



Factsheet #2: Impact of Rare Conditions on Mental Health & Wellbeing

There is no health without mental health. Poor physical health can increase the rate of depression and anxiety. Poor mental health can impact on physical health, the capacity to self-care and reduce resilience.

The accumulated impact of rare conditions on mental health and wellbeing can occur at both an individual and population level. At an individual level, people living with a rare disease (PLWRD) can have an associated mental health co-morbidity; whereas at a population level, the community lives with the increased psychological impact associated with the rare disease journey across all stages of life.

The rare disease community have called for us to now look beyond the physiological symptoms and take action to address the psychological impact that is associated with rare conditions (EURORDIS Rare2030 Recommendations, 2020). The community have reported that their psychological and emotional needs are not routinely taken into account in their care and treatment.

Impact of the Rare Disease Journey:

The rare disease journey has unique stressors that directly impact on the mental health and wellbeing of all people who travel this journey. Specifically, the diagnostic odyssey is often lengthy and traumatic, paved with a history of misdiagnosis and poor communication of diagnosis. How a rare disease diagnosis is given can cast a long shadow across the whole of the future rare disease pathway. When done badly it can reduce trust in all healthcare professionals; but when it is done well, it can empower the affected individual and family to best cope with an uncertain future and unpredictable life.

Living in uncertainty is a common reality for the majority of the rare disease community. Uncertainty is strongly associated with anxiety. The low awareness of rare conditions among professionals / public, can also increase feelings of isolation and frustration.

The high logistical burden of living with a rare condition, and care management, can increase the emotional impact on families who may have problems accessing treatment and support and may have to endure frequent monitoring, agonising waits for test results and invasive treatments. This can increase the traumatic experience of healthcare, especially for children and young people.

The combined effect of these strains and stressors impacts on family life as a whole and on parental and family relationships. For genetic conditions, there can also be an impact of genetic inheritance on identity, and life choices. This can also cause grief of a future life loss, and unwarranted guilt from passing on a genetic condition.



Protection Factors:

The rare disease community have identified a number of protection factors that can reduce the impact of living with a rare condition on the mental health and wellbeing of the individual and the family:

Access to psychologically informed medical care.

- Addressing physical symptoms can have a positive effect on mental health.
- Using inclusive communication and involving the individual in their own care enhances wellbeing.
- Being heard and listened to is important in establishing trust between professionals and PLWRD. Professionals should talk to the child/young person/intellectually disabled adult rather than addressing the parent/carer.
- Focus on supporting the family will help the PLWRD. Protecting family relationships looking after the wellbeing of those caring for PLWRD is imperative.

Coping strategies and support systems that were identified included:

- Access to information and support through social media platforms.
- Peer to peer support.
- The importance for affected children to find an outlet to allow for childhood enjoyment and development.
- Building the skill of parents and carers to adapt and be able to talk about rare conditions and empower the PLWRD or affected child to talk about how their rare condition affects them.

Being connected into a community is transformative.

- This helps form self-identity and lessen the feelings of isolation and stigmatisation.
- Breaking the silence, through being in a community of people who share similar experiences, creating opportunities for individuals to open up and share.
- Becoming an advocate provides a new sense of purpose and empowerment.

Self-care and development were also highlighted as important:

- To learn not to just fight your diseases but learn how to make the most out of life.
- To build self-esteem and self-acceptance which can contribute to a positive mindset and wellbeing.
- To challenge yourself by setting goals to help develop confidence and resilience.
- To recognise strengths, resilience, and capabilities rather than focusing solely on limitations.



About Rare Diseases and EURORDIS-Rare Diseases Europe

Rare conditions are frequently chronic and highly complex. Most people with a rare condition live with disabilities which can be visible, invisible, degenerative, or vary from one day to the next. Evidence demonstrates that PLWRD and their families face serious challenges to their health, their social inclusion and their day-to-day lives, which can have a severe impact on their mental health and wellbeing.

EURORDIS-Rare Diseases Europe is a non-profit alliance of over 1000 rare condition patient organisations from 74 countries that work together to improve the lives of over 300 million people globally living with a rare condition.

The vision of EURORDIS is for a world in which each person living with a rare condition can have a longer and better life, achieving their full potential in a society that values their well-being and leaves no one behind.

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