

INNOV Care

Innovative Patient-Centred Approach for Social Care Provision to Complex Conditions

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 with the INNOV Care project via EURORDIS Survey initiative - Rare Barometer - and the online community of survey respondents Rare Barometer Voices



www.innovcare.eu



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 This project is co-funded by the European Union

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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



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



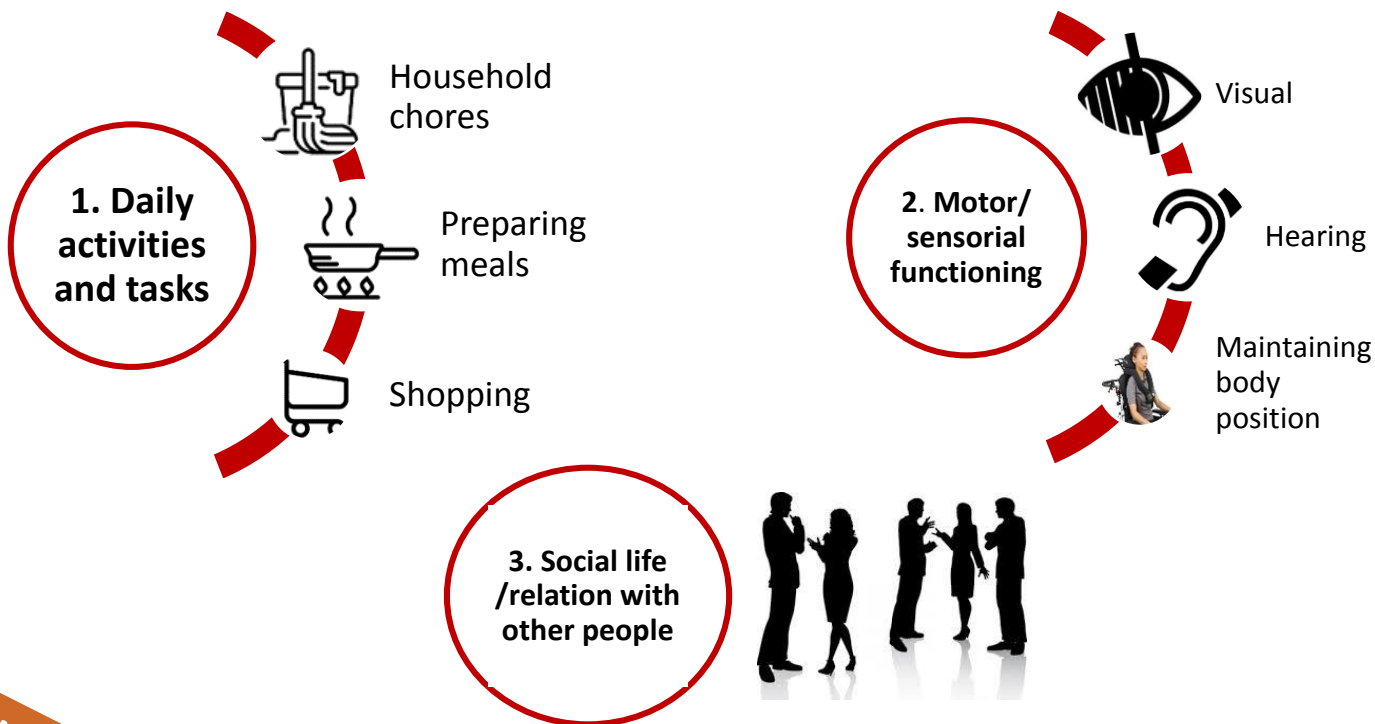
Patients and carers feel badly informed about their rights and feel that social services are badly prepared to support them



Rare diseases impact the mental health of patients and carers

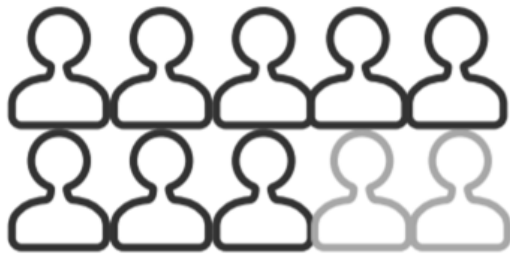
Serious impact on patients' everyday life

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



Disability

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

Discrimination

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

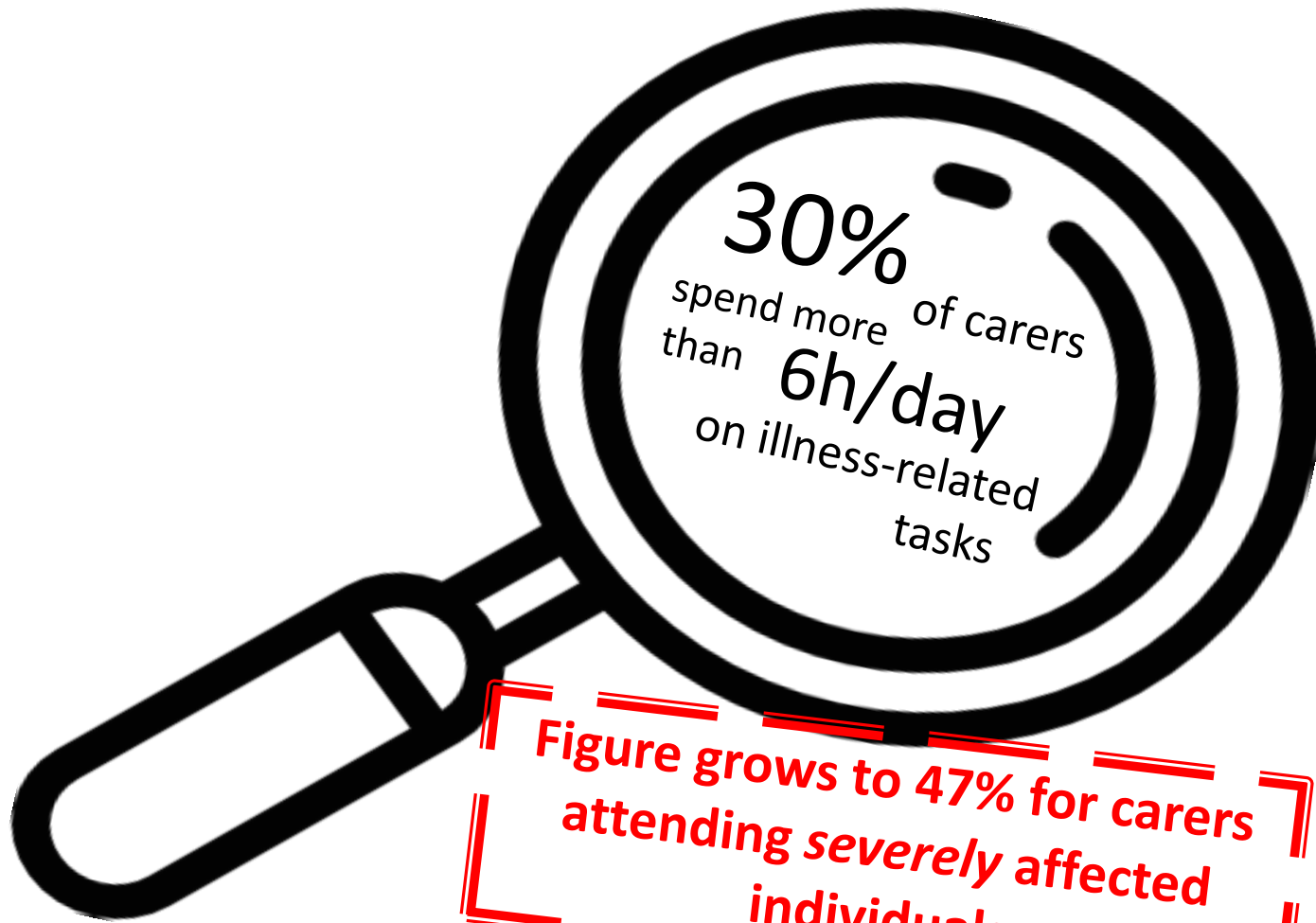


Helping patients to move



Time Burden

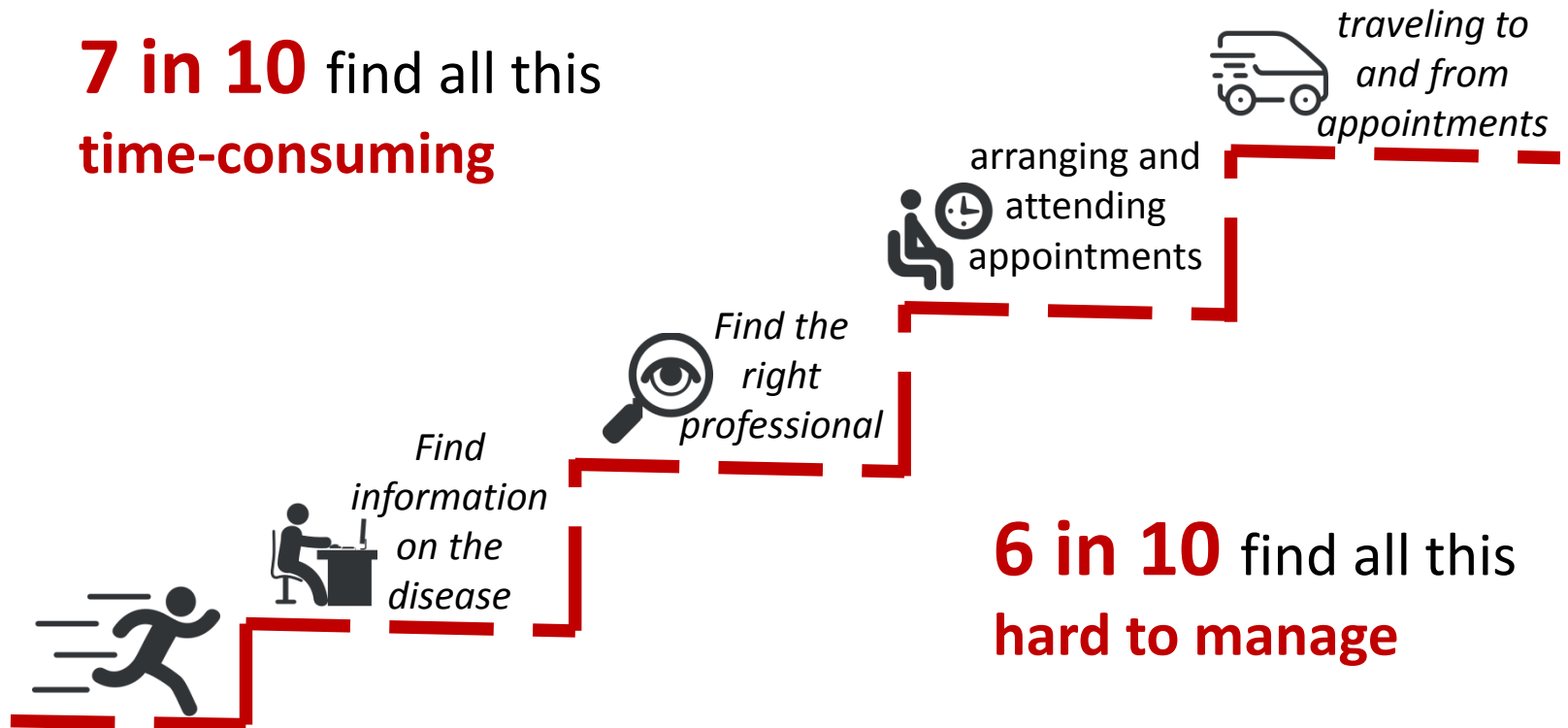
Heavy time burden for carers



Time Burden

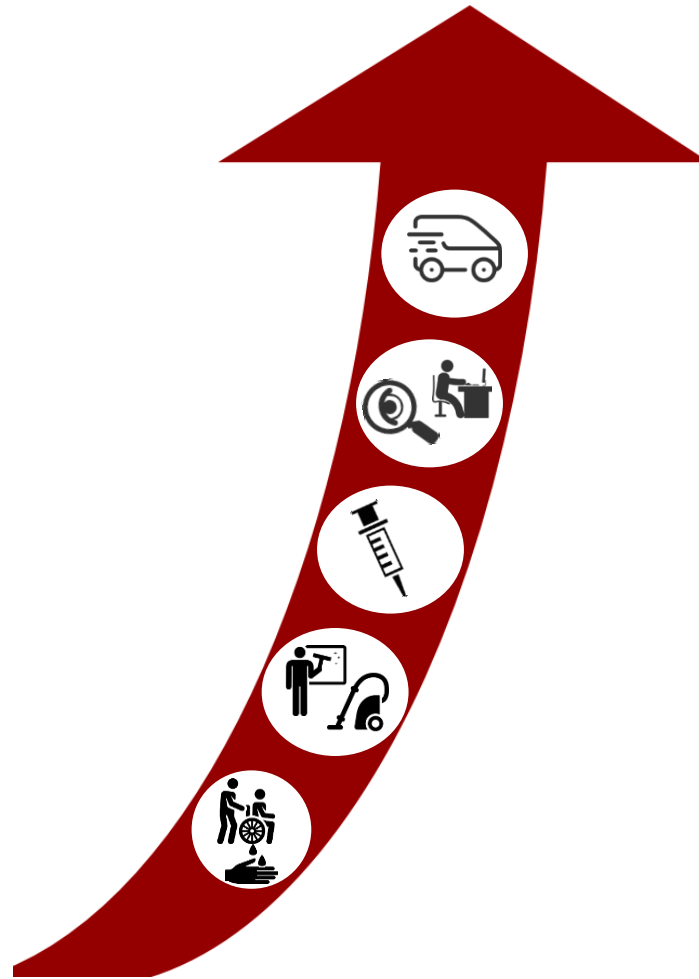
Organising care is time-consuming and hard to manage

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



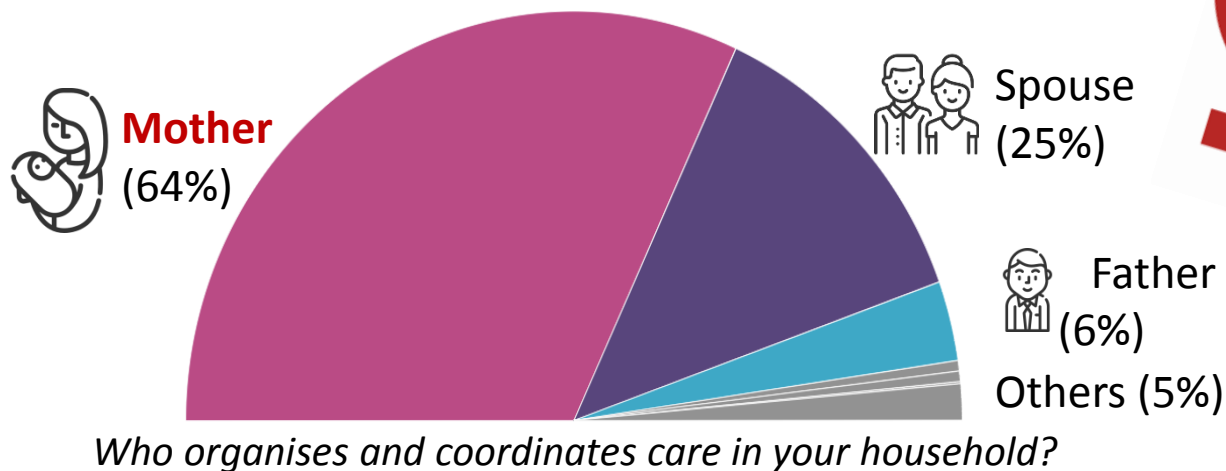
6 in 10 find all this **hard to manage**

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



Gender

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



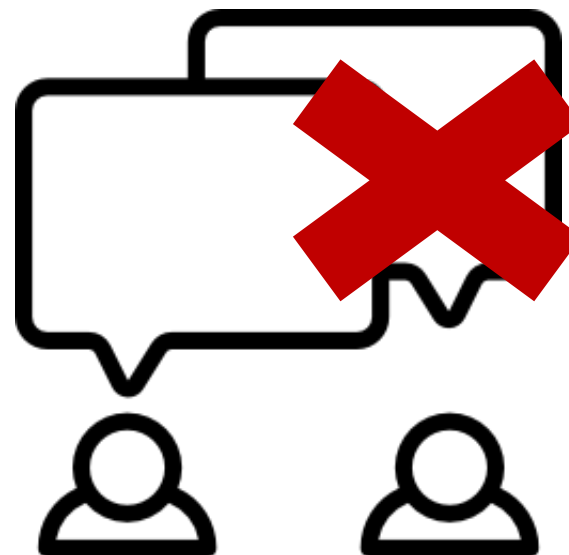
Image used for illustration purposes. Source: [Nationella Funktionen Själlsynta Diagnoser](https://www.nationellafunktionen.se/nyheter/2017/06/16/sjallsynta-diagnoser), Sweden

Complex Care Pathway

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*

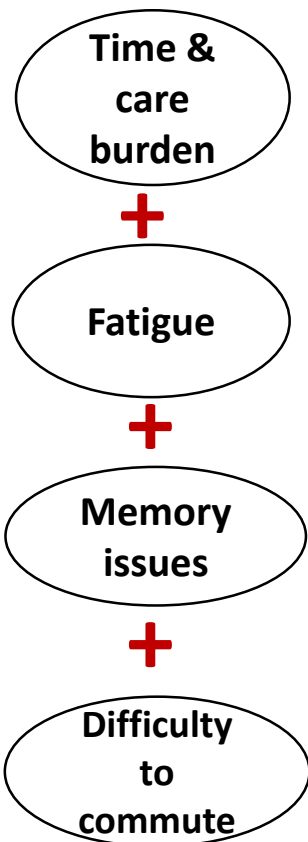


“The **appointments should be multidisciplinary** allowing for the various specialists to see the patient on the **same day and the same place**

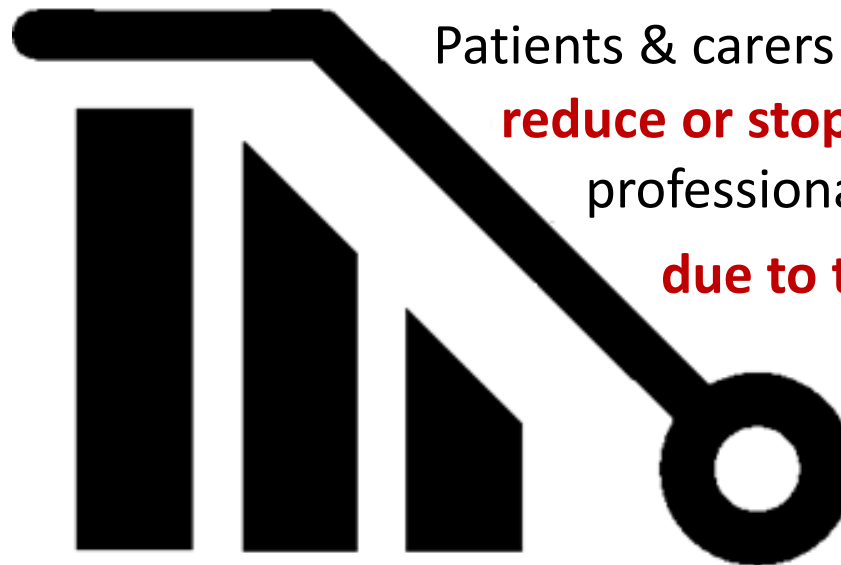
Besides **facilitating communication** and the definition of **adequate treatment** it would also **avoid that the patient has to travel** to different appointments and places, **being absent from work (loosing income** and facing **discrimination** at the workplace) and **spending** a lot in travel”

Female, Portugal

Significant impact on professional life



7 in 10



Patients & carers had to **reduce or stop** professional activity **due to the disease**

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



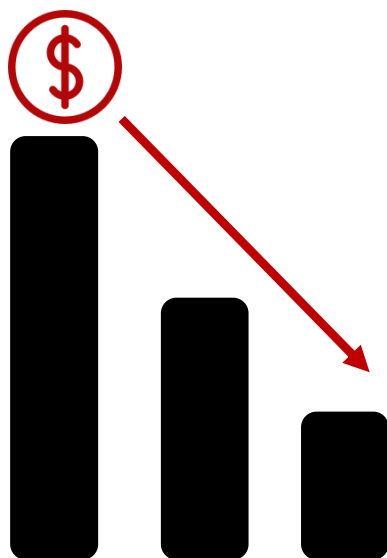
“The worse time, was the time we were **looking for a diagnosis, which took roughly 6 years.**

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.”

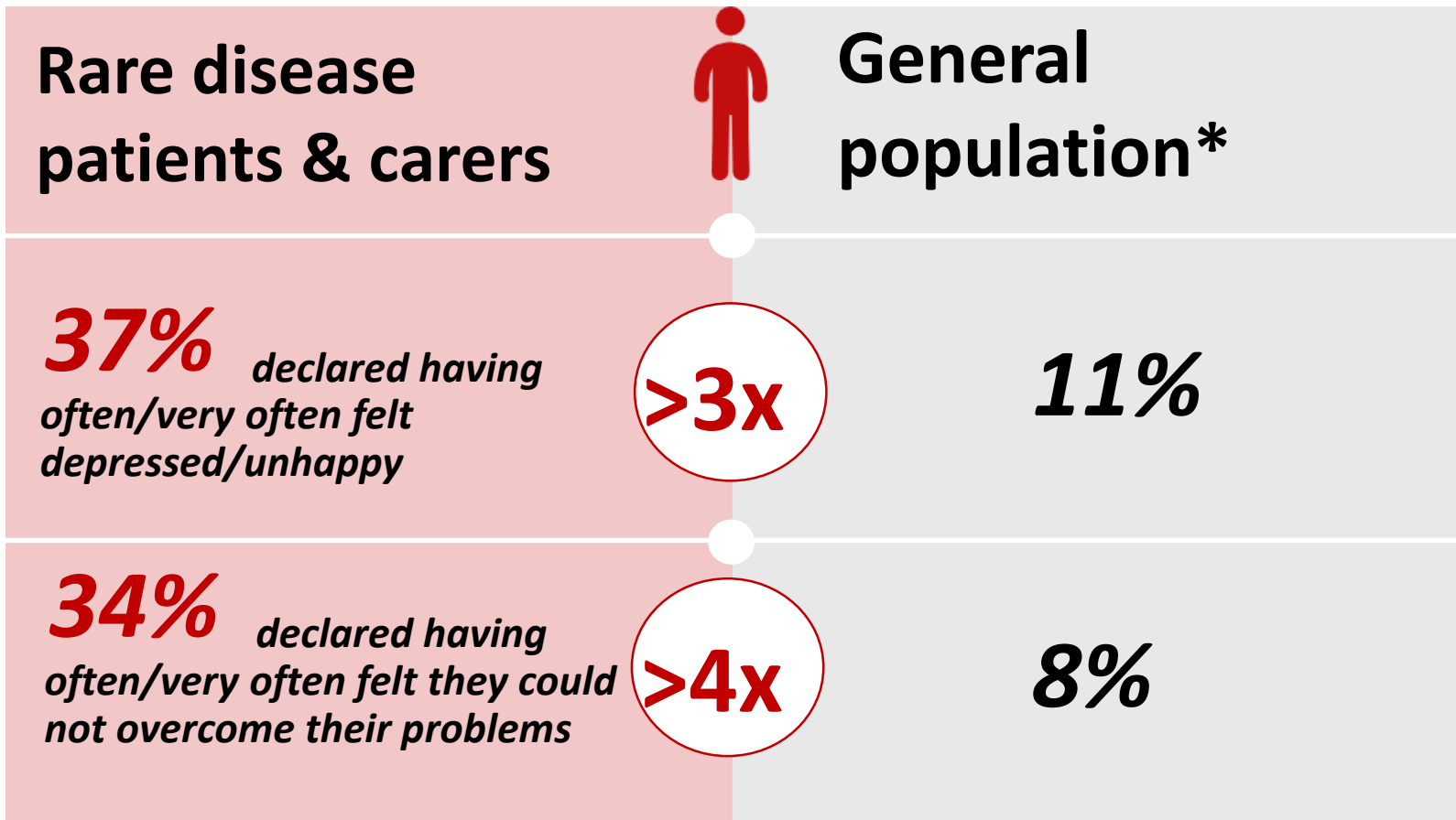
Female, Luxembourg

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

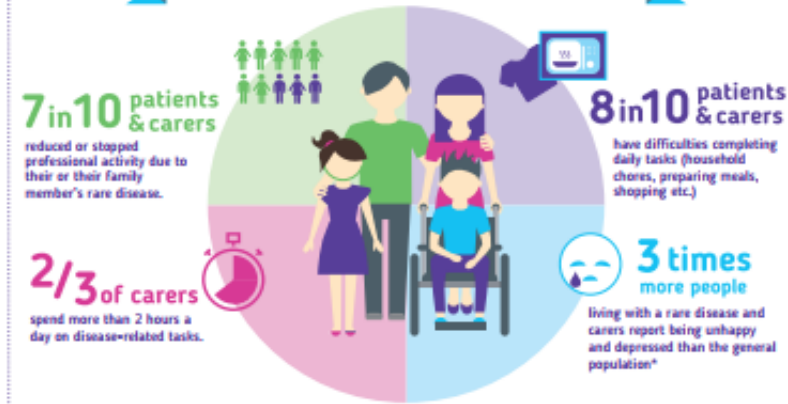


30 million
people are living with a rare disease in Europe
and 300 million worldwide



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.

3,071
people responded to the survey.

The survey was conducted in
23 languages
across
42 countries

Thank you to all Rare Barometer
Voices participants and partners!

www.eurordis.org/content/contribute-rare-barometer-programme

For more information visit
eurordis.org/voices or email
rare.barometer@eurordis.org

This survey was conducted in the scope of the EU-funded INN·V·Care projects.



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[Download the infographics here](#)



A EURORDIS INITIATIVE

www.eurordis.org/voices



EURORDIS would like to thank all Rare Barometer partners for their support to co-fund this survey conducted via Rare Barometer Voices, in the scope of INNOVCare

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Thank you

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