



Achieving Holistic Person-Centred Care to Leave No One Behind

A contribution to improve the everyday lives
of people living with a rare disease and their families

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eurordis.org/carepaper

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For **85%** of people living with a rare disease, the **disease impacts upon several aspects of their health and everyday life**

The ambition of EURORDIS is to have holistic care provided to the 30 million people living with a rare disease in Europe, and their families, by 2030



The time to act is now!

Louis and Matthieu, Becker muscular dystrophy, France

People living with a rare disease
should be integrated into a society
that leaves no one behind



Jorge and Maria, Prader-Willi syndrome, Mexico



Holistic Care



Holistic Care

360° spectrum of health, social
and everyday needs

Holistic Care

- Being aware of our **needs**
- Effectively providing **timely, high-quality care**
- **Breaking down barriers** in access to care, treatment, and all aspects of social inclusion
- Enabling us to **fully enjoy their fundamental human rights**

It is urgent to address the serious unmet needs

The time to act is now:

- Sustainable Development Goals
- European Pillar of Social Rights
- United Nations Convention on the Rights of Persons with Disabilities
- The 24 European Reference Networks
- European Network of Resource Centres for Rare Diseases
- National plan for rare diseases in 25 EU MS
- All stakeholders ready to engage and to co-create policies/services

Making holistic care a reality for people living with a rare disease

Pillar 1


Quality and
adequate social
services and
policies

Pillar 2

Integrated care:
bridging health
and social care

Pillar 3

Equity of rights
and opportunities



**All stakeholders
have a key role
to play**

**Only together, will we ensure
that no one is left behind**

Our recommendations to achieve holistic care for people living with a rare disease and their families, by 2030:



1. Making full use of EU instruments and European networks
2. Creating a supportive political environment at national level
3. Gathering and disseminating knowledge and good practices
4. Implementing specific mechanisms that ensure integrated care
5. Meaningful engagement in design and implementation of policies/services
6. Ensure access to adequate social services and social protection
7. Ensuring the recognition and compensation of disabilities
8. Creating conditions for access to adapted and sustainable employment
9. Implementing specific mechanisms for empowerment
10. Eliminating all types of discrimination

42 specific recommendations & action points. Print-out in your conference bag!
Full paper at www.eurordis.org/carepaper

We call upon all of you,
the EU, all European countries
and **all stakeholders**
within the health and social sector, **to:**

- ✓ **Disseminate**
- ✓ **Take action**

The time to act is now!



Thank you!



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