditions, recognising the strain this can place on family dynamics and mental health. Person G noted that in most cases, nothing has been offered to them before.

Person G believes that both physical and mental health services need better awareness of rare conditions. Within mental health statutory service settings in particular, knowledge of rare conditions and their effect on mental health is often extremely limited.

> *“We need more psychologically informed care within physical health services too – how you deliver a diagnosis, explain a procedure, or support someone post-surgery can deeply affect mental wellbeing. If done poorly, it can even lead to medical trauma.”*

Person H: A mother living with, and caring for her son with, a rare condition

> *“I know what he’s got to go through and I’m trying to fill him with confidence when I don’t always feel confident myself.”*

Person H has lived with a rare condition since birth. She experienced bullying during her school years, particularly in late primary and secondary school, which deeply affected her confidence and self-worth. Mental health support was never offered as part of her rare condition care.

> *“Support for mental health in rare conditions wasn’t a thing back then. It just wasn’t spoken about.”*

In her twenties, she made the decision to seek help herself. She accessed CBT through the NHS, which helped to some degree. But the real turning point came when she independently connected with a trauma-informed therapist – someone who helped her understand how her mental health challenges were linked to the trauma and isolation she had experienced living with a rare condition.

She also discovered coaching and courses that focused on the emotional and psychological impact of surgery – resources she believes would have made a significant difference had they been available earlier.

> *“If I’d had that kind of support at a younger age, it would have made a huge difference.”*

Her mental health challenges intensified during pregnancy. She was prescribed antidepressants toward the end of her pregnancy, and, during a particularly difficult period, she and her husband reached out to their GP for additional support. Because she was pregnant, they were fast-tracked into a mental health service, but even then, it required persistence and self-advocacy to access the support Person H needed.

"If you're asking for help, it's because you need it now, not in 6 weeks on a waiting list. Access to support can't just fall on charities – it has to be easier."

It's only in recent years that she has come to realise how much strain she had been carrying.

"I've felt it was normal to be on edge and uptight. But over the last four years, I've realised it's not. There's still a stigma attached to mental health – and I think that stigma is doubled when it's linked to a rare disease."

Her son has since been diagnosed with the same rare condition. At first, she felt prepared to support him. But as the reality of what lay ahead set in – the uncertainty, the future procedures, and his emotional wellbeing – she began to feel overwhelmed.

Unlike her own experience, however, her son's rare disease team includes a psychotherapist as a standard part of the care pathway. This integrated mental health support has made a real difference to her son's, and her, emotional wellbeing.

"We had conversations with the psychotherapist before I gave birth, and after. They spoke to me, to my husband, even to my daughter about how she was feeling. That recognition – that this affects the whole family – is so important."

She feels reassured that her son will receive emotional and psychological support alongside his physical care – but is also aware that this model isn't consistently offered to other families with rare conditions.

"It shouldn't depend on what rare condition you have. Every rare condition team should include mental health professionals as part of the core team, not just some."

Alongside the trauma-informed therapist, Person H has also found peer support and rare condition organisations important tools for her mental health. She has found comfort and solidarity in rare condition organisations' online communities, especially those which have space for parents to come together and talk about their experiences.

"Being able to talk to people who've gone through it. That's been really valuable."

Person H sees progress in how healthcare professionals approach mental health, but says real change requires more than a single question. To make a lasting difference, support needs to be ongoing – not just a one-off conversation.

"Just asking 'are you okay?' isn't enough. But it's a start."

She emphasised that mental health care must be integrated at every stage of the rare disease journey – not just at diagnosis – and made accessible without requiring relentless self-advocacy, and this support must extend to parents, siblings, and carers as part of whole-family care. She also believes that statutory mental health services should consistently apply trauma-informed practices, which have been transformative in her own experience.

Conclusion

Amid ongoing uncertainty in the external environment, one thing remains constant: the experiences of people living with or caring for someone with a rare condition. The stories in this report underline the lasting impact that rare conditions have on mental health and wellbeing, and that people continue to face isolation, emotional strain, and barriers to support. The findings presented here do not point to new or different needs – they echo the same challenges highlighted in our 2024 briefing. Through these stories, we hope to elevate the conversation and reinforce our previous recommendations. The SHCA is calling for mental health support to be:

1

Accessible in a timely and equitable way

Access to mental health support is neither timely nor equitable across the UK, leaving people feeling like help is beyond their reach.

Recommendation: The DHSC should prioritise the mental health impact of living with a rare disease in the next UK Rare Diseases Framework. The DHSC and devolved nation equivalents should develop actions in future Rare Disease Action Plans to improve timely and equitable access to mental health support, working in collaboration with local healthcare providers across the UK.

2

Integrated into wider care

Even when people are able to access mental health support, it is often poorly integrated into their wider care and not helpful in managing the specific challenges that living with a rare or complex condition brings.

Recommendation: The NHS and local care providers should ensure that professional mental health support is proactively offered and integrated into the wider care pathway; general mental health practitioners should have greater awareness of how living with a rare or complex condition can impact on mental health.

3

Available through peer support networks

There is a disparity between the overwhelming importance of peer support for people living with a rare or complex condition, compared with how accessible this support is.

Recommendation: The NHS should work more closely with charities to ensure that people living with rare or complex conditions are aware of and connected to peer support networks, as well as helping to establish new services in areas of unmet need.

4

Offered to family and carers

Living with or caring for someone with a rare or complex condition who may have challenging needs can have a significant impact on wellbeing, but support is difficult to find.

Recommendation: The NHS and local care providers should improve the availability of mental health support for families and carers, and work with healthcare professionals to ensure that this support is proactively offered at key points in the pathway.

5

Provided in collaboration with charities

Charities play a vital role in the care of people living with a rare or complex condition, including the provision of mental health support; however, this support should be complementary to specialist NHS care, not an alternative.

Recommendation: The DHSC and devolved nation equivalents should provide additional funding for NHS mental health services to alleviate the current burden on charities; the NHS should work collaboratively with charities to deliver the best possible holistic care.

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