

Rare Disorders. Common Struggles: Mental Health Support for People with Rare Disorders

Access to mental health support often proves elusive for everyone, navigating the labyrinth of the healthcare system and its painfully long wait times. People with rare disorders suffer greater than the general population in this challenge, grappling with both their disability, the stigma and navigating the overloaded mental health system. Statistics paint a sad picture of the toll exacted on individuals with rare disorders and their families, highlighting the urgent need for targeted interventions for their mental health.

In the Rare Disorders NZ's 2024 White Papers a staggering 1 in 3 people with rare disorders often felt unhappy and depressed and felt they could not overcome their problems. These rates of unhappiness and depression are markedly higher within this cohort than the general population. This depressed mood is an additional stressor in life, exacerbating the already daunting challenges posed by their conditions. The mental strain also impacts on their relationships, 57% have experienced increased tension between family members, and 69% experienced isolation from family and friends. The ripple effect extends to caregivers as well, with a significant portion—27-30%—reporting similar struggles, underscoring the pervasive impact on familial dynamics of the unmet mental health needs of people with rare disorders.

Amidst this landscape of adversity, the strength gained from connections within the rare disorder community cannot be overstated. A resounding 63% acknowledge the significance of solidarity with others sharing their condition, giving a great opportunity for grass roots peer support to flourish. Sadly, this need is also not being met as only a mere 37% of people with rare disorders report feeling adequately connected. This stark disparity underscores the imperative for tailored interventions to attend to the intricate tapestry of social and psychological needs of people with rare disorders.

Armed with this sobering awareness of the lived experiences of people with rare disorders, my commitment to effectuating change is unwavering. In caring for my own brother (diagnosed with a rare disorder), I have intimate familiarity with the difficulties of reaching a community of support, or being understood by mental health workers. Too often healthcare professionals, unfamiliar with rare disorders, do not take the time to listen to the patient themselves about their needs.

Moving into clinical practice, I will foster a safe space for open dialogue with people with rare disorders. By demonstrating empathy and active listening, I can provide validation and support, creating a safe space for them to express their emotions and concerns openly.

Additionally I will advocate within the multidisciplinary team for the integration of mental health support within their care, and ensure they connect to Rare Disorders NZ and the grass-roots networks of peer support in NZ. This practical support, assisting with navigating healthcare systems and connecting them with support groups, can alleviate feelings of isolation and helplessness. By advocating for their needs and ensuring they receive comprehensive care, addressing both their physical and emotional well-being, I can play a crucial role in promoting the mental health resilience of people with rare disorders.