



**This webinar will be  
recorded**

# *“EURODIS Outlined Position Paper”*

Webinar, 10.07.2024



# Welcome!

We will be starting shortly...



**Mute your microphones** when not speaking



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Use a **headset or earphones** to **minimize echo and background noise**



**Add your name** –in the 'Participants' list, on your name click and 'Rename'



**Raise your hand** if you wish to speak & use **chat box** for Q&A and comments

# Agenda

Time	Topic	Speaker
16.30 – 16.32	Welcome & Introductions (2')	Concha Mayo, EURORDIS
16.32 – 16.35	Opening Remarks (3')	Kirsten Johnson, Fragile X International & EURORDIS Board of Directors
16.35 – 16.45	Presentation of EURORDIS Position Paper on Mental Health (10')	Matt Bolz-Johnson, EURORDIS
16.45 – 17.15	Best Practice on Psychosocial Care (30')	Daniel Theisen, Director at Alliance Nationale Maladies Rares (ALAN)
17.15 – 17.28	Questions & Answers (13')	All
17.28 – 17.30	Final & Closing Remarks (2')	Kirsten Johnson, Fragile X International & EURORDIS Board of Directors



# Opening Remarks

Kirsten Johnson, Fragile X International &  
EURORDIS Board of Directors



# EURORDIS Position Paper on Mental Health

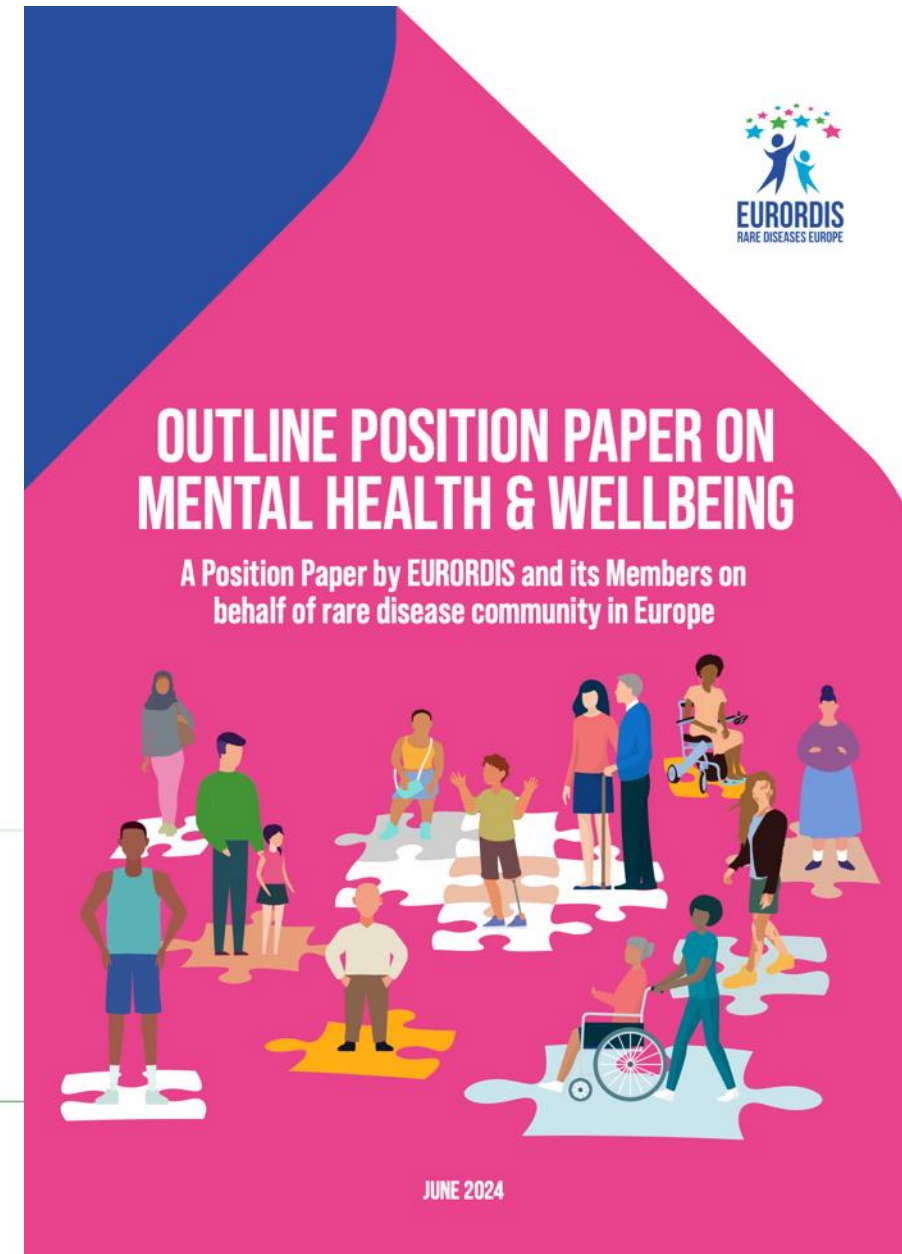
Matt Bolz-Johnson, EURORDIS



# Outline Position Paper on Mental Health & Wellbeing

Published: 28 June 2024

<https://www.eurordis.org/publications/position-paper-on-mental-health-and-wellbeing/>



# Policy Context



## ***UN General Assembly Resolution on Addressing the challenges of persons living with a rare disease and their families:***

10. Urges Member States to implement effective programmes to promote mental health and psychosocial support for persons living with a rare disease, and to promote policies and programmes that enhance the well-being of their families and caregivers. [A/RES/76/132](#)

## ***World Health Organisation, 2022:***

The World Health Organization (WHO) recognized “people with an existing health condition” as one of the main vulnerable groups who were more likely to develop symptoms of mental disorders following the pandemic, along with young people and women ([WHO 2022](#)).



## ***European Union, 2023:***

- Mental health is now being recognized as a public health priority in the European Union, notably in Commission President von der Leyen’s State of the Union speech at the European Parliament on the 14 September 2022.
- The new Commission Communication on a [Comprehensive Approach to Mental Health](#) was published on 7 June 2023.



# Improve outcomes through care delivery

## UN GA Resolution A/RES/76/132 (2021)

UN urges Member States to implement psychosocial support programmes for PLWRD



**European:** visibility of rare diseases in mental health policy, call for a more inclusive approach of all populations in vulnerable situations and dedicated actions.

## Recommendations

**National:** visibility of mental health in rare disease national plans and strategies specifically to establish psychosocial support programmes through “psychologically informed medical care.”

### Reference:

Smits RM et al. 2022 *Common needs in uncommon conditions: a qualitative study to explore the need for care in pediatric patients with rare diseases.*


Schröder HM. Et al. 2019. *Psychosocial Care in Paediatric Oncology and Haematology.*

**Model for Psychosocial Care<sup>2</sup>** should strengthen the resources and resilience of everyone affected by rare conditions.

Integrated approach in **all interactions** with healthcare professional as well as **include psychologists in core team.**

# Build on Evidence-base & Advocacy

Our key ask is that people living with a rare diseases are recognised as a population living in vulnerable situations, due to the multiple intersectional needs, requiring specific attention in the new Communication.



**Call for Evidence: A Comprehensive Approach to Mental Health**  
Response from EURORDIS-Rare Diseases Europe  
On behalf of the 30 million people living with a rare disease in Europe  
February 2023

EURORDIS-Rare Diseases Europe (EURORDIS) welcomes the European Commission (EC) procedure to establish a new Communication on a Comprehensive Approach to Mental Health and would like to offer the following input to ensure that all vulnerable groups with higher risk to mental health and well-being are included in the future Communication, leaving no one behind.

We call for the EC Communication on a Comprehensive Approach to Mental Health to recognise the 30 million people living with a rare disease (PLWRD) in the EU as a vulnerable population living with a 'triple burden' on their mental health and well-being, and to promote actions in all policy areas beyond the health system. Most rare diseases appear in childhood, the mental health impact on these children is very high as well as on their siblings and parents.

Risk factors for poor mental health are strongly associated with social inequalities. Indeed, the World Health Organization (WHO) recognises that the greater the level of inequality, the higher the risks to mental health and well-being (Social Determinants of Mental Health, WHO, 2014). People with rare diseases live with the cumulative effect of:

- Multiple co-morbidities that impact on mental health and wellbeing (Health-Related QoL Study 2022)
- Increased psychological impact across all stages of life (Courbier et al. 2017)
- Increased exposure to social inequalities and discrimination (EURORDIS Foresight Study)

This triple burden supports the call to recognise people affected by rare diseases and their families as a vulnerable population with a higher risk to poor and mental health and detrimental impact on their well-being.

**Summary of the Evidence:**

- 19% of PLWRD surveyed felt worried, anxious, stressed and/or depressed and 19% had suicidal thoughts (Spencer Family 2022)
- 1/3 of parents of a child with an undiagnosed disease meet clinical criteria for mild to moderate depression or anxiety (McConkie-Rosell 2018)
- The diagnosis of a rare disease has a significant psychological impact upon the whole family, not just the affected individual (Kenny 2022)
- 85% PLWRD declare that the rare disease impacts upon several aspects of their physical and mental health and everyday life. (Courbier et al. 2017)
- PLWRD and their families report being 10 times more unhappy and depressed compared with the general population. (Courbier et al. 2017)
- 7 out of 10 patients and carers must reduce or stop their professional activity due to the rare disease and associated burden. (Courbier et al. 2017)

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EURORDIS Response to the EC  
Call for Evidence, 2023



**A COMPREHENSIVE APPROACH TO MENTAL HEALTH**  
#MentalHealth #MentalHealth  
#Health4All #Health4All

**BACKGROUND**

Increased mental health risks are a reality for a range of vulnerable populations including youth, elderly, women, people with pre-existing health conditions\* (such as chronic conditions and rare diseases) or disabilities, migrants, ethnic minorities, LGBTQIA+. Without mental health promotion, prevention and support, the psychological burden and mental health co-morbidities detrimentally impact on vulnerable populations' participation in society. The Comprehensive Approach to Mental health needs to include all vulnerable populations and detail actions that are holistic, flexible and can be tailored to the specific needs of each population, across all policy areas.

Evidence demonstrates the link between physical health and mental wellbeing, with a correlation between the severity and complexity of a physical medical condition and the impact on mental health and wellbeing. This is true for chronic conditions and rare diseases, with an increased psycho-social vulnerability in these populations. Rare diseases are complex, chronic, and often debilitating disorders with multiple intersectional unmet needs. Frequently affecting children, rare diseases lead to social exclusion and discrimination, impacting access to education and employment. The accumulative impact of living with increased co-morbidities, psychological stressors, and social inequalities results in a higher prevalence of depression and anxiety disorders.

**CONCRETE ACTION**

**Idea:** To strengthen the capacities and empowerment of vulnerable groups to become mentally healthy communities, by developing a Mental Health & Wellbeing Toolkit for Vulnerable Populations. This toolkit can be generated by identifying best practices and evidence-based tools that can be tailored by each vulnerable population to address their specific needs.

**EU added value and potential benefits:** Addressing the needs of vulnerable populations present an area of added value for the European Union where EU community actions help to strengthen national measures. It is reported that each vulnerable population comprise a significant sized community – young people (87 million), older people (24 million), chronic diseases (50 million) and rare diseases (30 million).

There is a large discrepancy in health and social services available across EU countries to support these vulnerable populations. The development of a Mental Health & Wellbeing Toolkit for Vulnerable Populations would help address these gaps by strengthening the capacity of patient organisations and Civil Society Organisations (CSO) with EU-shared best practices and tools to support their respective communities, reducing avoidable downstream health, social and economic costs.

**How will this help to strengthen action on mental health at EU level and enhance the overall health of European citizens?**

A Mental Health & Wellbeing Toolkit for Vulnerable Populations could be used by patient groups, healthcare professionals and social service providers to build knowledge and understanding of the needs of each vulnerable population and the associated impact on mental health, allowing to better target simple effective psycho-social interventions for different populations.


Increasing resilience and capacities among the civil society organisations and patient groups, can support and empower them to better alleviate the risk factors and drivers of poor mental health, preventing mental health co-morbidities and addressing the high levels of unmet needs of these vulnerable populations.

**Specifically:**

- Reducing the impact on the lives of the affected individuals and their family members, increasing social inclusion and supporting access to education, employment and independent living.

\* World Health Organization - (2020) 20 pandemic triggers 47% increase in prevalence of anxiety and depression worldwide, 2022.  
\* The King's Fund, Long term conditions and mental health: the cost of co-morbidities, 2022.

EURORDIS Poster of a Proposal for  
a Concrete Action, 2023



**Commission Communication on 'A Comprehensive Approach to Mental Health'**  
Response from EURORDIS-Rare Diseases Europe  
On behalf of the 30 million people living with a rare disease in Europe  
June 2023

EURORDIS-Rare Diseases Europe welcomes the European Commission Communication on 'A Comprehensive Approach to Mental Health' and stresses the need for recognition of the mental wellbeing challenges specifically impacting the rare disease community. This initiative is a first and important milestone in renewing the political commitment to address the mental health needs of all Europeans.

We strongly agree with the Communication's proposal to identify high-risk groups and target support, resources and tailored policies to meet their specific needs. People living with a rare disease and their families live with severe, progressive and chronic conditions and disabilities. Children, young adults and adults of all ages are impacted by rare diseases, with women being the majority among family caregivers. People living with a rare disease and their families frequently find themselves at the intersection of numerous diverse vulnerable situations, including psychosocial risks at work or school, medical uncertainties, economic hardship, discrimination and stigma. As such, EURORDIS welcomes the Commission's ambition to take a comprehensive approach to addressing the psychosocial and structural determinants to mental health. We also call on the Commission to ensure each of its flagship initiatives is implemented with an intersectional approach.

**(A) Integrating Mental Health Across Policies**

EURORDIS welcomes the Commission's ambition to take a comprehensive approach to addressing the psychosocial and structural determinants to mental health and calls for a coordinated and integrated approach that promotes mental health across all policies. This is truly an ambitious and innovative approach, one which requires unified and dedicated EC-structures to oversee and guide its implementation across the European Union.

The Communication is an important step in establishing a new, comprehensive approach to address the mental health crisis that has resulted from the significant and accumulated impact of unprecedented crises<sup>1</sup>. However, this first step needs to be scaled up to be truly comprehensive, coordinated under a new EU Mental Health Strategy and supported with the development of national plans on mental health in all policy areas to coordinate and steer meaningful action at both European and national levels, in each EU Member State.

**EURORDIS supports the call from Mental Health Organisations, along with the European Parliament Alliance on Mental Health and several other stakeholders, for the Commission to establish a dedicated internal Commission structure and to strengthen action across the European Union under a new EU Mental Health Strategy, supported by the creation of dedicated national action plans on mental health in all Member States.**

<sup>1</sup> Including the COVID-19 pandemic, Russia's war of aggression against Ukraine, the cost of living crisis and the worsening planetary crisis (climate change, biodiversity loss and pollution).

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EURORDIS Response to the EC  
Commission Communication on  
the Comprehensive Approach to  
Mental Health, June 2023

# European Recommendations

**Call on the European Commission to better prevent and protect mental health problems and reduce further exclusion and marginalisation of the most vulnerable members of society, by recognising the 30M persons living with a rare condition in the European Union as a population living in vulnerable situations and taking action to address these high unmet needs.**

## **SPECIFICALLY**

- ✓ **Be inclusive** of all populations in vulnerable situations (including rare conditions) in the actions to implement the Comprehensive Approach to Mental Health.
- ✓ Translate the implementation of the Comprehensive Approach into a dedicated Flagship Initiative with **supporting actions and adequate financial support for all vulnerable groups**, including rare conditions and improve access to psychological support.
- ✓ Allocate funding for a **Mental Health & Wellbeing Toolkit for Populations in Vulnerable Situations** in order to build the capacities and empowerment of these groups to become mentally healthy communities.

# National Recommendations

**Call on EU Member States to honour the United Nations General Assembly Resolution's (A/RES/76/132) call for the development of effective programmes and national strategies to promote mental health and psychosocial support for persons living with a rare condition, and to coordinate EU action to develop and promote policies and programmes that enhance the wellbeing of their families and caregivers.**

## **SPECIFICALLY**

- ✓ Increase and include the visibility of mental health in the revision of Rare Disease National Plans & Strategies and commit to action to address the unmet mental health needs of PLWRD and their families.
- ✓ Integrate psychological support as an integral standard of holistic care, by incorporating psychosocial personnel as core members of the medical team, and through enhancing medical care to be psychologically informed.
- ✓ Recognise and support patient organisations to provide community and peer support, and access to trusted information, as the foundation of psychosocial care, enabling earlier detection and access to preventative support.
- ✓ Support new and targeted medical training to strengthen cross-specialty training, for all professionals to better understand the relationship between physical and mental health, and specifically for mental health practitioners to become more 'rare aware' and medical and nursing care practitioners to become 'mental health' aware.

# Development Process

## Q1-2 2023

- Gathering Evidence
- Submitted Response for the Call for Evidence on RD & MH
- Submitted a Poster of a Concrete Action
- EMM2023 Satellite Workshop on Mental Wellbeing

## Q1 2024

Draft Outline Position Paper

Feedback from:

- EURORDIS Mental Health Partnership Network
- Council of National Alliances
- EURORDIS Board of Directors & Team

## Q3-4 2023

- Published Full Response on the new Communication
- Contribution to MEP Own Initiative (INI) Report
- EP Policy Event on People in Vulnerable Situations

## Q2 2024

- “What psychosocial care looks like for PLWRD” Webinar
- WG1 Advocacy Sub-Group co-created the “blueprint for psychosocial care for PLWRD”
- Final version completed.



# Blueprint for Psychosocial Care



# Blueprint for Psychosocial Care

Reference: Schröder HM, Lilienthal S, Schreiber-Gollwitzer BM, Griessmeier B. Psychosocial Care in Paediatric Oncology and Haematology. Arbeitsgemeinschaft der Wissenschaftlichen Medizinischen Fachgesellschaften (AWMF). Psychosoziale Arbeitsgemeinschaft in der Pädiatrischen Onkologie und Hämatologie (PSAPOH), 2008.



# Impact of Rare Diseases on Mental Health & Wellbeing

**54%** people living with a rare disease declare that the rare disease caused or amplified isolation from friends and family.

(Juggling life and care Survey, 2019)

## Emotional Wellbeing

**>90%** of PLWRD surveyed felt worried, anxious, stressed and/or depressed.  
**19%** had suicidal thoughts.

(Spencer-Tansley 2022)

## Financial Independence

**7/10** PLWRD have reduced or stopped professional activity due to their own or their family members' disease.

(Coubier et al. 2017)

## Access Support, Faster Diagnosis

Average time to diagnosis of **3.8 Yrs.**  
vs **5.1 Yrs.**

PLWRD whose needs for psychological support were met accessed a diagnosis faster.

EUR. RB Survey on Diagnosis, 2022

## Holistic Care

**50-85%** of PLWRD were not offered or received sufficient psychological support in an Expert Centre.

(Coubier et al. 2017; Nunn et al. 2017)



# Stressors Associated with Rarity

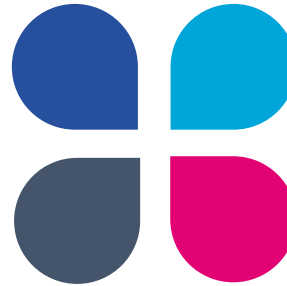
Progressive, degenerative, disabling and frequently life-threatening conditions.

## Diagnostic Odyssey

- Lengthy/traumatic diagnosis odyssey (consult x5 doctors, av. 5 years).
  - History of misdiagnosis (av. x3).
- Poor communication of diagnosis > Reduced trust in HCP's.

## Complex interacting emotional and physical symptoms

- High impact of mental health aspects of a rare condition.
- High logistical burden of frequent hospital appointments.
- Extremely intensive tests and treatment. Medical trauma and impact on physical, social and development



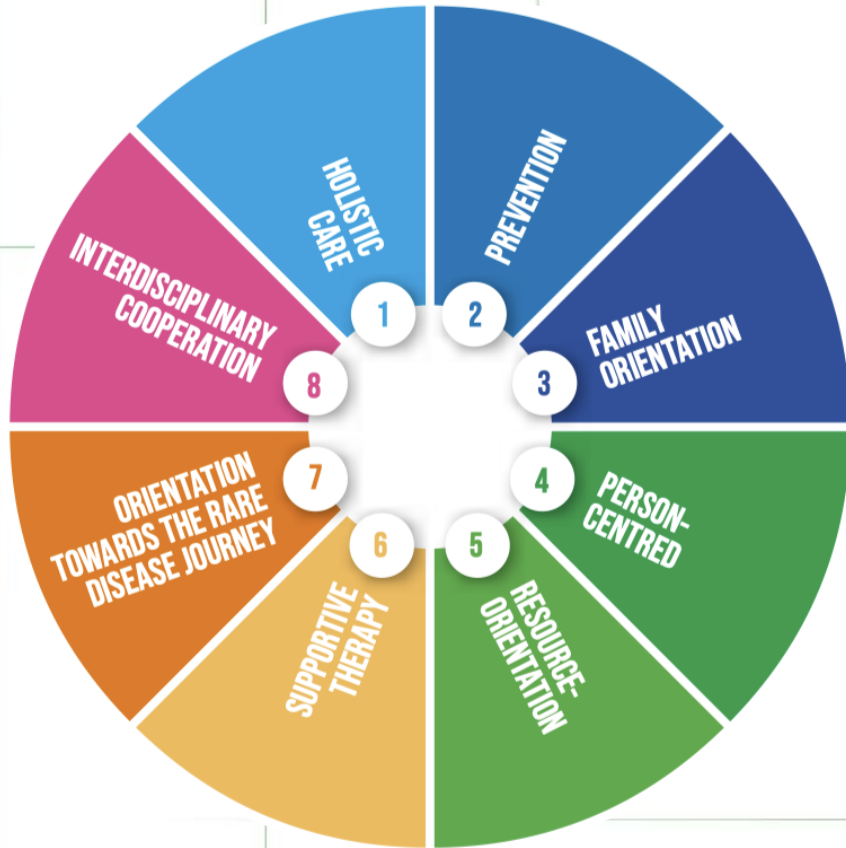
## Living with uncertainty

- Multiple uncertainties – prognosis and future increases anxiety.
- Low disease awareness among professionals / public, increases isolation and frustration.

## Stress & Strain on Relationships

- Stress and strain on family life / couple relationships
- Impact of genetic inheritance on identity, and life choices
- Increased grief and loss

# Domains for Psychosocial Care



**Pillar 1:** Holistic Care

**Pillar 2:** Prevention

**Pillar 3:** Family Orientation

**Pillar 4:** Person-Centred

**Pillar 5:** Resource Orientation

**Pillar 6:** Supportive Therapy

**Pillar 7:** Orientation towards the Rare Disease Journey

**Pillar 8:** Interdisciplinary Cooperation

# Definition of Psychosocial Care

Psychosocial care is concerned with the **psychological and emotional wellbeing of the patient and their family/carers**, and may encompass issues around **self-esteem, insights into adaptation to the illness and its consequences, communication, social functioning, and relationships**. (Onyeka TC et al., 2010).

Psychosocial care is conducted in cooperation with the medical treatment team and **emphasises supporting the resources of the patient and family** throughout the course of the disease, during therapy and follow-up care. The basis for psychosocial care rests upon a **supportive and informative relationship with the affected individual, family and social environment**.

It is oriented towards the **physical, emotional, social and developmental potential** of the affected child, adolescent or adult, as well as their **social environment**, and takes into account individual styles and capacities to cope and adjust (Schröder et al., 2008).

# Standards for Psychosocial Care (I)

## Pillar 1: Holistic Care

1. The **primary aim of psychosocial care is to identify the psychosocial implications of living with a rare disease**, which are often complex, chronic, multisystemic conditions, and the impact of treatment (or lack of treatment), which can **result in acute and chronic psychological stress and mental health issues** for patients, family members and caregivers.
2. A **case manager should be appointed to coordinate care** and mitigate the stress factors associated with uncoordinated care, consultations and treatments, and provide timely access to psychosocial support.

## Pillar 2: Prevention

3. Early preventative support should be aimed at reducing psychosocial risk factors and safeguarding the mental health and wellbeing of the person living with a rare disease and their family. Such **support should aim to prevent or reduce social isolation, financial hardship, and the overall uncertainty, stress and anxiety** associated with the rare disease journey.
4. Psychosocial care should have a **low threshold** for accessing psychosocial assessment support and be **tailored to meet the needs** of the people living with a rare or undiagnosed condition and their families
5. Medical care should include **regular and routine assessment and early detection for psychological stressors** and include measures to prevent the deterioration of mental health of the person affected by a rare disease as well as all family members.

# Standards for Psychosocial Care (II)

## Pillar 3: Family Orientation

6. Families of PLWRD are the primary source of support for coping with the rare disease. Assessing the ability of parents and/or the caregiver and support system to cope with the demands and uncertainties of living with a rare disease and providing robust psychosocial support can optimise the resources of the family to provide emotional support, security and protection.
7. Psychosocial care should encompass the provision of timely information, advice and interventions aimed at optimising resilience, coping strategies and stress management as well as reducing the uncertainties experienced by the family.

## Pillar 4: Person-Centred

8. Psychosocial support and guidance should be tailored to the specific needs and circumstances of an individual, as well as their family members, informed by the specifications and course of the disease and treatment. At each consultation or intervention, members of the medical team should allow time to enquire how the individual and family are coping with the rare or undiagnosed condition and treatment.
9. Information regarding the disease and treatment should be offered both during and after disclosure of the diagnosis, complementing the information and advice provided by the medical team and signposting for support when needed.

# Standards for Psychosocial Care (III)

## Pillar 5: Resource Orientation

10. Psychosocial care aims to promote functional coping mechanisms in PLWRD and families, strengthening resistance to psychological stress factors associated with rare or undiagnosed conditions and associated treatments.
11. Psychosocial care should leverage the individual abilities and skills of the individual and their family, promoting personal resources such as self-esteem, self-efficacy, optimism, hope and resilience, to help PWLRD and their families cope with living with a rare or undiagnosed disease.
12. Healthcare professionals should share information with the family on the local support groups and/or referrals to appropriate patient organisations that can provide peer and community support as well as access to trusted information.

## Pillar 6: Supportive Therapy

13. Psychosocial care should provide supportive care, oriented towards the course of the disease through the diagnostic process and treatment. Monitoring of psychosocial needs should be a standard part of every consultation and provide advice and support throughout the whole course of the disease.
14. Psychosocial care requires sufficient time during consultations to build trusting relationships with the PLWRD and their family and to optimise support and resources.

# Standards for Psychosocial Care (IV)

## **Pillar 7:** Orientation towards the Rare Disease Journey

15. Psychosocial care should start when a rare disease is first suspected, as this can reduce the time to diagnosis; and should continue throughout the entire course of the disease. Wider-family counselling should be offered in cases with a genetic diagnosis.
16. Accurate diagnosis empowers families to strengthen their resources by connecting with a patient community and accessing peer support.
17. Healthcare professionals should be trained to ensure that the presentation of significant, life-changing news is conducted in an appropriate and sensitive manner. Follow-up consultations should be scheduled within a month of a confirmed clinical and/or genetic rare condition diagnosis, with regular follow-up consultations scheduled annually thereafter.

## **Pillar 8:** Interdisciplinary Cooperation

18. Psychosocial care is an integrated component of medical care, requiring close interdisciplinary cooperation with the medical, nursing and social team members.
19. The psychosocial team should be led by a psychologist or clinical psychologist, nurse-specialist, with an educator and social worker, both with an additional psychotherapy qualification, and be supported by a genetic counsellor, music and art therapist, a psychotherapist and a psychiatrist.
20. The medical team members should be trained to provide psychologically informed medical care to detect underlying unmet needs early and to communicate in a sensitive manner; conversely, the psychosocial care team should be trained to be 'rare aware' to understand the common challenges rare diseases pose for affected individuals and their families.

# Best Practice on Psychosocial Care

Daniel Theisen, Director at Alliance Nationale  
Maladies Rares (ALAN)



# Questions & Answers



# Final & Closing Remarks





# Satisfaction Survey for the webinar

<https://form.jotform.com/241852997297375>

THANK

YOU

