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Ymateb gan: | Response from: Genetic Alliance UK



Which groups of people are disproportionately affected by poor mental health in Wales?

People living with rare, genetic and undiagnosed conditions are at a greater risk of experiencing poor mental health. Approximately 1 in 17 people are affected by a rare condition.

Genetic Alliance UK conducted a survey in 2018 of the rare disease community, exploring the experiences of people living with rare conditions, their parents and/or carers with respect to mental health. Almost 2,000 people affected by a rare condition completed the survey and the results were published in a report (<https://www.raredisease.org.uk/wp-content/uploads/sites/7/2018/07/living-with-a-rare-condition-the-effect-on-mental-health-pdf.pdf>) with recommendations.

Because of their rare disease, 95% of respondents to the survey have felt worried or anxious, 93% have felt stressed, 90% have felt low, 88% have felt emotionally exhausted and 70% have felt at breaking point. A proportion of respondents to our survey also had suicidal thoughts (36% of patients and 19% of carers).

What factors contribute to worse mental health within these groups?

There is a clear understanding that chronic or progressive conditions, of which many rare conditions are, can negatively impact a person's mental health.

On average it takes four years for someone to reach a diagnosis for a rare condition and during this journey individuals are faced with many difficulties that all contribute towards poor mental health.

We have heard of many cases where a patient's symptoms are not believed by healthcare professionals and are instead being labelled as neurotic or having health anxiety.

'It's like you don't want to die, you just want some help and a little bit of relief, for someone to take on board what you're saying seriously and not tell you it's all in your head, because I think more than anything, I mean the pain's bad enough and the other [physical] symptoms, but this, it's like mental - I feel like I'm being tortured every single day, that's what it's like.' - Patient

Parents who have concerns that their child may have a rare condition are often particularly susceptible to not being believed. For families who have a child with an undiagnosed rare condition, we have heard of examples where social services threaten to take away the child.

A lack of awareness among healthcare professionals is a significant factor in poor mental health for people living with a rare or undiagnosed condition. This leads to feelings of isolation and worrying about prognosis as healthcare professionals are not able to answer their questions.

'My GP keeps telling me that my disease is so rare, he doesn't have time or need to learn about it and starts every consultation with 'what am I googling today then?' which really upsets me as I feel I don't matter.' - Patient

Most rare conditions have no effective treatment or cure. Knowing that there is a lack of treatment options for your condition negatively impacts mental health.

People living with rare conditions are often seen by multiple doctors across different specialties, requiring a multitude of appointments and tests that are often based in different hospitals. The lack of coordination of care for rare conditions significantly impacts mental health as patients and carers are required to coordinate their own care. Many people from the community tell us that coordinating their own care feels like a full time job and adds additional stress and burden onto individuals. Where care is well coordinated, mental health care is rarely incorporated.

SWAN UK (syndromes without a name), is the only UK-wide network providing information and support to families of children and young adults affected by undiagnosed genetic conditions, run by the charity Genetic Alliance UK. Members from this group have told us that having a child with an undiagnosed genetic condition means that you don't fit into any specific community, leading to feelings of isolation and loneliness, which can result in poor mental health.

The need for mental health support in the undiagnosed community is much higher because there are so many unknowns:

- planning for the future is stressful as prognosis is often unknown, and families are sometimes told their children might not live long
- as the cause is unknown some parents experience guilt regarding whether they could be somehow to blame for their child's condition

There is also many of the challenges any family might face with a child with additional needs whether or not they are diagnosed:

- parents experience sleep deprivation due to providing full time care for their child
- sometimes one parent has to give up work to become a full time carer for their child, impacting on the financial position of the family
- although there may be services that may support different aspects of having a child with an undiagnosed condition, managing all of these different aspects can be stressful as there is no one place to go to get support added on top of the caring needs of the child
- this all accumulates and has a detrimental impact on the whole family, not just the affected individual
- parents often have to fight for their child to get appropriate care and social services support

For the groups identified, what are the barriers to accessing mental health services? How effectively can existing services meet their needs, and how could their experience of using mental health services be improved?

A lack of awareness of rare conditions among healthcare professionals is a big barrier to accessing mental health support for people living with rare, genetic and undiagnosed conditions. Without awareness of the impact of having a rare condition can have on one's mental health, individuals who need the support aren't being referred to mental health services or even being signposted to support groups/organisations. Around half of survey respondents said that they are never asked about their mental health when they visit healthcare professionals.

People who access counselling through the NHS often get six weekly sessions and no more. For people living with rare conditions, most of the time spent in those sessions is used to explain the condition and how having a rare condition impacts their mental health due to the lack of awareness.

From Genetic Alliance UK's survey 85% of respondents said accessing psychological support is not as easy as it should be and that easier access would improve wellbeing. Due to this lack of access, some individuals choose to go privately however, this is not financially feasible for most individuals.

There appears to be an element of a 'postcode lottery' when it comes to accessing mental health support across Wales. Some young people are able to access counselling through schools but it's not available in all schools, some GP's offer in-house counselling but this is not routinely available across Wales.

There is a significant demand for mental health support however not enough resources are available. Waiting lists are often months long and we've heard that getting support from Child and Adolescent Mental Health Services (CAMHS) is difficult to achieve.

People living with rare, genetic and undiagnosed conditions sometimes have poor mobility that means travelling to access face to face counselling sessions is another barrier.

To what extent does Welsh Government policy recognise and address the mental health needs of these groups? Where are the policy gaps?

The Welsh Action Plan of the UK Rare disease Framework is due to be published in the coming months and we hope that the opportunity to include mental health provisions for people living with rare conditions has been taken.

What further action is needed, by whom/where, to improve mental health and outcomes for the groups of people identified and reduce mental health inequalities in Wales?

It's not expected that every healthcare professional knows everything about all rare conditions, instead they need to be able to recognise the pattern between rare conditions and mental health and make appropriate referrals. Patients and carers feel strongly that better awareness among healthcare professionals of the emotional challenges of living with a rare condition would improve their emotional wellbeing.

Healthcare professionals and GP practices need to be equipped to be able to signpost to appropriate support groups and organisations.

Our report 'Living with a rare condition: the effect on mental health' outlines three key recommendations: <https://www.raredisease.org.uk/wp-content/uploads/sites/7/2018/07/living-with-a-rare-condition-the-effect-on-mental-health-pdf.pdf>

- 1) Healthcare professionals should be provided with the skills, knowledge and capacity to:
 - Demonstrate awareness of the emotional challenges of living with a rare disease;
 - Handle discussions about mental health sensitively
- 2) Patients and carers should be routinely signposted to sources of support by healthcare professionals.
- 3) Coordinated rare disease services should include assessment of mental health needs and access to mental health services. This should be extended to carers.