



Rare Minds Matter

Rare Disease & Mental Health
2023 Survey Results

rareminds

Mental Health for the Rare Disease Community

About Rareminds

Rareminds is the first specialist rare disease counselling and psychotherapy service in the UK

Our vision is that the psychological and emotional aspects of living with a rare condition are recognised as an integral part of rare disease care, with access to specialist quality services for all.

Our mission is to provide affordable, timely access to highly specialised counselling for the rare disease community, and campaign for recognition of the importance of specialist mental health support by informing policy, practice and promoting standards of excellence.

All of our counsellors/psychotherapists have additional post-Diploma (or equivalent) level experience, and have completed Rareminds innovative internal training programme on 'Counselling for those impacted by Rare Diseases.' Our clinical team currently consists of 9 counsellors and psychotherapists, and two Honorary Counsellors. We also have an our Associate Team comprised of a Mindfulness Programme Teacher, Clinical Psychologist, Clinical Supervisor and Consultant Psychiatrist. 23% of our team come from a non-white background and 54% have lived experience of rare conditions.

We are an approved member of The Association of Counsellors and Therapists Online (ACTO).

Conflict of interest declaration

As a provider of counselling and mental wellbeing services to the rare community, we recognise that Rareminds could benefit from the recommendations in this report. At present however we believe we are the only organisation in the UK working psychotherapeutically in clinical practice across a range of rare conditions. As such, we have unique insights and feel a responsibility to use these to advocate for the mental health needs of the rare disease community. In time we hope there will be further research, development and standards of good practice in this area. In an ideal world Rareminds would not need to exist.

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Depending upon your personal circumstances, some of the material we have included in this report may feel upsetting.

If you need someone to speak with the Samaritans can be contacted at anytime via <https://www.samaritans.org>.

Introduction

“Managing my mental health is crucial to managing my physical health.”

This report presents the results of our ‘Rare Minds Matter - Mental Health Survey 2023’. It provides a ‘snapshot’ of the post pandemic experiences of the UK’s rare community in relation to their mental health and wellbeing.

We hope it will open up further conversations on this fundamental aspect of living with a rare condition, as well as stimulate further in depth research in this area. We particularly look forward to the findings of the upcoming EURORDIS Rare Barometer survey also focused on mental health.

In 2018 the Rare Disease UK report, ‘Living with a Rare Condition: The Effect on Mental Health’ demonstrated that rare conditions have a significant impact on mental wellbeing. Of the report’s 1,800 respondents, 93% felt stressed, 88% emotionally exhausted and 70% at breaking point. 36% of patients who responded, and 19% of carers had suicidal thoughts. Since this report was published the rare community has lived through the Covid-19 pandemic, increased pressure on the NHS and the cost of living crisis.

For a long time the ‘poor relation’ to physical health, the importance of supporting mental health and wellbeing is now finally becoming recognised as an integral aspect of living with a rare condition. The current England and Scotland Rare Disease Action Plans have made mental health a key focus area, and EURORDIS - Rare Diseases Europe recently launched their new Mental Wellbeing Partnership Network.

Despite this welcome focus, we are aware of the ongoing need for up-to-date information to guide and support such initiatives, and to ultimately inform good practice for mental health and wellbeing over the longer-term.

Where we feel appropriate, we have offered some reflections or comments on the survey findings presented here. These are informed by our clinical perspective of providing counselling and mental wellbeing support to the rare community since our foundation in 2020.

All quotes included in this report are from survey respondents.

**Thank you to everyone who shared their experiences with us.
We know your time is precious.**

Respondents

**In total 695 people completed our survey
Over 188 rare conditions were represented**

Our online survey was a mix of open text, multiple choice and scoring questions, and launched on Rare Disease Day 2023.

It was shared via email, social media, our website and rare condition organisations (including our charity partners).

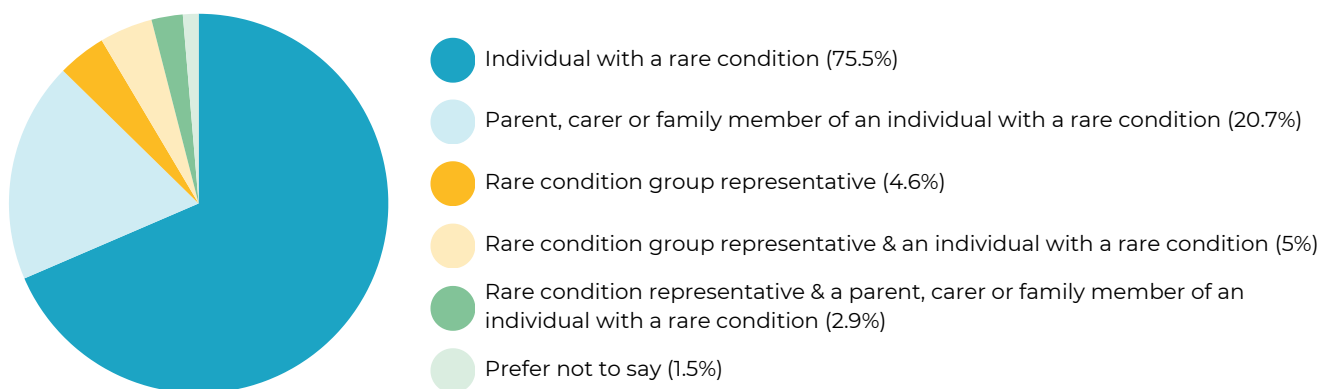
We wanted to explore not just individual experiences of people affected by rare conditions and their friends/family, but also the experiences of rare leaders providing front-line support. Many staff and volunteers leading these groups are also personally impacted by those same rare conditions.

As statutory services for mental health support are increasingly under pressure and waiting lists long, an increasing burden is being placed on third sector organisations to provide a wide range of support, including for increasingly complex mental health needs. We wanted to learn more about the experiences of rare leaders in this regard.

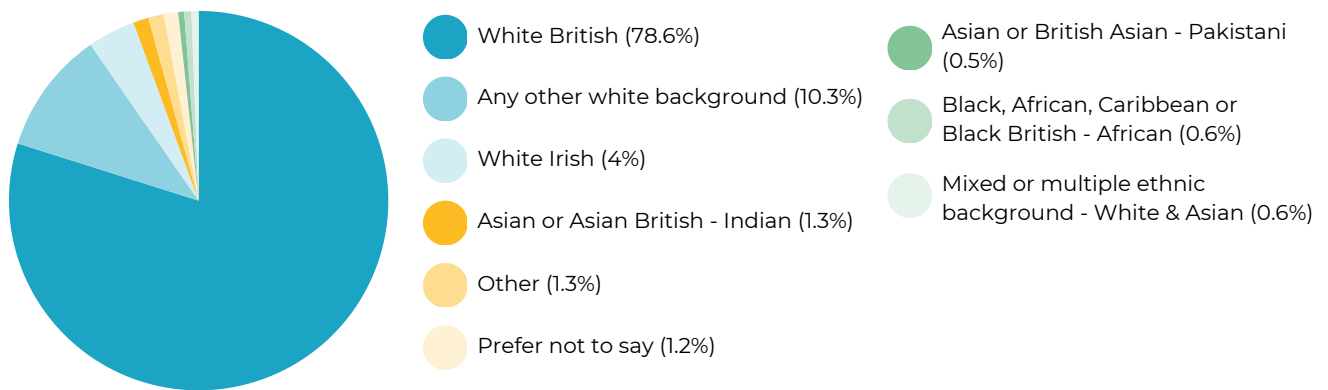
Part 1 of the survey was for people affected by, or caring for someone with, a rare condition.

Part 2 of the survey was for rare condition group or organisation leaders (some of whom may also be personally impacted and completed part 1).

Capacity in which people responded to the survey



Ethnicity of survey respondents



Not represented on chart:

0.4% - Any other Asian background, Any other mixed or multiple background and Other ethnic group - Arab.
0.1% Asian or Asian British - Chinese and Mixed multiple ethnic group - White & Black Caribbean.

Survey respondents were predominantly from the white British community (78.6%) and the majority of all responses were from white respondents. Their experiences may therefore not represent the experiences of those from other ethnic communities or cultural backgrounds who often face additional pressures such as racism, stigma and discrimination that can create even greater pressures upon mental health.

Part one responses

People affected by, or caring for someone, with a rare condition

Based on the breakdown of the responses received, the experiences shared in this report speak more to the experience of individuals affected by a rare condition (74.4%) than those of their parents, carers or family members (20.7%).

188 rare conditions were represented including genetic and non-genetic conditions. We have chosen not to share a condition-specific breakdown in order to preserve the privacy of respondents and avoid possible identification as a result of the rarity of their condition.

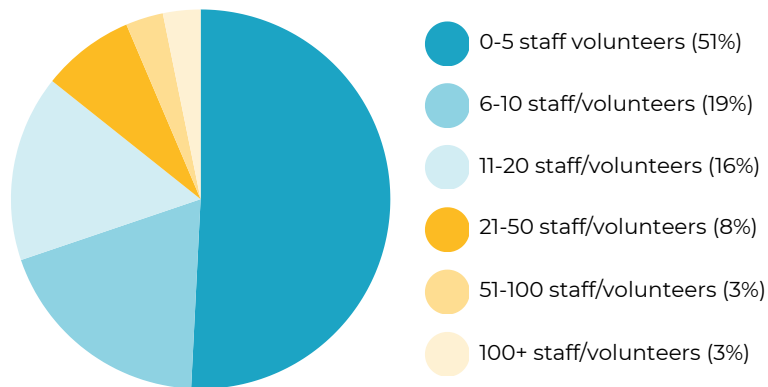
Part two responses

Rare condition group or organisation leaders

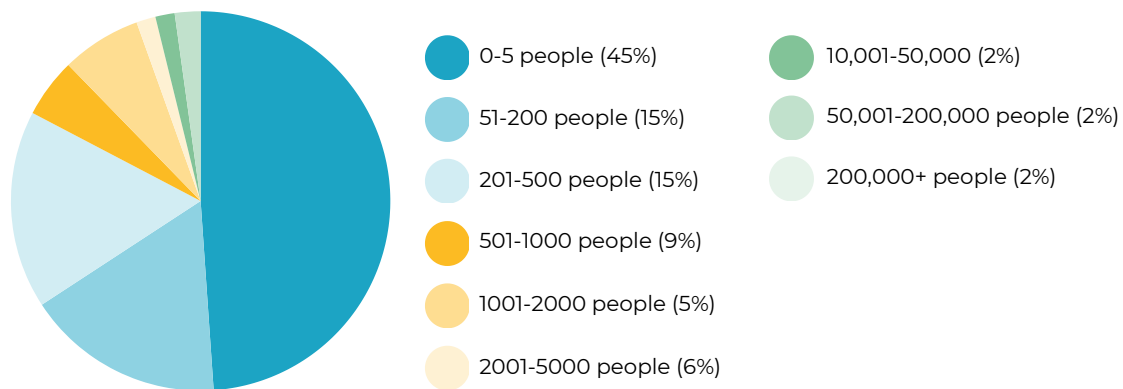
The majority of responses (over 50%) were from small rare condition groups/organisations (those with less than 5 volunteers or staff, supporting under 50 people (44.6%).

As such, their experiences may be less representative of those working for some of the larger organisations, and/or with bigger communities.

No. of staff/volunteers associated with the rare condition groups/organisations who responded



No. of people supported by the rare condition groups/organisations who responded



Key findings & recommendations

Key finding - Living with a rare condition creates additional and particular challenges for mental health & wellbeing.

Our survey results support the themes that frequently emerge from within our counselling service, and that are increasingly recognised across the rare disease sector. Having, or caring for someone with, a rare condition goes beyond just managing physical symptoms. It invariably impacts all areas of life including on personal identity, self-esteem, family and social relationships, work and finances.

The most challenging issues identified were:

63% worrying about the future

51% fatigue

44% lack of awareness among healthcare professionals

42% managing uncertainty

40% anxiety

Respondents told us that having, or caring for someone, with a rare condition resulted in them feeling anxious, worried about the future, and isolated.

85% felt having, or caring for someone with a rare condition, had negatively impacted their mental health or emotional wellbeing.

41% felt having, or caring for someone, with a rare condition had negatively impacted their family relationships.

Recommendation - A holistic, integrated approach to the care of people impacted by rare conditions that includes consideration of mental and emotional wellbeing is essential.

Key finding - Rare conditions can affect the protective function usually played by family and couple relationships to support mental health & wellbeing.

Supportive family (or close) relationships are generally acknowledged to play an integral role in promoting positive mental health and wellbeing for everyone.

Given the many and diverse ways that rare conditions can impact couple and family dynamics, it is unsurprising that relationships are often subject to considerable degrees of stress, strain, and sometimes, conflict.

Respondents told us about worries of the impact on siblings and about relationships with partners. Some also expressed anger and sadness about the impact on relationships with extended family members (like older generations and adult siblings).

It is clear that rare conditions do not just impact on an individual's mental health and wellbeing, but also that of the immediate and extended family.

16% of respondents felt having, or caring for someone, with a rare condition had positively impacted their family relationships.

41% of respondents felt having, or caring for someone, with a rare condition had negatively impacted their family relationships.

Key themes in how rare conditions affect family life:

- symptoms negatively impacting activities and daily life
- coping with conflict, differing opinions or coping styles between family members
- pressures of parenting
- feeling lonely or different to family members
- experiences bringing family closer together
- the emotional impact of genetic inheritance

Recommendation - Individuals, couples and families need support to help manage the impact of rare conditions on the dynamics of personal relationships.

Key finding - Relationships and interactions with healthcare professionals have a significant impact on the mental health & wellbeing of people affected by rare conditions.

The role of healthcare professionals and services was clear. A significant number of respondents identified difficult experiences with healthcare professionals, or navigating the healthcare system, as a contributing factor to poorer mental health.

Insensitive delivery of difficult news, lack of disease awareness, poorly delivered or delayed diagnosis, and lack of coordinated follow-on care and sign-posting were all cited as contributing factors to poorer mental health.

75% had never had a healthcare professional offer support (or sign posted them to support) for their mental health.

Of the 25% who were offered, or signposted to mental health support, 87% took up the support.

Positive encounters with healthcare professionals and services however can promote and support mental wellbeing. Good care coordination and psychologically-informed care can itself mitigate and prevent distress for individuals and families. This may in turn help prevent further decline in mental health, allowing difficulties to be addressed earlier, and thus driving down the use of more time-and-cost intensive mental health provision.

96% of respondents felt that if accessing mental health support, it was important that mental healthcare professionals had an understanding of rare conditions and how they can impact mental health.

Recommendation - Anyone impacted by a rare condition should receive psychologically-informed 'rare aware' care from the healthcare professionals they encounter.

Key finding - Mental health support is desirable, but accessing appropriate services is not always easy.

Access to counselling was cited as strongly desirable by both rare leaders and individuals as a means of supporting mental health and wellbeing.

Just under half of individual respondents had independently tried to access mental health support, and the majority of those who had been offered support by a healthcare professional took up that support.

It was clear from the experiences shared with us however that accessing support was not always straightforward - lengthy waiting lists, lack of rare disease awareness in mental health services, and irrelevant or inappropriate interventions all can act as barrier to accessing support.

96% of respondents felt that if accessing mental health support, it was important that mental health care professionals had an understanding of rare conditions and how they can impact mental health.

The top 5 types of support identified as most helpful for mental wellbeing:

- 70%** individual counselling
- 58%** self help resources, tools & techniques
- 50%** group programmes
- 49%** better care coordination
- 36%** financial support

41% of respondents had tried independently to seek support for their mental health.

Recommendation - Training is required for the existing mental health workforce on the impact of rare conditions on mental health and wellbeing.

Key finding - The level of mental health support provided by rare condition group leaders can impact their own mental health & wellbeing.

Rare condition specific groups and organisations bring together a wealth of lived experience and expertise. They help ease isolation and provide a range of post-pandemic hybrid support for mental wellbeing. However, given the strain on statutory services and waiting lists, the pressure on rare condition groups and organisations to 'fill the gap' in mental health support is high. We know many rare groups are increasingly aware of unmet mental health need, and in response are offering - or feel they should be offering - direct provision for mental wellbeing.

Rare leaders describe feeling that their role is personally satisfying, but also often stressful, exhausting and overwhelming.

Many are also managing their own rare condition, that of a family member, and/or become very closely attached to people in the community they support. This creates additional risks to their own mental wellbeing. The overlap between personal and professional, combined with the demands of running a small group/charity (often in isolation) puts many at increased risk of burnout.

66% of rare leaders felt access to counselling would help their community.

62% of rare leaders told us their biggest concern in managing the mental health needs of their community was responding to people in crisis.

61% of rare leaders were concerned about maintaining boundaries and knowing it's 'ok to step back'.

Recommendation - Lived experience and third sector support for mental health & wellbeing should not be seen as a replacement for statutory provision.

Recommendation - Ongoing support & training for rare leaders and peer-to-peer supporters is needed to safeguard their mental wellbeing.

Living with a rare condition

“It's taken away me & my previous life, as well as robbing me of the future I planned and wanted.”

Responses show the degree to which rare conditions can negatively impact mental health and wellbeing is complex and variable.

Accepting change and loss was a consistent theme. Reluctant, or unexpected changes, to domestic or professional roles and 'identity' were often cited as a contributing factor to poorer mental wellbeing.

Coming to terms with what having a rare condition may - or will - mean for you and your 'future self' is challenging, complex, and ultimately very personal. It demands a degree of psychological flexibility to manage the many uncertainties (around progressions, treatment etc) involved. This in itself is a big psychological 'task.'

Respondents described a detrimental impact on self esteem, reduced confidence in their abilities, and frustration with (personal or practical) limitations of services, friends or employers to accommodate the impact of their rare condition. Frustration and distress about lack of support, understanding and acknowledgement from others was expressed by respondents impacted by both visible and invisible rare conditions.

Some respondents also stated how having, or caring for someone with a rare condition, had made them feel emotionally 'stronger'. A nuanced theme emerged about a pride in one's capacity to cope, and a more 'philosophical' attitude about what 'really matters' in life.

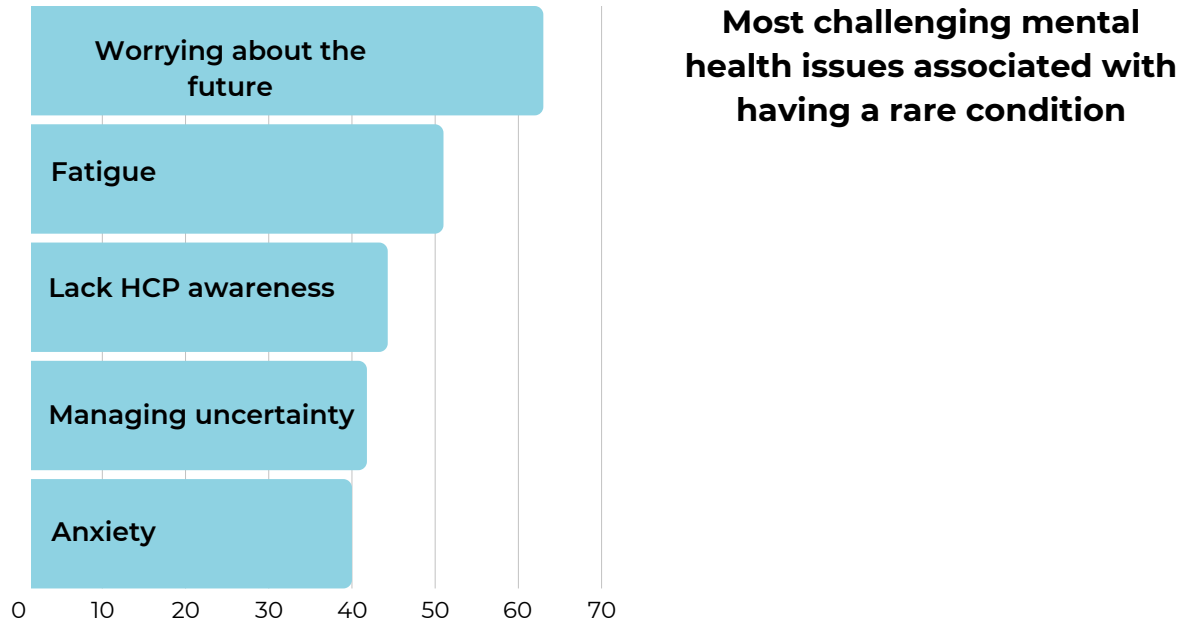
85% of respondents felt having, or caring for someone with a rare condition, had negatively impacted their mental health or wellbeing.

“It's not easy and not everyone can do it. It has made me stronger..”

Key finding - Living with a rare condition creates additional and particular challenges for mental health & wellbeing.

Biggest mental health challenges

Respondents told us that the key issues they find most challenging in relation to their rare condition and mental health were:



When asked to expand further ‘in their own words’ about the impact on their mental wellbeing, additional themes included:

- managing difficult or unpredictable symptoms
- feeling isolated or alienated
- depression, low mood, or despair
- loss of self esteem and confidence
- the strain on relationships
- financial strain
- lack of disease awareness (or acknowledgement) amongst friends or wider family

Respondents with conditions associated with a biological impact on mental health (such as hormonal or neurological) can also face particular challenges in accessing mental healthcare that can address this appropriately.

“Having to cope with a rare condition every day is exhausting and can cause adverse, long term effects on mental health. Also, people sometimes think that if you're having a good day, that you're 'better' which can cause anxiety, bring up concerns that they think that you're exaggerating”

Worries about the future

The rare disease journey involves processing many different types of change and loss. It includes not just the dealing with the news of diagnosis, and anxieties at that point about what the future may hold. As most rare conditions tend to become more difficult and impactful upon health over time, associated fears emerge depending on the individual and their condition. These are often around future dependency needs (physical or emotional) life expectancy or pain.

“It's almost a grieving process, a readjustment to your expectations for your life. And not just for you, but for your family too.”

It was clear that many respondents live with varying degrees of anticipatory loss and grief. This in itself has the potential to erode mental wellbeing.

Fatigue

Living with a rare condition can impact on energy levels for both carers and the people who are affected by a rare condition.

Fatigue may be as a result of:

- the biological impact of a condition
- living in, or with, pain
- the additional 'stress and strain' on daily life
- anxiety or low mood
- lack of sleep (or disrupted sleep)
- a lack of practical and emotional support

“I'm finding a lot of things more difficult and physical activities have a greater impact on my body in terms of fatigue, pain and discomfort and this in turn has a negative impact on my emotional wellbeing.”

Frustration and despair about fatigue was expressed by many respondents. The loss of previous levels of energy, and the consequential impact on daily life, can be very distressing. For conditions associated with fatigue, it may be unclear to both professionals and individuals what can be addressed, or what has to be accepted. Carers of children or adults with high dependency needs (and/or complex behavioural problems) are also highly represented in our counselling services, some of whom are living in a state of near permanent exhaustion. Inevitably this negatively impacts mental health and wellbeing.

Managing uncertainty

One of the most challenging aspects of living with a rare condition is the amount and complexity of uncertainty that can be involved. Rare conditions tend to behave unpredictably and variably, with no two individuals necessarily impacted the same way. There is often insufficient data to make specific assumptions about progression, or about responses to treatment and management over the longer-term.

“Like living your life in foundations of sand not knowing what you will be able to accomplish next week or next month.”

Life with a rare condition involves living with, and managing, a range of macro and micro uncertainties, depending on the rare condition and its impact.

Macro uncertainties

‘What will my child’s life expectancy be?’
‘How will my condition impact on my work or future life choices?’

Micro uncertainties

‘Will today be a good or bad day in terms of my symptoms?’
“Will my new GP have heard of my condition?”

Uncertainty has a strong association with anxiety (see below). Psychological support (professional and peer) to help improve tolerance and acceptance of uncertainty can be invaluable.

Mitigating ‘avoidable’ uncertainties, such as around the timing and communication of test results, good care coordination, clear information and sign-posting by healthcare professionals has a clear role to play in supporting mental wellbeing.

***“Not knowing how much ongoing support either myself or my daughter will need is a constant worry.
I remain on edge more often than I would like.”***

There are multiple challenges to living with a rare condition that can provoke worry and anxiety. The impact of these on quality of life can be considerable. It is clear that most respondents are managing varying degrees of varying anxieties on an ongoing basis.

“I get depressed as I spend a lot of time alone and have to rest. When I am tired/fatigued my anxiety is worse. Worrying about my health and the future.”

Some conditions themselves also biologically stimulate anxiety and/or depression (see below).

Some respondents described the stress of chronic ‘low level’ anxiety and being hyper-vigilant about one's own or another's health. This included the challenge of how to make sense of any changes to health or possible new or changing symptoms, and whether these indicated disease progression or activity. For conditions which impact cognitively or neuro-psychiatrically as well as physically, this included vigilance about mental health too.

“I now have severe health anxiety that wasn't triggered until I was first diagnosed with a tumour. Now, because I know I have a tumour condition, I'm constantly on edge and unsure if even 'normal' issues are actually part of the condition and could mean I need scans/bloods/treatments/surgeries/etc. My brain easily spirals out of control thinking the worst is fast approaching.”

Physiological & biological impacts

Some rare conditions directly impact mental health by changes to brain chemistry, function or hormones. Rare conditions that biologically or physiologically impact mental health create unique challenges, especially if psychiatric medication to help is either unacceptable, ineffective, or contra-indicated.

“I have less control over my emotions and cry quite often. This has impacted me at work and confuses family.”

Individuals who have experienced mental health difficulties as part of their journey to diagnosis may also face further difficulties in how best to both understand and manage their mental health going forward. Trust in both mental, and medical, healthcare professionals may be reduced, especially if difficulties during the diagnostic odyssey were 'over-psychiatrised'.

Physical healthcare professionals may also focus primarily in addressing physical symptoms, and de-prioritise mental symptoms or signifiers. A lack of guidelines for both rare conditions, or with respect to contra-indications (given many rare disease patient may already be taking treatments 'off label or at unusual dosages) may further inhibit prescription of medication that could help alleviate anxiety and low mood.

Non-specialist mental health professionals and services may also have limited understanding of, or capacity to adapt, existing support or treatment options.

“Due to my mood swings and mini fits, it would cause a lot of arguments with people who didn’t understand it was being caused by my severe hormone changes as well as the pain my body was going through, not having the correct treatments, care or team of doctors put me and my immediate family in a lot of stress.”

Recommendation - A holistic, integrated approach to the care of people impacted by rare conditions that includes consideration of mental and emotional wellbeing is essential.

Family life & relationships

Supportive family and close relationships are generally acknowledged to help promote positive mental health & wellbeing. These relationships can however also be complicated, especially when managing a rare condition is thrown into the mix.

Respondents told us of the challenges their relationships had faced after a diagnosis or on the rare disease journey. They also told how it had sometimes made them feel closer to a partner or their family. Others told us they felt resilient, or 'good about' how they were managing, even when things were hard.

When asked to expand further 'in their own words' about the impact on their family life and relationships the themes included:

- symptoms negatively affecting family activities and daily life
- coping with conflict, different opinions or coping styles across family members
- the pressure on couple relationships and parenting
- feeling lonely or 'different'
- experiences bringing the family closer together
- the emotional impact of inheritance

Also mentioned was financial strain, feeling like a burden on family/friends, poor quality of life and managing time.

16% of respondents felt having, or caring for someone, with a rare condition had positively impacted their family relationships.

41% of respondents felt having, or caring for someone, with a rare condition had negatively impacted their family relationships.

Key finding - Rare conditions can affect the protective function usually played by family and couple relationships to support mental health & wellbeing.

Symptoms affecting daily life & activities

Pain, fatigue, and unpredictable or embarrassing symptoms, can all impact not just the individual affected by a rare condition, but also those around them. Personal relationships (including sex and intimacy), work and social relationships can be negatively impacted.

“I want to do normal things with my family but having to rely on them for support has a negative impact on my interactions with them and theirs with me.”

The day-to-day ‘micro uncertainty’ of symptoms, or the inability to commit to future social or working events due to unpredictable health (or treatments) can be very challenging (both practically and emotionally) for everyone involved. Conditions with visible impact on appearance can also impact self-esteem and confidence.

Coping with conflict, differing opinions and coping styles

All families are different in terms of how they deal with difficult or unusual situations, or how openly they talk about feelings. This includes issues around physical and mental health, relationships or ‘difference.’

“Educating those around you is important - but so is managing how much info those around you can handle. There is a balance between shielding and including them - getting it right is like walking a tightrope.”

Disappointment, sadness or anger about little or no family support, or even acknowledgement of a rare condition’s impact, was a not uncommon theme in responses. Family tensions and ‘rifts/ emotional distancing’ sometimes seem to have resulted.

It is clear from responses that a diagnosis of, and living with, a rare condition impacts family dynamics in a multiplicity of ways, but how - or even if - to talk about this within a family was very unclear for many respondents.

“Most family members simply don’t get the all consuming job it is and the constant stress. I get no support from any family which is incredibly hard when I see other children in our family being doted on and their parents living a carefree life with family support.”

Pressures on couple relationships & parenting

A theme across both our counselling services and this survey, is the strain that rare conditions can place on family and couple relationships as a result of the stressors that are common to many rare conditions.

A rare condition diagnosis has a range of potential ways it can impact on a couple dynamic. For some, it may involve a transition to one partner becoming a carer/supporter (either to a partner, or child) with all the attendant psychological changes to personal identity and interpersonal dynamics that result. This transition will be more complex for some than others.

Trying to balance the various needs of all family members can sometimes mean parents are being pulled in lots of different directions at the same time. There can be a lot to juggle, especially when the child/ren affected by a rare condition have high daily care needs. Concern about the future diagnosis of a younger sibling can also weigh heavily.

“Even though I was so overwhelmed, I tried so hard to make sure all my other kids (altogether four) feeling being listened and loved but it required me so much effort. I wanted my husband to be my teammate to tackle with our daughter’s rare disease and keep our family healthy, but sometimes it was challenging for me to express my needs to him. So we ended up having arguments often. It’s getting better though.”

It was notable from responses that the ordinary guilt, worry, and stress of parenting and family life is amplified when parenting a child/ren with a rare condition.

Several respondents spoke of their concerns about the psychological impact for siblings, for children where the parent had a rare condition (whether genetic, or non-genetic) or where a child is taking on young carer responsibilities.

“I can’t ignore the impacts on the siblings but it’s hard to say whether it’s positive or negative because as they grow, the impact might affect them unexpectedly positive in their future which I have been hoping.”

Feeling lonely or different

Understanding and awareness about rare conditions in wider society is still limited. This can affect the capacity of both services and individuals to respond supportively and sensitively to those who are living with a rare condition.

Symptoms which impact communication or socialising can lead to additional isolation, and/or be associated with difficult feelings that are also difficult to express. Despite attitudes changing, stigma about disability and difference are also still high across society.

Changes to roles, appearance or physical and emotional capacity all impact profoundly on identity. A theme across all respondents (partners, parent or affected people) emerged as *'who am i now? What will this mean for me?'*

"I'm 32 years old, single, no kids. I would like to go back to dating, but really... at what point do I tell someone I have a rare progressive disease and my future outlook is uncertain - I'm not looking for a girlfriend, I'm looking for a carer."

Experiences bringing family closer together

Some respondents described a diagnosis causing the family unit to feel closer. This was seen as a positive outcome of difficult experiences. Others also described the experience of 'caring and being cared for' (especially in later life) as very tender and rewarding.

"The whole family is now closer than ever because we realise how blessed we were that my son was diagnosed just in time, whereas others before and after his hospital admission died before diagnosis."

Strong and supportive family and couple relationships are widely acknowledged as a positive factor for wellbeing. They help alleviate stress, provide a sense of belonging, and support both individual physical and mental health.

"As my condition deteriorated my husband has been very caring and positive about having to do so much more to help me. It has brought us closer."

The emotional impact of genetic inheritance

The personal psychological and emotional impact of inheritance can be significant, as can the impact on family dynamics and relationships. Guilt, fear and grief (anticipatory or current) was expressed by many affected respondents.

“My mother has the same condition so I can see every day what may be in store for me. Being dependent on my husband for so many things. Worry about the future and the lack of knowledge of GP's etc.”

Respondents witnessing the decline of a family member with the same condition as themselves face particular challenges to mental wellbeing. Worry and anxiety about future dependency, changes to health status, pain, or decline in physical or mental abilities was expressed frequently.

If different family members have the same condition impacting differently, strong feelings can be stirred in those individuals including guilt, envy and shame.

Inheritance can have a range of impacts on both nuclear and extended family dynamics. It can also have implications for family planning. This sensitive area can often provoke deeply held personal beliefs and opinions, with the potential to cause tensions or conflicts within couples, or between family members and in friendships too.

“I think you feel a great sense of burden when you have passed a genetic condition on to your children. Of all the challenges there are living with a rare disease this has definitely been the biggest.”

Recommendation - Families and individuals need access to support at different points on the rare disease journey to help address family dynamics, and personal life choices.

Role of healthcare professionals

The role of healthcare professionals and services in promoting mental health and wellbeing (or antagonising it) was clear in responses across the survey.

Themes that emerged were:

- lack of healthcare professional's awareness of rare conditions
- the impact of not being believed
- the psychological strain of waiting for appointments and results
- pressure of needing to be the 'expert patient'
- lack of information and signposting to support
- lack of empathy from healthcare professionals
- desire for support at diagnosis

75% of respondents had never had a healthcare professional offer support, or signpost to support for their mental health.

44% of respondents said healthcare professionals lack of awareness was one of their key mental health challenges in relation to their rare condition.

Key finding - Relationships and interactions with healthcare professionals have a significant impact on the mental health & wellbeing of people affected by rare conditions.

Lack of healthcare professional awareness of rare conditions

The lack of awareness and acknowledgement amongst healthcare professionals of rare conditions (generally and specifically) contributed to greater fears about the future, increasing anxiety and emotional 'stress and strain.'

Lack of awareness or support for the psychological challenges and mental health impact (including as a result of biological/neurological disease features) was also cited as a further source of distress and frustration.

"It's emotionally draining as doctors don't know a lot about how to deal with symptoms."

“It is distressing when healthcare professionals have no idea about your illness or how it impacts you physically and mentally..”

Upskilling both the medical and mental health workforces to be more aware of rare conditions generally, including the need for more psychologically informed care, sensitive interactions, and mental health impact, could contribute significantly to improved mental wellbeing for the rare community.

Not being believed

It is increasingly acknowledged that lack of awareness amongst healthcare professionals about rare conditions can contribute to an often long and complex journey to diagnosis. This lack of awareness can sometimes result in the minimising or dismissing symptoms that are later shown to be associated with a condition.

A long or traumatic diagnostic odyssey can provoke anxiety, frustration and distress, and reduces trust in healthcare professionals and services. These factors can in turn contribute to a decline in mental wellbeing.

“Being diagnosed with (rare condition) was traumatic because I KNEW something was wrong yet was told for two years it was in my head. By the stage I was diagnosed I was in crisis and almost at death.”

Psychologically informed care

Not everyone affected by a rare condition will need to access mental health services.

But everyone impacted by a rare condition should be able to receive psychologically informed care.

It lies at the heart of the person-centred, multi-disciplinary holistic care that is needed for those with rare conditions, and has the potential to transform the experience of people and families impacted by rare conditions.

Psychologically informed care can be direct and indirect:

Indirect means designing systems, services, interactions and interventions with mental health and wellbeing in mind.

Direct involves patients and family members having access to a mental health care professional with a specialist understanding of rare conditions as and when needed.

Psychological strain of waiting

The search for a diagnosis can be mentally exhausting. Several respondents also cited the psychological strain of the multiple 'waiting' periods such as for appointments, tests or results, for (more) symptoms to appear, or for treatments. Few felt that this strain was understood by healthcare professionals.

“There needs to be more support during the diagnosis process. Being provided with diagnoses and then waiting for an appointment with a professional to discuss takes months, and it’s a very uncertain time for parents.”

Responses also suggested that that once a diagnosis (and also news of progression or changes) had been given, some respondents felt as though they were then left very much to 'make sense' of the news alone, with little or inconsistent follow-up and after-care.

“I think the specialists are very keen to diagnose people with rare diseases. They must find it all very exciting, but sometimes they forget that there is a real person with feelings at the other end.”

Pressure of needing to be the 'expert patient'

Many people with rare conditions have to juggle multiple appointments with different healthcare professionals, often in locations that may be geographically far apart. This is logistically very stressful, with additional implications for managing work, finances and childcare.

Having to repeatedly recount medical history to multiple services and professionals was cited as very stressful and emotionally 'wearing'. Returning to often distressing and difficult personal experiences as part of history-taking is unsurprisingly challenging to mental wellbeing, particularly when the 'stakes' are so high and ones life may literally be in that healthcare professionals hands.

Many respondents had embraced the role of 'patient-expert' out of necessity, but the emotional burden of this role was also felt by some to be heavy and frustrating.

“Pressure to be 'the expert' and co-ordinate professionals care ... Anxiety making decisions regarding surgical procedures...”

Lack of information

A lack of reliable or current information about what a diagnosis meant, what to expect, or care-planning was not uncommon.

This left patients feeling abandoned, with very little to 'hold onto' after receiving life-changing information.

“Lack of information from medical community means the future is blank. Stressful and difficult. Feel alone.”

In the absence of information from professionals, individuals often resorted to their own search for information. However, online information can be upsetting to read, particularly when it includes (possible out-dated, or small sample size) statistics about life-expectancy or disease progression.

Having even just one healthcare professional that individuals felt was 'on their side', and that they could approach to help digest information and ask questions, conferred a much greater sense of psychological safety and emotional resilience in the face of difficult information.

Lack of empathy from healthcare providers

A consistent theme emerged of respondents describing feeling talked 'about', or 'at', by some healthcare professionals.

The impression was of significant challenges still ahead about improving the quality of interactions with healthcare professionals. Anger, frustration and distress was consistently expressed about 'not feeling listened to.'

Distress was also expressed about feeling 'abandoned' to cope with difficult or debilitating symptoms alone when healthcare professionals were 'at a loss' about how to understand or treat them.

“There is a certain level of insensitivity from consultants and doctors when discussing your disease. When I was diagnosed I was just given a letter. They only care about medicating your symptoms. I often feel rushed like I can't ask any questions. I am not listened to. The impact on mental health is huge.”

Desire for support at diagnosis

There is still some way to go for a holistic approach to the care of those with rare conditions that robustly integrates physical and mental health.

“Counselling at the time of diagnosis (40+ years ago) for me, parents and siblings would have been extremely helpful as it was a taboo subject, borne of guilt, shame and anger.”

A strong call from respondents was how helpful they would have found it to have received more professional emotional support and/or counselling after news of a diagnosis.

“After my child was diagnosed, no one asked me how I felt or if I needed help. But when a parent is told such news, it is very difficult. For 2 years I could not come to terms with this diagnosis. It would be nice if every parent would be told what awaits them in the future.”

Recommendation - The principles of psychologically-informed 'rare aware' care must be embedded across health services and interactions.

Mental health support

Rare conditions vary considerably in terms of their nature, timing and the severity of their impact. They also do not exist 'in isolation', but can be experienced alongside other health conditions or intersectional challenges such as those related to gender, race and socio-economic status.

Respondents identified more mental health provision such as counselling, self-help resources and group programmes as both helpful and desirable. Most felt that it was important that this support was provided by someone with an understanding of how rare conditions can impact mental health.

“When your counsellor knows a little of the disease it makes all the difference. I felt understood for the first time in many years.”

Even a small amount of rare disease awareness among mental health professionals is likely to help facilitate take-up of support, and inform appropriate interventions. A working knowledge of the psychological impact of rare diseases and services adapted to this population, could transform the quality and efficiency of care.

96% of respondents felt if accessing mental health support, it was important that the professionals they saw had an understanding of rare conditions and how they can impact mental wellbeing.

“... all mental health services are issued in 6-8 weekly session blocks. If only our challenges were in 6-8 week blocks”

Support identified as most helpful for mental wellbeing:

- 70%** individual counselling
- 58%** self help resources, tools & techniques
- 50%** group programmes
- 49%** better care coordination
- 36%** financial support

Key finding - Mental health support is desirable, but accessing appropriate services is not always easy.

Access to mental health services

Demand for mental health support across the general population is increasing. At the same time as the NHS workforce faces challenges with recruitment and retention for mental health services.

“The NHS wouldn't offer me any help until I literally begged. Even then I was referred to an online course where each day you logged how much you'd had to drink (I don't drink) and it was then watching a video of a patronising woman saying “well you feel ill or think there's something wrong don't call the GP, do breathing exercises and it will calm you”. It was essentially for hypochondriacs. I privately sought help from hypnotherapy that did ensure I could go to hospital appointments without crumbling into hysterics.”

75% of respondents had never been offered, or signposted to, mental health support. This is significant given the degree of distress indicated in this survey, and elsewhere. The majority of those who were offered it, took up that support. This indicates that the desire for support translates into both 'help-seeking behaviour', and uptake when it is available.

The main types of support offered, or signposted to were:

- counselling
- patient organisation or peer support
- crisis support services
- couples or family therapy

Of the 25% of respondents who were offered, or signposted to mental health support by health care professionals, 87% took up the support.

Other respondents reported trying to access mental health support independently through private therapy, their GP, charities, the NHS and hospital treatment or psychology referrals. Various barriers to access, including long waiting lists, often frustrated timely access at the point of felt need.

41 % of respondents had tried independently to seek support for their mental health.

“Tried speaking to gp. Tried accessing a well-being service but it's all generic... I can't afford to go private. Waiting lists too long.”

Barriers to accessing mental health services

Generally, the reasons why people do not access support for mental health even if it is offered are often complex, and personal. They can include stigma, fear, practical difficulties, a previously poor experience, or a reluctance to explore distress or difficulties. Popular awareness of difficulties in accessing statutory support and long waiting lists may also inhibit some from even trying. Some services may also have intake criteria that screen out those with symptoms associated with some rare conditions.

Those with rare conditions can face additional psychological hurdles that relate back to a long or complex diagnostic odyssey, and the low trust or expectations of healthcare professionals that can result from this. This can include fears of being misunderstood, having to explain their condition and its impact again, or worry about being 'over-psychiatrised'. The logistical burden of managing physical care may also result in mental health support needs being de-prioritised.

“Visited my GP to ask for help with anxiety and depression. Was simply told if I wanted any form of counselling/therapy the waiting list was almost two years so I would be better taking medication.”

Of the small percentage of respondents who were offered support but did not take it up, various reasons were cited. These included:

- not wanting to have to be the patient 'expert' and educate a counsellor about their condition
- feeling others needed it more
- not/no longer needed
- feeling scared, shy or embarrassed
- not having time
- still waiting/waiting list too long

Experiences of mental health support

“My diagnosis made me feel alone, so I reached out to charities who support people with my condition and provide peer support but there is no psychological assistance available.”

Respondents who had managed to access mental health support reported mixed experiences. For some it was a generally positive experience, for others the support offered did not meet their specific needs.

“I went to MIND they put me in on a active monitoring programme which has helped me look forwards and not back at what I used to be able to do and be more positive in my outlook.”

People impacted by rare conditions may face additional barriers to accessing appropriate mental health support due to the general lack of understanding of rare conditions in healthcare.

“Through my GP I had one meeting with a counsellor which was not helpful at all. She left me with a leaflet about my local hospice!!!”

Many conditions have complex interacting physical and emotional symptoms. This may lead to inappropriate or unhelpful interventions or assumptions by some mental healthcare professionals.

“I got in a very dark place due to numerous traumas related to medical experiences. The mental health team I was put under had no idea about chronic illnesses and one even told me that my weeping ulcers were actually ‘my body crying at the world’! I realised that maybe I wasn’t the one with mental health issues then!”

Recommendation - Training is required for the existing mental health workforce on the impact of rare conditions on mental health and wellbeing.

Role of rare condition groups

“It’s a great comfort when you know you are not alone - the sense of sharing the worries would help a lot as most of us do not have friends/family who have the same condition.”

Rare condition groups and organisations play an integral and valuable role in supporting the mental health and wellbeing of the communities they serve.

Many rare groups and organisations are small and volunteer-led. Lived (and life) experience, empathy and ‘common-sense’ are often optimally utilised to support community members. However, the associated risks of burn-out and overwhelm for the staff and volunteers can be high.

*“Asked gp, was told to come back when feeling suicidal!!
Rang (condition specific group) ... was helpful.”*

The majority of rare group leaders felt they were fairly or somewhat confident supporting the mental wellbeing of their community, but felt that coping with people in crisis was the biggest challenge in this area. Some respondents were leaders of very small rare condition groups, some of whom were also impacted themselves by the rare condition of those they support.

This identification, coupled with small community size, can add significant intensity and complexity to the relationships that evolve between small group leaders, and their members.

62% of rare group leaders told us their biggest concern in managing the mental health needs of their community was responding to people in crisis.

61% of rare group leaders were also concerned about maintaining boundaries and knowing it’s ok to step back.

Key finding - The level of mental health support provided by rare condition group leaders can impact their own mental health & wellbeing.

Supporting the supporters

It is clear that rare conditions organisations hold a great deal of lived expertise that can support the mental wellbeing of community members.

“When supporting a community you end up being a counsellor without training. Training would be helpful.”

The difficulties they expressed in being able to maintain and deliver emotional and wellbeing support are common to most ‘front-line’ services. However, what is significant is the lack of support and training to preserve their own mental wellbeing and resilience.

“Emotional burden of listening to problems experienced by our members especially access to healthcare and mental health problems, to which I can offer no tangible solutions.”

Rare leaders biggest concerns about managing the mental health & wellbeing needs of their community were:

- Responding to people in crisis
- Maintaining boundaries
- Managing member expectations
- Knowing where to signpost for mental health support
- Assessing severity and urgency of need

Other challenges rare leaders told us about included:

- managing the group dynamics in online support forums
- juggling global support which includes language challenges
- finding a cure
- lack of qualifications or expertise to manage needs of community

36% of rare group leaders felt supervision, psychological support or therapeutic coaching for their staff and volunteers would be useful.

49% of rare group leaders told us workshops and training would be useful to support their staff and volunteers.

Reflecting on the mental health needs in their community

We asked rare leaders to reflect on what they thought were the biggest mental health challenges for their community.

Similar to the responses from individuals, many of the answers reflected that it is often the overwhelming and traumatic experience of the diagnostic journey, difficulties in navigating healthcare, insensitive encounters with professionals, and the lack of ongoing support that are primary antagonists for mental health and wellbeing.

Some respondents described difficult experiences of healthcare, or as a result of the condition's impact as 'traumatic' for members of their community.

“They are overwhelmed with the need to advocate for themselves, afraid that they won't be safe even when they seek out care because doctors don't know enough to keep them safe and well in hospital, and struggle with the uncertainty about their/their children's futures.”

“Patients have committed suicide as a way out. Abandoned by Doctors, coping with pain and confusing debilitating symptoms. Unable to care for themselves or family makes them feel isolated, worthless, hopeless and a burden on loved ones.”

Trauma

Trauma results from frightening, distressing or stressful events in which we do not feel any control, or were very difficult or demanding to cope with

Ordinary psychological defences in that moment were overwhelmed.

It can result from the impact of a rare condition itself, a treatment or intervention, a medical crisis/event, the nature and timing of difficult news, and/or how one is spoken and responded to.

It can result from a single event, but also from difficult experiences that accumulate over time.

Given there is an association between trauma and increased risk of both mental health difficulties and suicide, recognising and treating trauma for those living with the impact of rare conditions seems essential.

“We try to help people focus on what they can do with the limitations that [rare condition] puts on them rather than focussing on what they cannot do.”

Recommendation - Lived experience and third sector support for mental health & wellbeing should not be seen as a replacement for statutory provision.

Recommendation - Ongoing support & training for rare leaders and peer-to-peer supporters is needed to safeguard their mental wellbeing.

Our thoughts & observations

Since our foundation in 2020, Rareminds has championed the case for better integration of mental and physical health for everyone impacted by rare conditions. As the UK Rare Disease Action Plans launched, we were gratified to see mental health receiving more recognition as an area of unmet need. However, we believe that those impacted by rare conditions have particular needs and experiences that are still not well understood by both medical or mental healthcare professionals.

The third sector has a long tradition of supporting the mental health needs for specific (and often marginalised) communities that may struggle to access statutory support. Small groups and organisations play an invaluable role in supporting the mental wellbeing of those with rare conditions.

However, support for the mental health needs of those with rare conditions exists on a continuum of severity and complexity, and must be fundamentally preserved within statutory care in order to promote parity of access across the population as a whole according to need. The third sector has a key role to play in complementing (but not replacing) statutory provision.

It is clear that the mental health and wellbeing needs of the rare community are complex and varied, but there are common themes and experiences. The diagnosis of, and challenges of living with, a rare condition can have profound implications for personal identity, life choices, resources, family dynamics and future wellbeing. Many of these are linked to having to tolerate a high degree of uncertainty, change and loss over time.

Our survey (and our clinical services) also indicate that experiences of the diagnostic odyssey, care coordination, levels of awareness of rare conditions, and interactions with healthcare professionals or services, also play a key role in supporting or antagonising mental health and wellbeing.

One size will not 'fit all' in terms of support for rare mental health and wellbeing. Different types of support will be needed at different times. Our survey indicates that better collaboration across medical and mental health services sectors, and the third sector (including rare condition organisations) is needed. This integrated support, alongside psychologically informed 'rare-aware' care, is fundamental to supporting the mental health and wellbeing needs of the rare community.