

SHCA survey: unmet mental health needs of people living with a rare or complex condition

1 in 17 people in the UK are living with a rare disease. Whilst the impact on a person's physical health is life-altering and potentially life-limiting, the effect on mental health and wellbeing can be just as significant, but is underappreciated. Being diagnosed with a rare or complex condition, undergoing treatment, and adjusting to a new life presents emotional challenges for the individual, their family and the wider community.

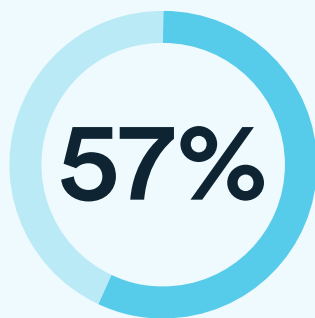
Mental health is a particularly important area for the Specialised Healthcare Alliance (SHCA), a coalition of over 140 charities and corporate supporters, which advocates on behalf of people living with rare and complex conditions.

In 2024, we surveyed our charity members on the importance and accessibility of mental health support, with the results set out in this briefing alongside quotes from survey respondents. **The findings tell a clear story: for people living with a rare or complex condition and their families, timely, equitable and high-quality mental health support is a vital need which is not currently being met.**

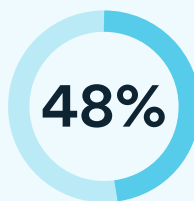
Our survey reveals that mental health support...

...is vital given the significant impact of a diagnosis

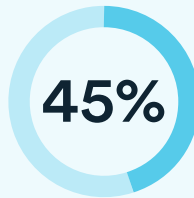
When asked what the most common mental health concerns are for people living with a rare or complex condition:



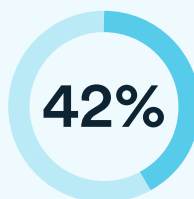
said feeling isolated or alone



said coming to terms with a rare disease diagnosis



said feeling misunderstood by healthcare professionals

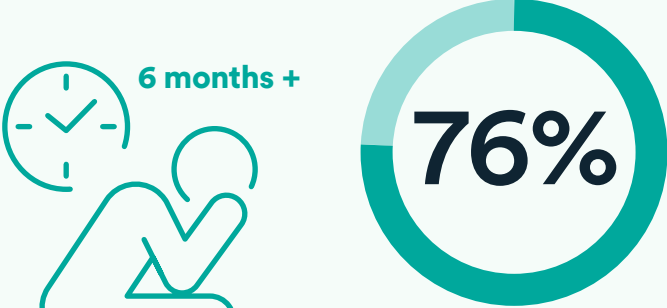


said fear of the unknown and what the future might bring

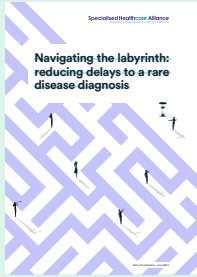


“Mental health support is a huge, growing and vital need”

...takes too long to access



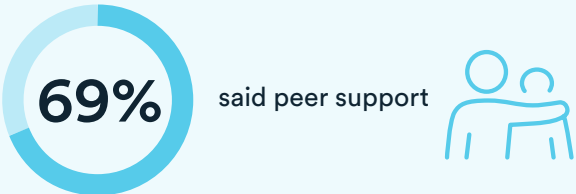
said that the average wait to access mental health support is **six months or longer**; only **3%** said support is accessible in six weeks or less



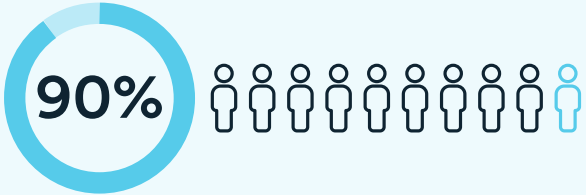
To explore the issue of delays further, read our SHCA report *Navigating the labyrinth: reducing delays to a rare disease diagnosis*

...is most commonly accessed outside of the NHS

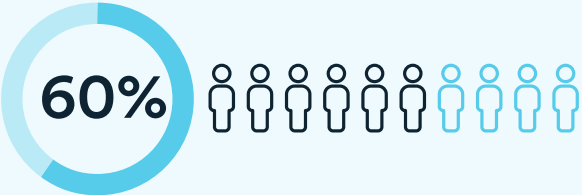
When asked what types of mental health support is commonly offered to people living with a rare or complex condition:



“There is a big difference between mental health and emotional health needs. We can provide some aspects of emotional support but currently can't provide more specialist mental health support. **This is not systematically offered to people impacted by specific conditions, nor is the impact particularly acknowledged or supported**”



said that peer support was important for people living with a rare or complex condition, but only



said this support is accessible

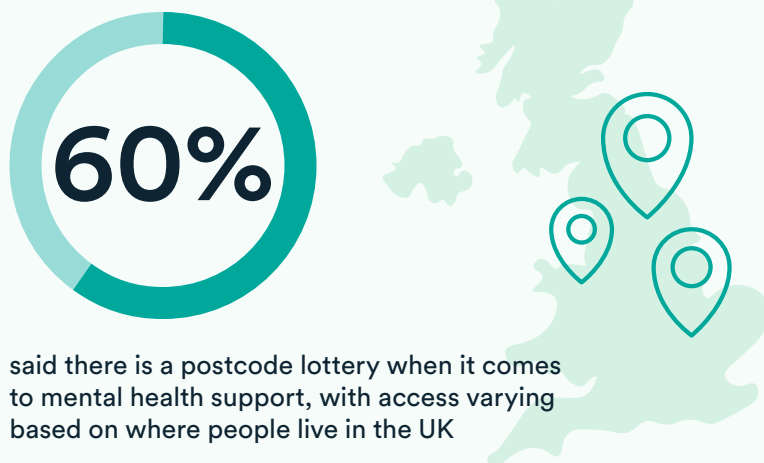
“We need to **remove the barriers** to setting up peer to peer support groups”

...is of low quality and poorly integrated into wider care



“ Fundamentally, **mental health support should be an integral part of the care pathway**, as often people don't realise they need support – over time they do, but then they cannot access it ”

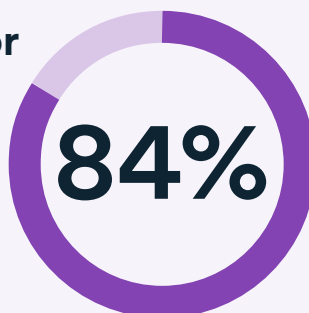
...varies across the UK



To explore the issue of inequalities further, read our SHCA report [Rare diseases, common inequalities: Bringing rare diseases into the health inequalities agenda](#)

“ The reality is people are largely unable to access support – it is a huge unmet need ”

...is not available for families and carers

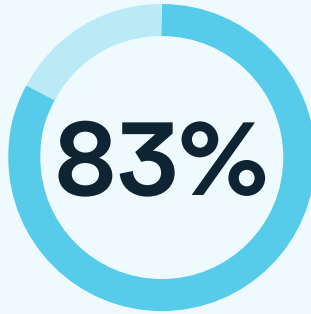


described the availability of mental health support for the family, parents and carers of people living with a rare or complex condition as poor

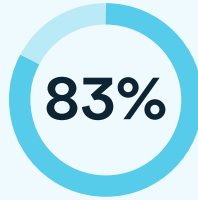
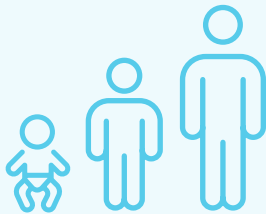
“ **There is so much more that can be done for families** – often, just being given the opportunity to share their concerns and be listened to. We are constantly signposting people to mental health charities about anxiety, stress, depression and loneliness, which are themselves under strain ”

...is not adequate for children

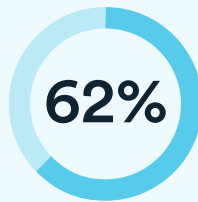
When asked what should be done to improve mental health support for children living with a rare or complex condition:



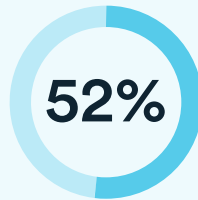
said more support with the transition from paediatric to adult care services



said more mental health support for family, parents and carers



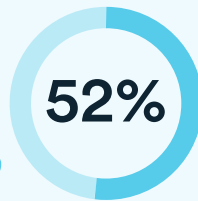
said greater access to a dedicated healthcare professional for their condition



said more mental health support in schools, care or community settings



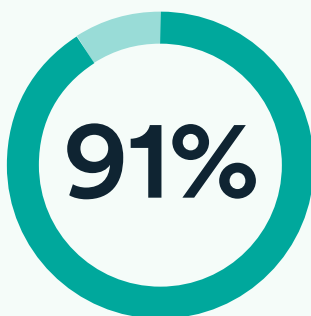
“The transition to adult services is a minefield in terms of support... Consultants have never seen an ‘adult’ version of the disease and therefore do not understand the condition”



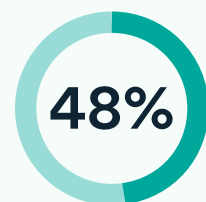
said more funding for care needs related to their condition



...is putting charities under unsustainable pressure



of charities supporting people with rare or complex conditions are under increased strain since the COVID-19 pandemic, as they are having to offer mental health support which should be typically provided by the NHS



described this pressure as “unsustainable”



“Like many other patient groups working in the rare disease field, we have had to create our own mental health support programmes for our community, to ensure they receive appropriate support that is available for as long as it is required. The financial impact on our organisation is unsustainable”

In light of our findings, 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 Department of Health and Social Care (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.