



EURORDIS
RARE DISEASES EUROPE

BLUEPRINT OF PSYCHOSOCIAL CARE

for people living with a rare disease and their families



JUNE 2024

Blueprint of Psychosocial Care

People living with a rare disease (PLWRD) live at an intersection of multiple challenges with an array of complex needs that cut across all aspects of life, including physical health, mental health and social and independent living, rendering it impossible to separate out any one of the needs.

EURORDIS' Outline Position Paper focuses on the mental health and wellbeing needs of PLWRD, elaborating on the United Nations General Assembly Resolution on "Addressing the Challenges of Persons Living with a Rare Disease and their Families" (RES/76/132, 2021), to create a vision of how a psychosocial programme could look.

This paper has the value of bringing together the concrete recommendations and actions that can be harnessed by both the rare disease community and Member States to support the development of psychosocial programmes for PLWRD by enhancing existing medical care to be psychologically informed.

Psychosocial support has been evidenced to improve the mental health and wellbeing of patients and their families, improving their ability to adapt to the course of the disease, increasing adherence to medical care and interventions and reducing related stress factors (Askins & Moore, 2008; Kazak, 2005).

The robust evidence-base for psychosocial care has resulted in it becoming an integrated component of medical care for cancer. However, PLWRD face significant barriers to accessing psychosocial care, creating increased inequalities which in turn further escalate the risk to mental health and wellbeing.

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).

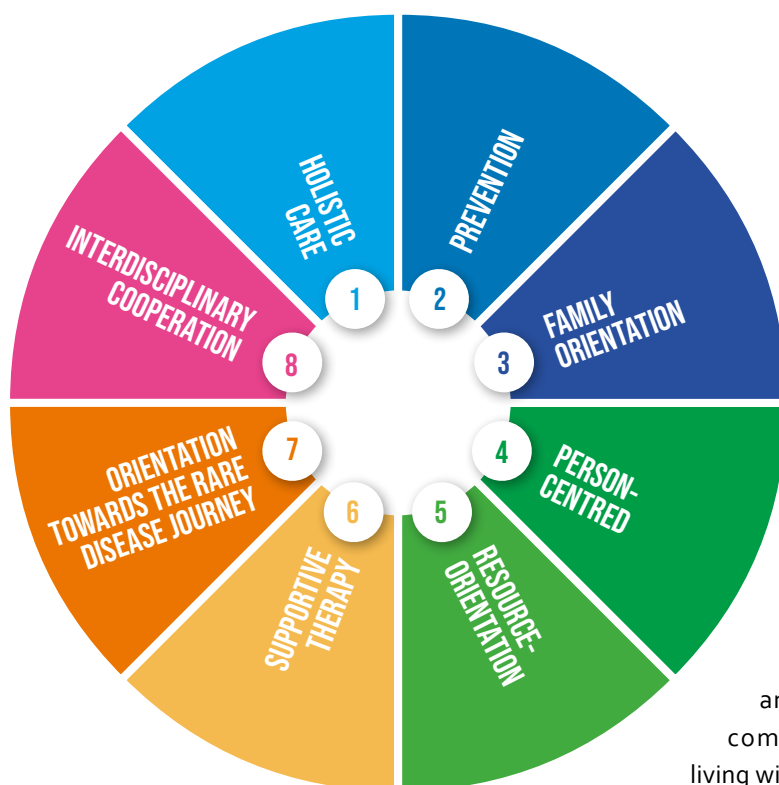
BARRIERS TO EXISTING PSYCHOSOCIAL SUPPORT

Even when psychosocial care is available, there are barriers to access, including a lack of awareness or information on available psychosocial care resources, such as peer support or patient groups (Witt et al., 2023). Other cited barriers include:

- Medical care is not provided in a holistic way and the individual and their family are not routinely asked about the need for psychosocial support.
- Time management constraints due to medical appointments, managing daily life activities and taking care of family needs.
- Difficulties accessing existing therapies due to geographic distances travel, cost implications and/or waiting times.
- Information inaccessible due to linguistic and cultural difficulties.
- Psychosocial support not delivered in an accessible language and format.

Psychosocial care services must address these identified barriers to enable families to benefit from care to address and reduce the psychological stress factors associated with rare diseases.

PSYCHOSOCIAL CARE TO ADDRESS THE NEEDS FOR RARE CONDITIONS CAN BE STRUCTURED UNDER THE FOLLOWING 8 DOMAINS:



The 8 domains and supporting standards are based on the PSAPOH Guideline on Psychosocial Care in Paediatric Oncology and Haematology (Schroder et al., 2008) and have been adapted to address the common needs experienced by people living with a rare disease and their families.

Standards for Psychosocial Care

1. HOLISTIC CARE

1. The primary aim of psychosocial care is to identify the psychosocial implications of living with a rare condition, 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.

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.

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.

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.

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.

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.

7. ORIENTATION TOWARD 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.

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.



EURORDIS-RARE DISEASES EUROPE

Plateforme Maladies Rares ♦ 96 rue Didot
75014 Paris ♦ France

EURORDIS BRUSSELS OFFICE

Fondation Universitaire ♦ Rue d'Egmont 11
1000 Brussels ♦ Belgium

EURORDIS BARCELONA OFFICE

Recinte Modernista Sant Pau ♦ Pabellón de Santa Apolonia
Calle Sant Antoni M^a Claret 167 ♦ 08025 Barcelona ♦ Spain

EURORDIS.ORG

This paper was produced thanks to
funding received under an operating
grant from the European Union's Health
Programme (2014-2020).



Co-funded by
the Health Programme
of the European Union