



# JUGGLING CARE AND DAILY LIFE: The Balancing Act of the Rare Disease Community

*First Europe-wide survey on social impact of rare diseases,  
involving 3000 people living with a rare disease & carers*

*Study performed via Rare Barometer Voices and within the EU-funded INNOVCare project*



A EURORDIS INITIATIVE

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# First Europe-wide survey on social impact of rare diseases

Juggling care and daily life:

The balancing act of the rare disease community

- Carried out via Rare Barometer Voices
- Over 3000 patients and carers participated  
(62% patients; 48% carers -> 110% as some are both)
- 802 diseases, 42 countries
- Performed in 23 languages



[Full results here](#)

# Summary of key results



Rare diseases have a serious impact on everyday life



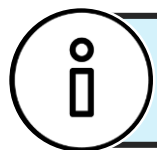
Significant time and care burden for patients and carers



Strong impact on work-life balance: absence from work, hampered professional activity, economic burden



Care pathways are complex and hard to manage e.g. need to visit different services in short time; lack of communication between providers



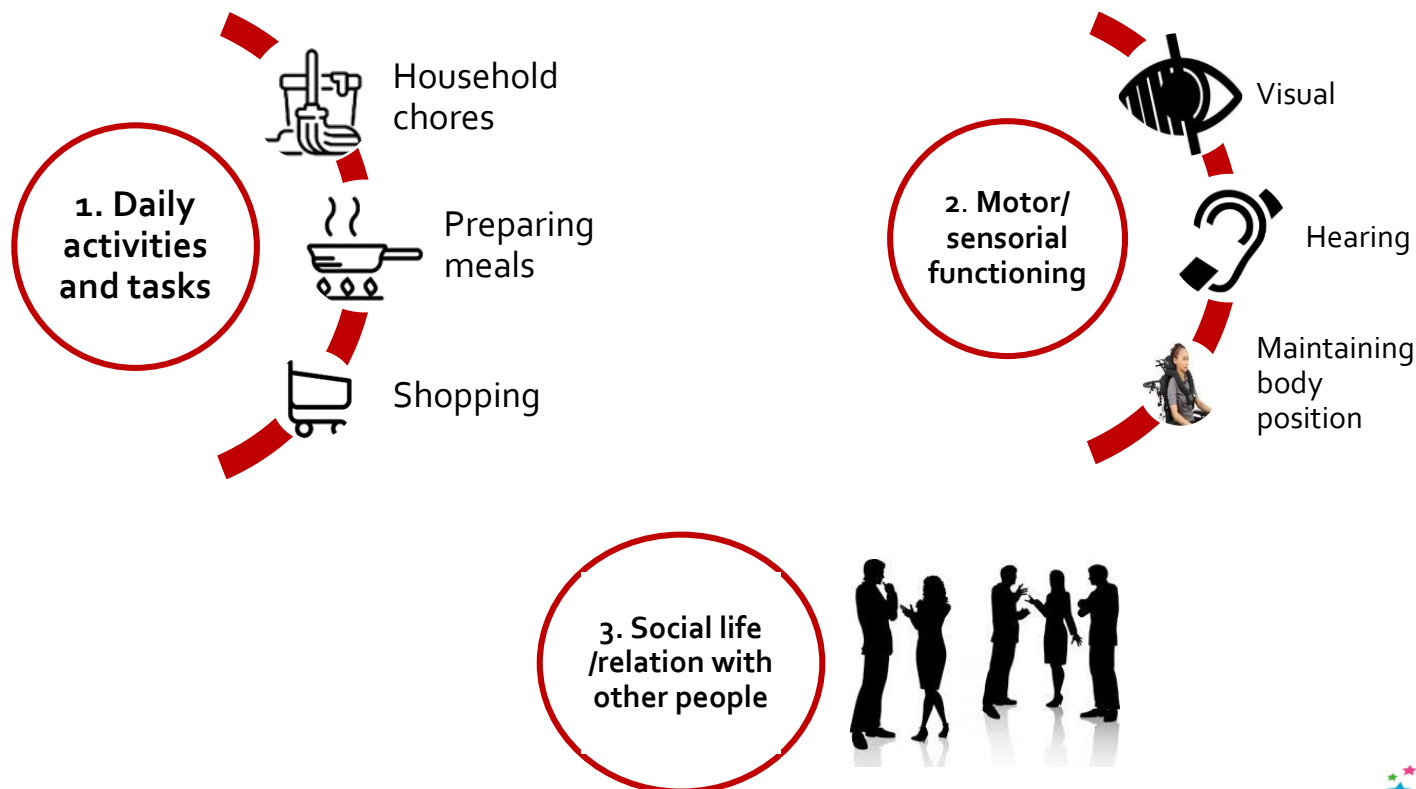
Patients and carers feel badly informed about their rights and feel that social services are badly prepared to support them



Rare diseases impact the mental health of patients and carers

# Serious impact on patients' everyday life

More than 70% of people living with a rare disease have difficulties with:



# Serious impact on patients' everyday life



**8 in 10** people living with a rare disease face **difficulties** in more than one aspect of their everyday life

# Complex & often invisible

“The difficulty lies in the **impossibility of carrying a routine** (...). The problem arises when **one day you appear completely healthy, the next day you are sick**, and two days later you appear completely normal again. Many people find it difficult to understand the disease and the process, and the absenteeism that entails”

Female, Spain



Symptoms **vary** & can be **invisible** in many ways

*Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo. Source: [EURORDIS Photo Contest](#)*

# Heavy time burden for patients & carers

**42%** of patients & carers spend **more than 2h/day** on **illness-related tasks**

Hygiene



Administration of treatments



Helping with house chores

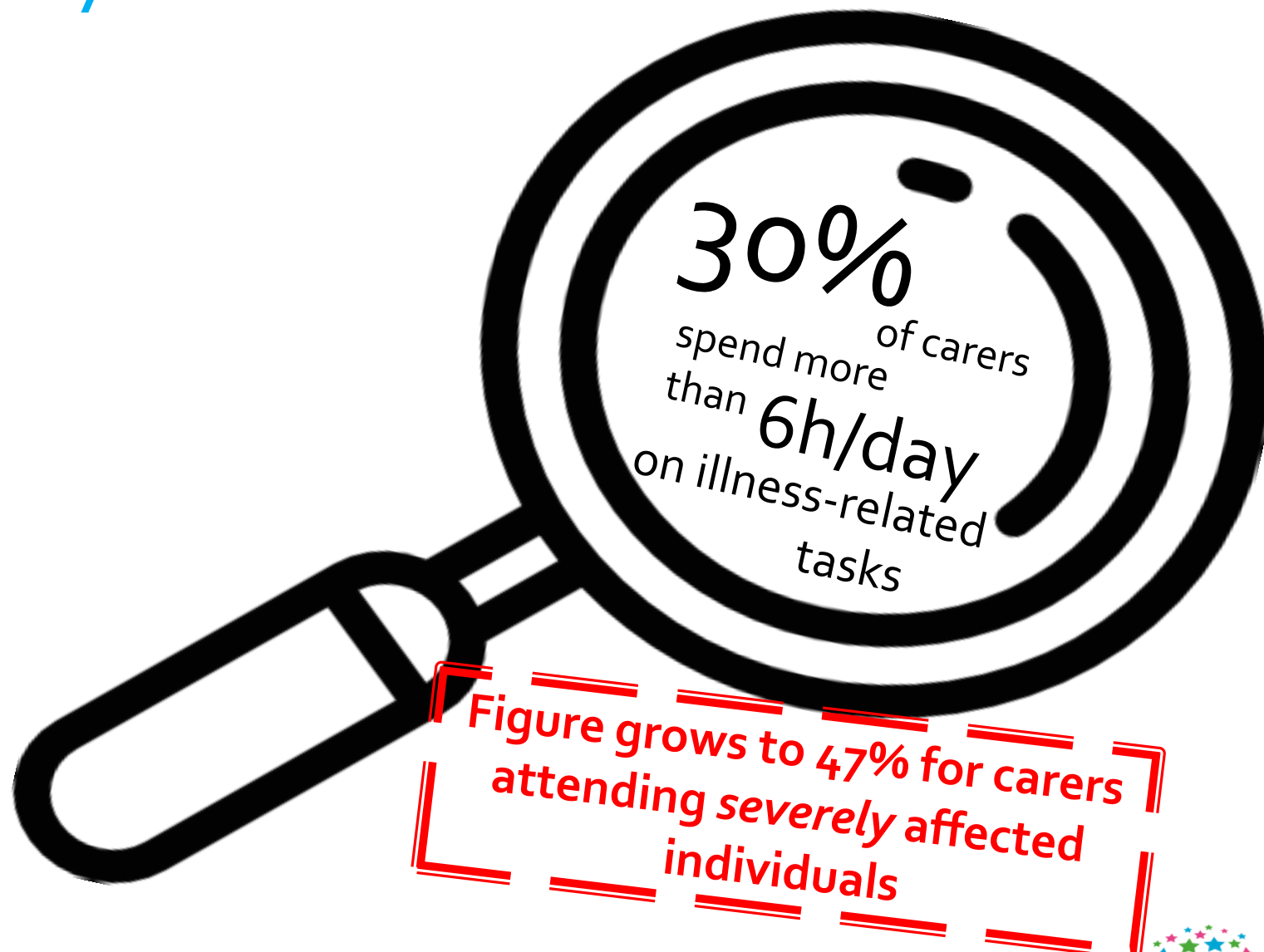


Helping patients to move



# Heavy time burden for carers

Time Burden





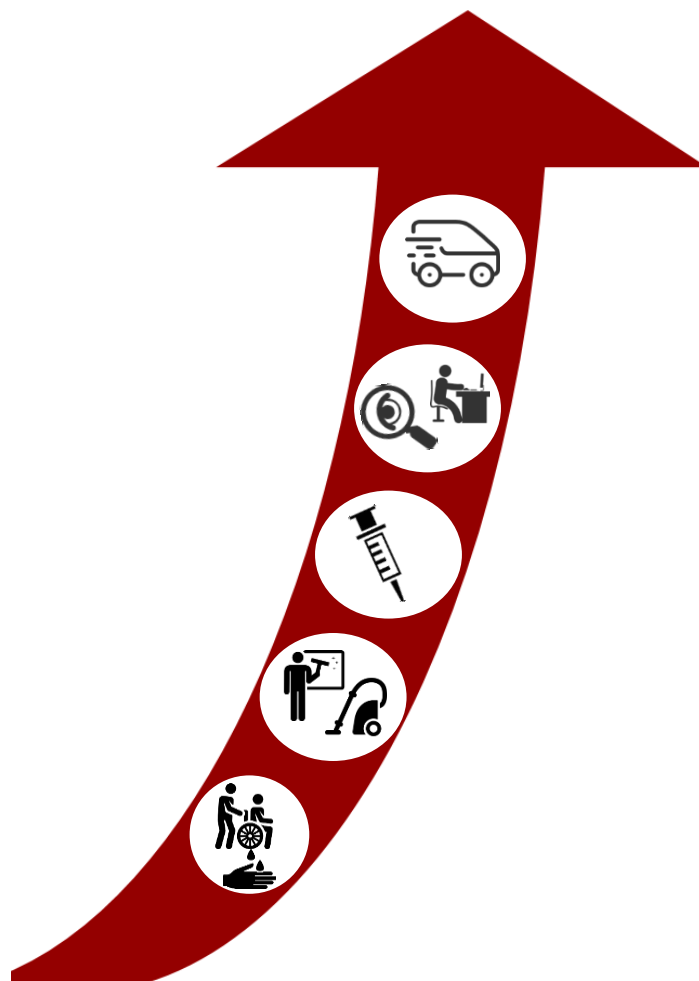
# Organising care is time-consuming and hard to manage

**7 in 10** find all this  
**time-consuming**



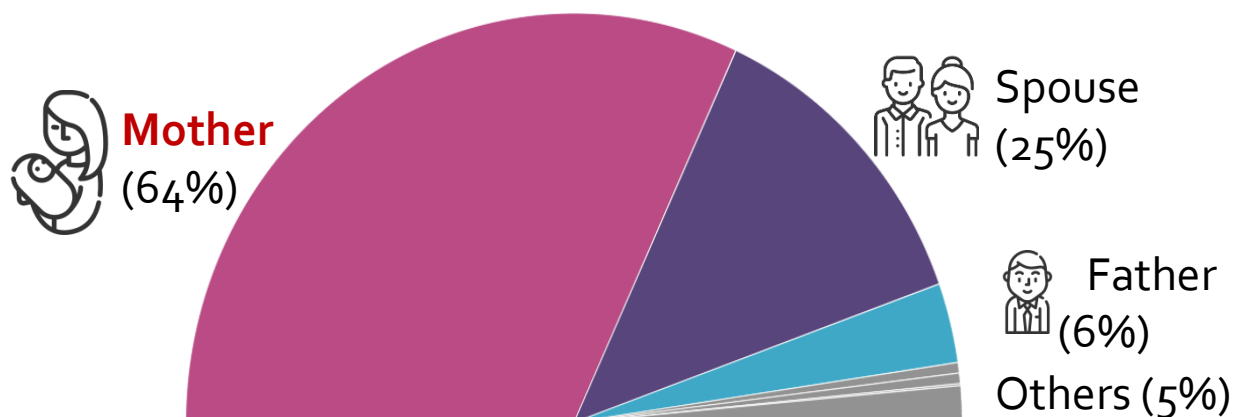
**6 in 10** find all this  
**hard to manage**

# Accumulation of tasks= increased burden



# A burden that heavily falls on women

The role of the primary carer for people living with a rare disease is primarily assumed by women



*Who organises and coordinates care in your household?*

“The disabled person has to **deal with several different services** to receive help and benefits

There are therefore often **waiting times** of around 6 months whilst dealing with each service or **waiting for service A to send your paperwork to service B.**

**During this time, you have not had time to employ someone and you are still not working”**

Female carer, France



Image used for illustration purposes. Source: [Nationella Funktionen Sällsynta Diagnoser](#), Sweden

# Lack of coordination between care providers

**67%** of the patients and carers say that health, social and support professionals **communicate badly**

About:

- Patient
- Disease & consequences
- Treatment

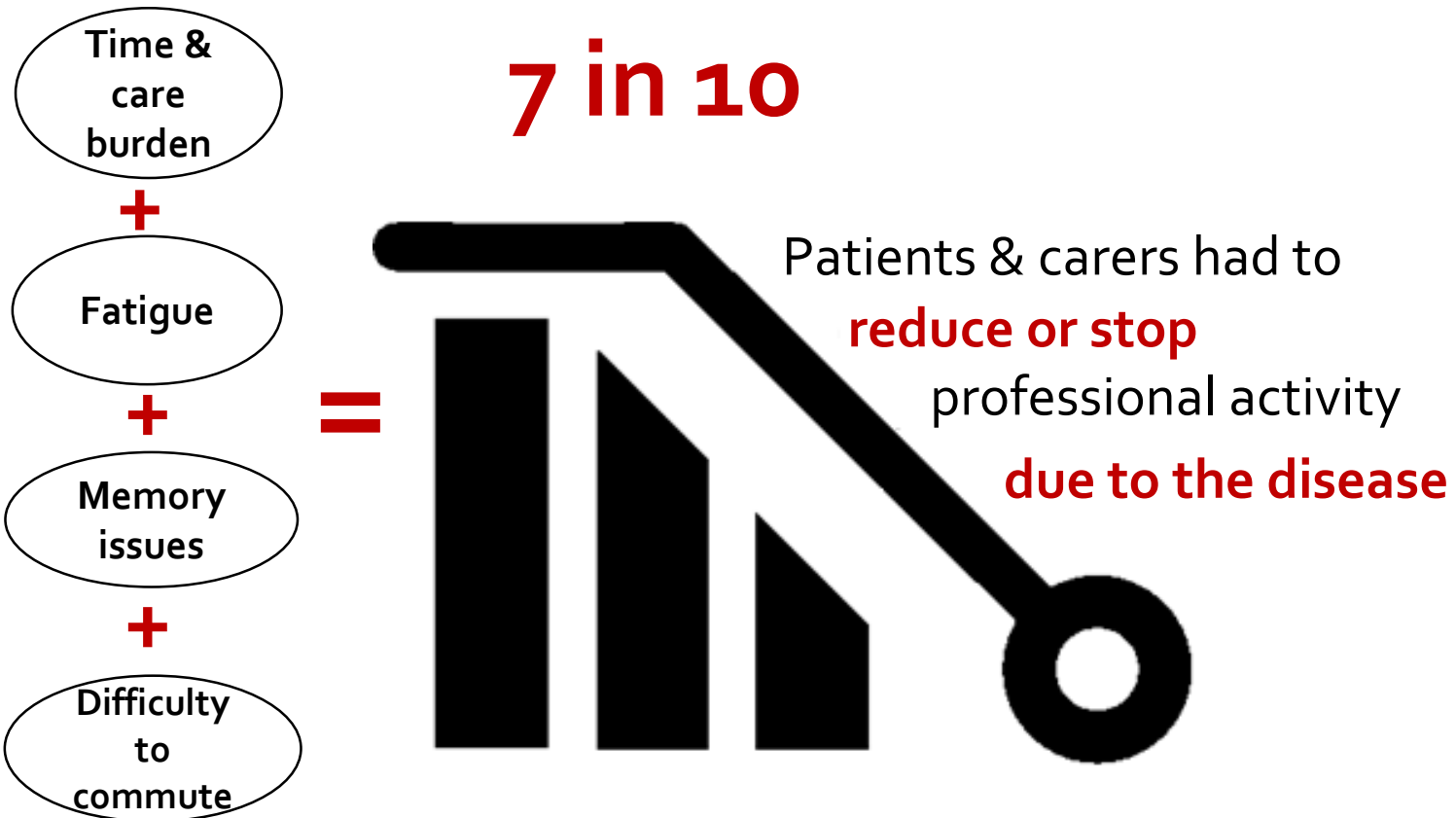


“ The **appointments should be multidisciplinary** allowing for the various specialists to see the patient on the **same day and the same place**

Besides **facilitating communication** and the definition of **adequate treatment** it would also **avoid that the patient has to travel** to different appointments and places, **being absent from work (loosing income** and facing **discrimination** at the workplace) and **spending** a lot in travel”

Female, Portugal

# Significant impact on professional life



# Lack of flexibility and adaptation of tasks

Need to stop working during most challenging times:

- **58%** absent from work over 15 days/year
- **41%** asked for special leave from work but could not obtain it





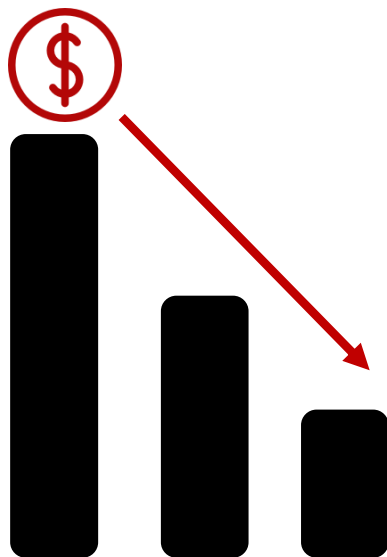
**“The worse time, was the time we were **looking for a diagnosis**, which took roughly **6 years**.**

**By asking a year "non paid break" (...) I received a **refusal from the employer**. So I decided to **give up my job** and stayed unemployed for **4 years**.**

**(...) After the diagnosis (...), I decided to **pick up work again**. One year: **part-time** and thus **earning half** as much as before.”**

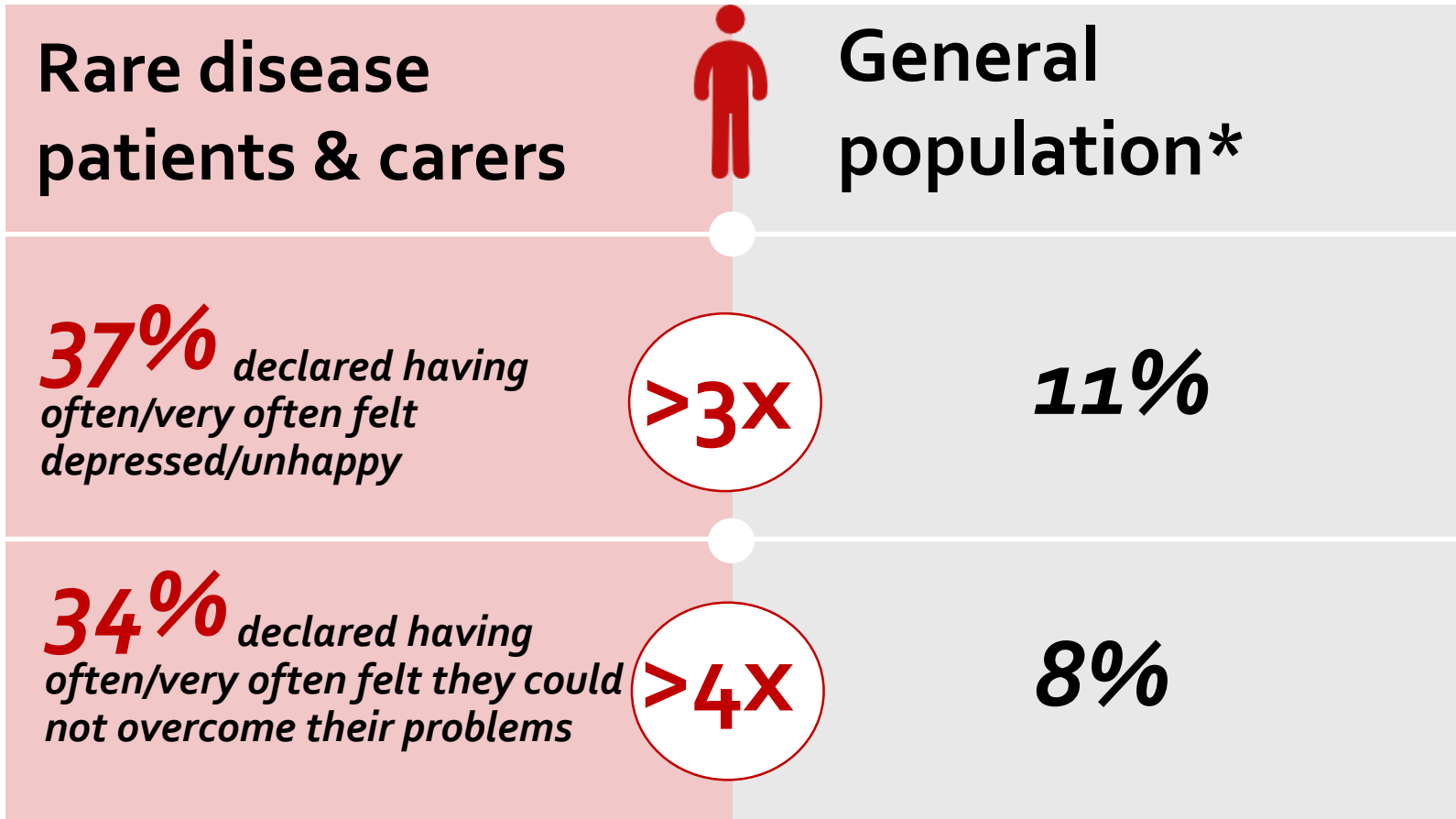
**Female, Luxembourg**

# Decrease of income



The rare disease led to an **income decrease** for 69% of patients and carers

# Deteriorated mental health



\* International Social Survey Programme. Health module, International Social Survey Programme, 2011

“

(...) **I don't look ill but am very ill** with a condition which no one understands or has heard of, **so get no sympathy**. There's no cure or any hope of improvement, **it's depressing and I feel alone. (...)**”

Female, United Kingdom



## JUGGLING CARE AND DAILY LIFE: THE BALANCING ACT OF THE RARE DISEASE COMMUNITY

Through its survey initiative Rare Barometer Voices, EURORDIS-Rare Diseases Europe carried out the first European-wide survey on the impact of rare diseases on everyday life. The survey covered issues including coordination of care, mental health, employment and economic impact. See the full survey report at [eurordis.org/voices#studies](http://eurordis.org/voices#studies)

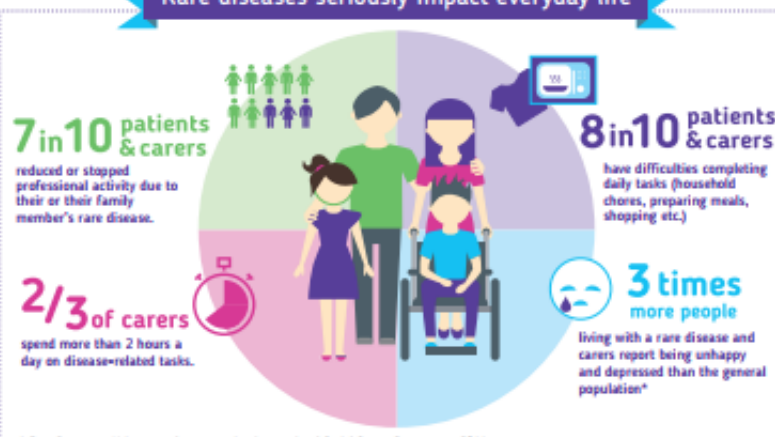


**30 million**  
people are living with a rare disease in Europe  
and 300 million worldwide



No cure for the vast majority of diseases and  
few treatments available

### Rare diseases seriously impact everyday life



\* Rare Barometer Voices sample compared to International Social Survey Programme, 2011



Rare Barometer Voices is a EURORDIS-Rare Diseases Europe online survey initiative. It brings together over 6,000 patients, carers and family members to make the voice of the rare disease community stronger. Results are shared with policy decision makers to bring about change for people living with a rare disease.



Thank you to all Rare Barometer  
Voices participants and partners!

[www.eurordis.org/content/contribute-rare-barometer-programme](http://www.eurordis.org/content/contribute-rare-barometer-programme)

**3,071**  
people responded  
to the survey.

The survey was conducted in  
**23** languages  
across  
**42** countries

For more information visit  
[eurordis.org/voices](http://eurordis.org/voices) or email  
[rare.barometer@eurordis.org](mailto:rare.barometer@eurordis.org)

This survey was conducted in the scope of the EU-funded INNOCare project



This project is co-funded by the  
European Union

[Download the infographics here](#)

*EURORDIS would like to thank all Rare Barometer partners for their support*



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DG Employment, Social Affairs and Inclusion*