



# Juggling care and daily life:

## The Balancing Act of the Rare Disease Community

Avril Daly, EURORDIS Vice-President  
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Launch event of the Parliamentary Advocates for Rare Diseases

[#ParliamentAdvocate4Rare](#)

[EURORDIS.ORG](http://EURORDIS.ORG)



# Rare diseases

A rare disease is defined in Europe as affecting  
**fewer than 1 in 2,000 citizens**

- Over **6,000** distinct rare diseases
- **30 million** people living with a rare disease in Europe
- Many are of **genetic** origin but 20-30 % rare diseases are non genetic
- Many **children** are affected by rare diseases. Onset occurs in childhood for 50% of rare diseases.
- Some main groups: metabolic, neuro-muscular, autoimmune, developmental anomalies, bleeding disorders, cardiovascular, respiratory, skin diseases, rare cancers...

# The challenges

Most rare diseases are chronic, progressive, degenerative, disabling and frequently life-threatening



- Patients and experts are few, geographically **scattered** and often **isolated**
- Patients are undiagnosed, misdiagnosed or wait years for a diagnosis
- Reliable **information is scarce**
- **Fragmented research**, data and expertise
- Lack of **treatments and challenges** to access adequate care
- High social impact and **marginalisation** within society at large and within healthcare systems designed for common diseases
- **Heavy psychosocial burden**

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



A EURORDIS INITIATIVE

## 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
- 802 diseases, 42 countries
- Performed in 23 languages



[http://download.eurordis.org.s3.amazonaws.com/rbv/2017\\_05\\_09\\_Social%20survey%20leaflet%20ofinal.pdf](http://download.eurordis.org.s3.amazonaws.com/rbv/2017_05_09_Social%20survey%20leaflet%20ofinal.pdf)

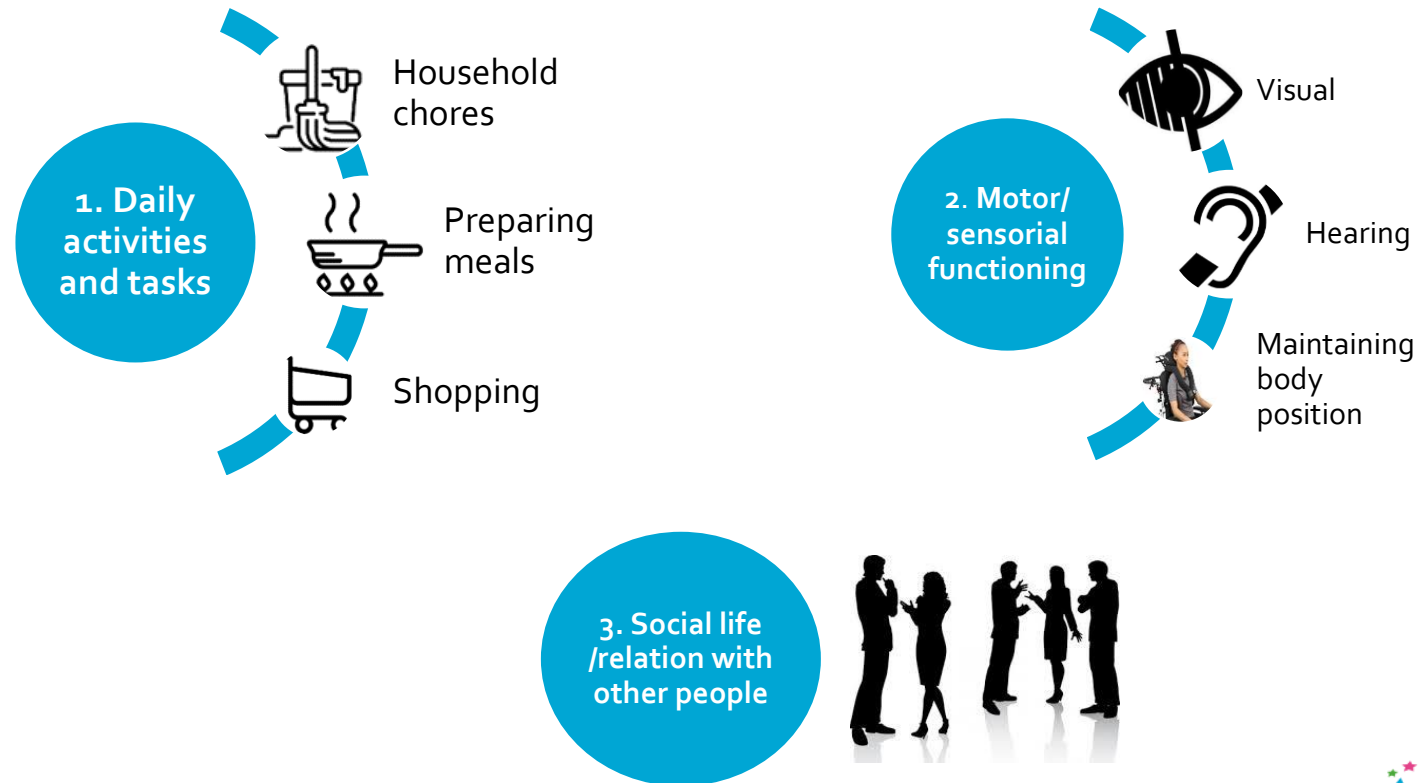
# Summary of key results

1. Rare diseases have a serious impact on everyday life
2. Significant time and care burden for patients and carers
3. Impact on work-life balance: absence from work, hampered professional activity, economic burden
4. Rare diseases impact the mental health of patients and carers

# 1. Impact on everyday life

# 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”

Woman, 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](#)

## 2. Time and care burden for patients and carers

# Heavy time burden for patients & carers

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

Hygiene



Administration of treatments



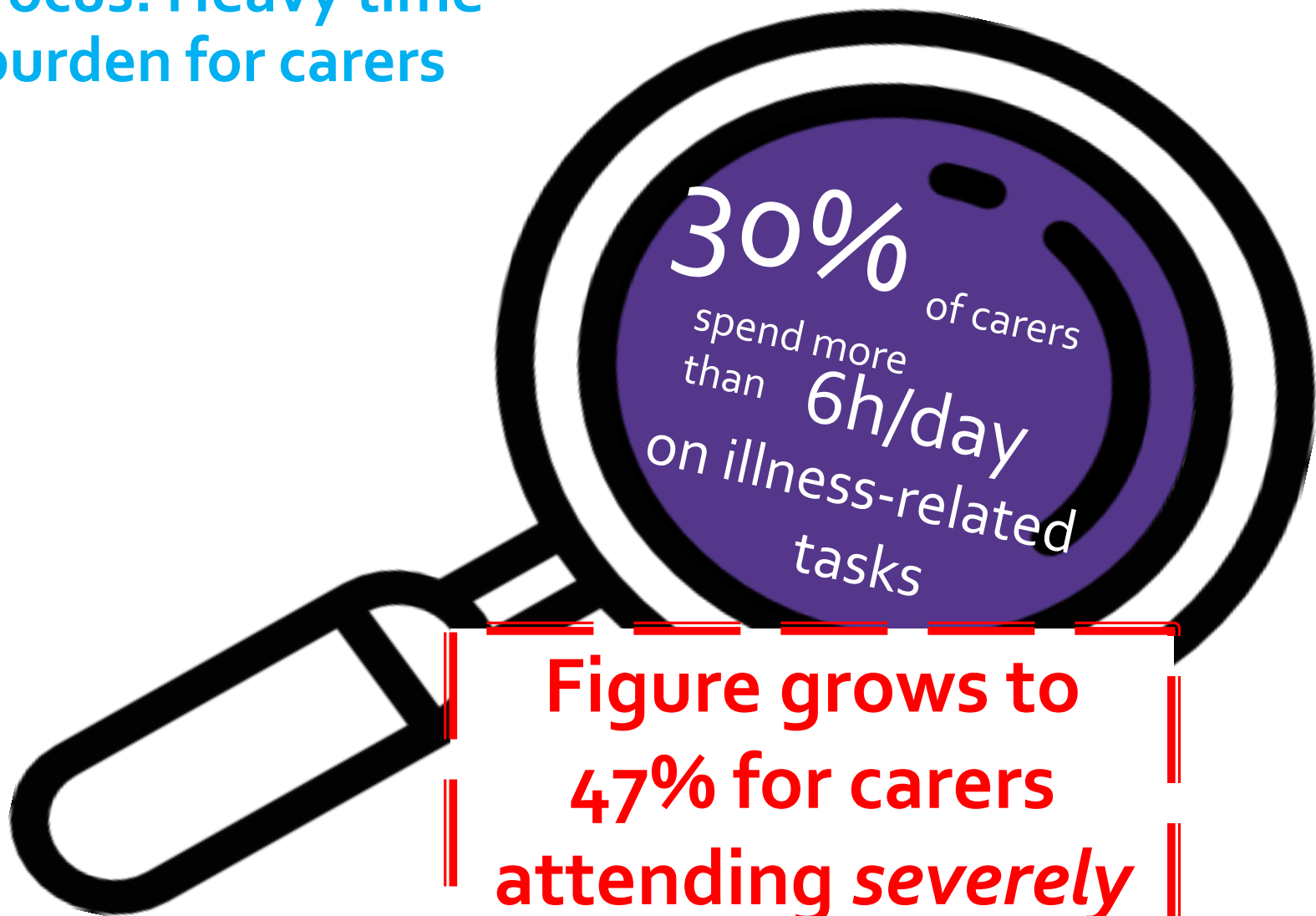
Helping with house chores



Helping patients to move



## Focus: Heavy time burden for carers



30% of carers spend more than 6h/day on illness-related tasks

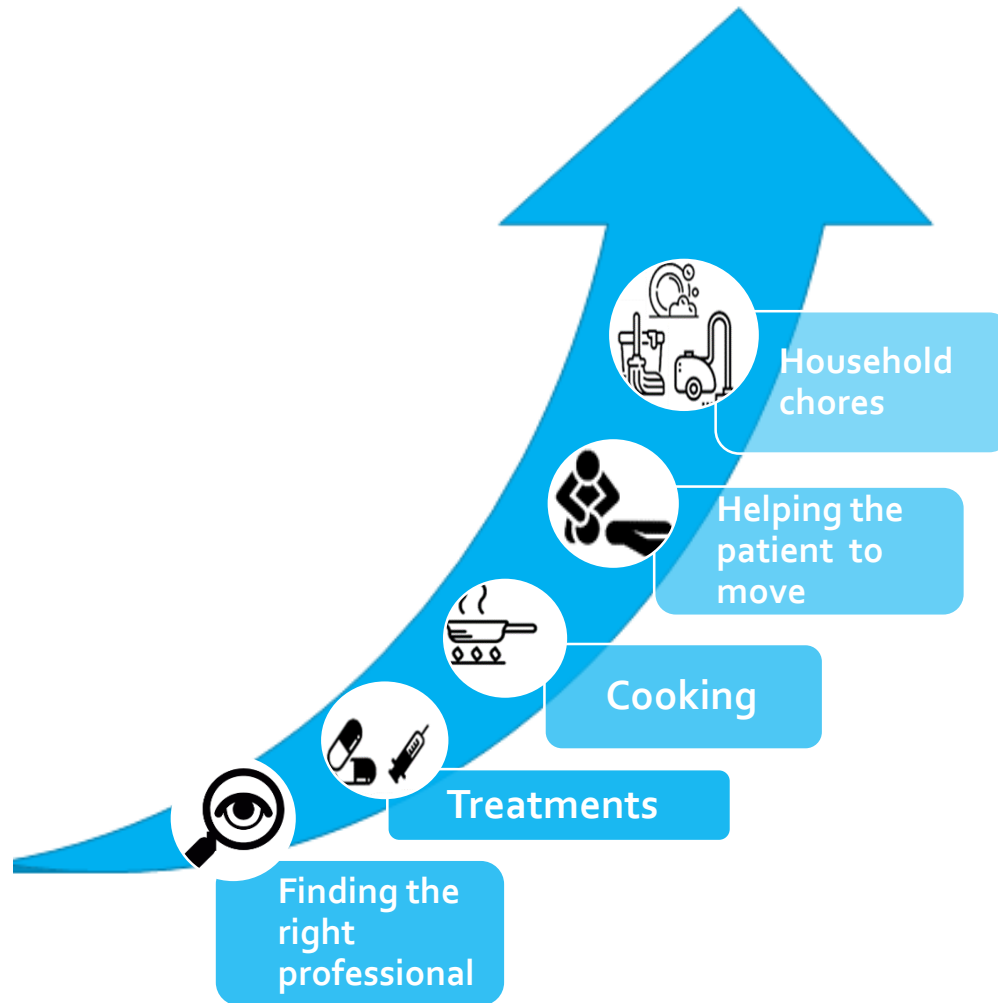
**Figure grows to 47% for carers attending *severely* affected individuals**

# Organising care is time-consuming and hard to manage

In addition to essential daily tasks, people living with a rare diseases and carers have to deal with the coordination of care

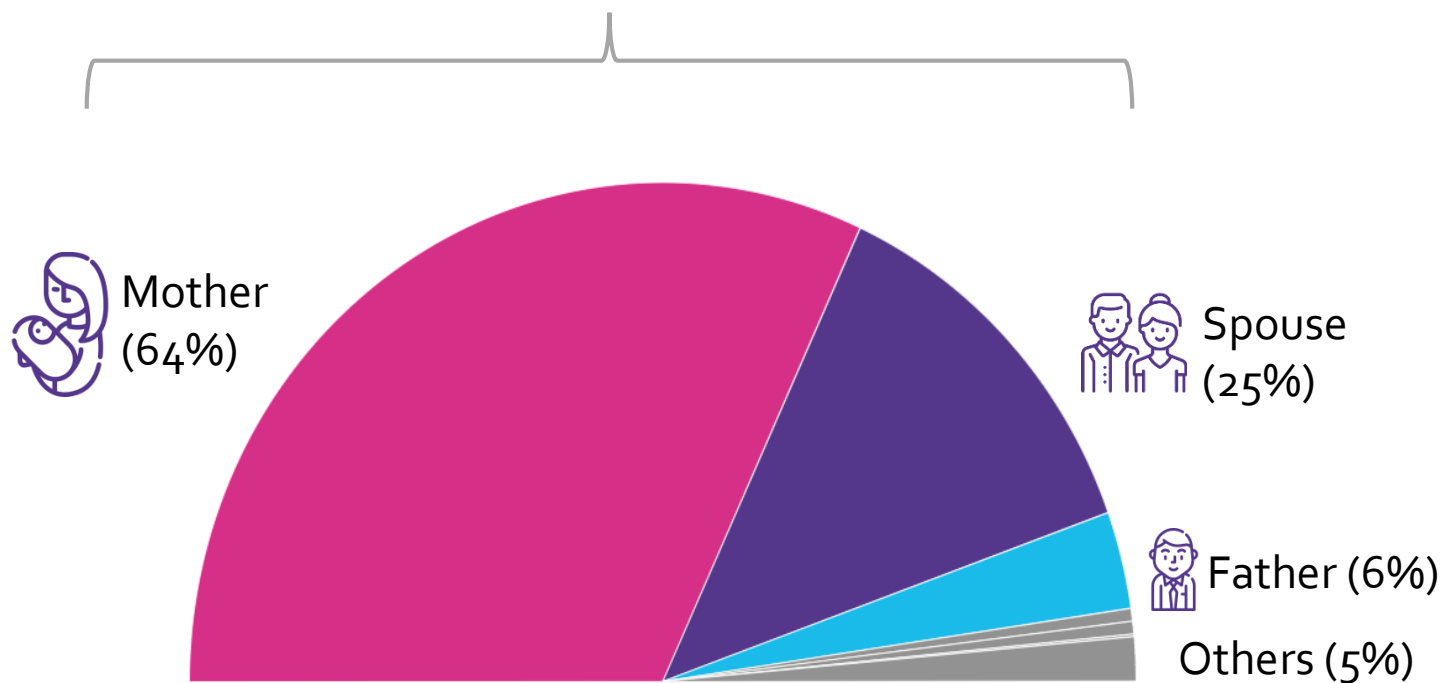


# Accumulation of tasks= increased burden



# 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.**

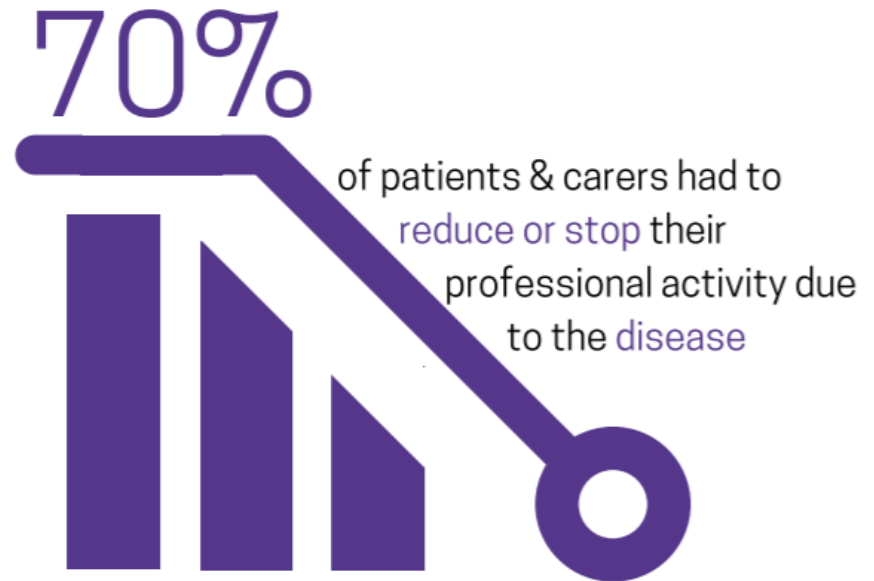
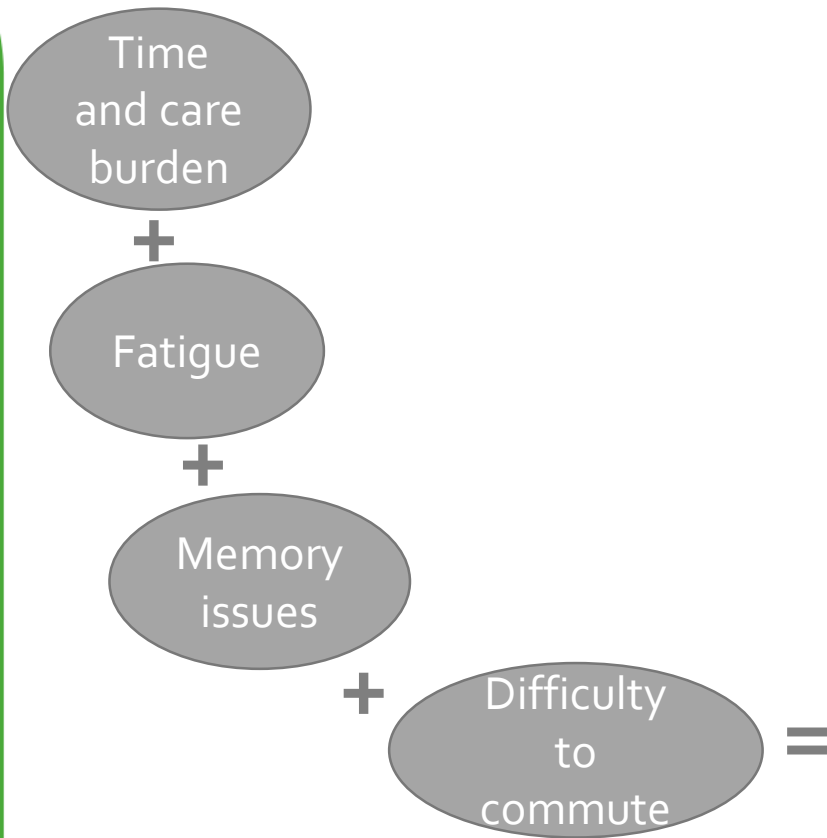
**During this time,** you have not had time to employ someone and **you are still not working”**

Woman carer, France



# 3. Impact on work-life balance

# Significant impact on professional life



# Lack of flexibility and adaptation of tasks

Rare disease patients and carers in employment face certain needs that are not always met by employers:

- People living with a rare disease often need to stop working during most challenging times:

**58%** absent from work over 15 days/year

**21%** absent from work over 90 days/year

- The possibility of asking for special leave is a high unmet need for rare disease patients:

**41%** asked but could not obtain it

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

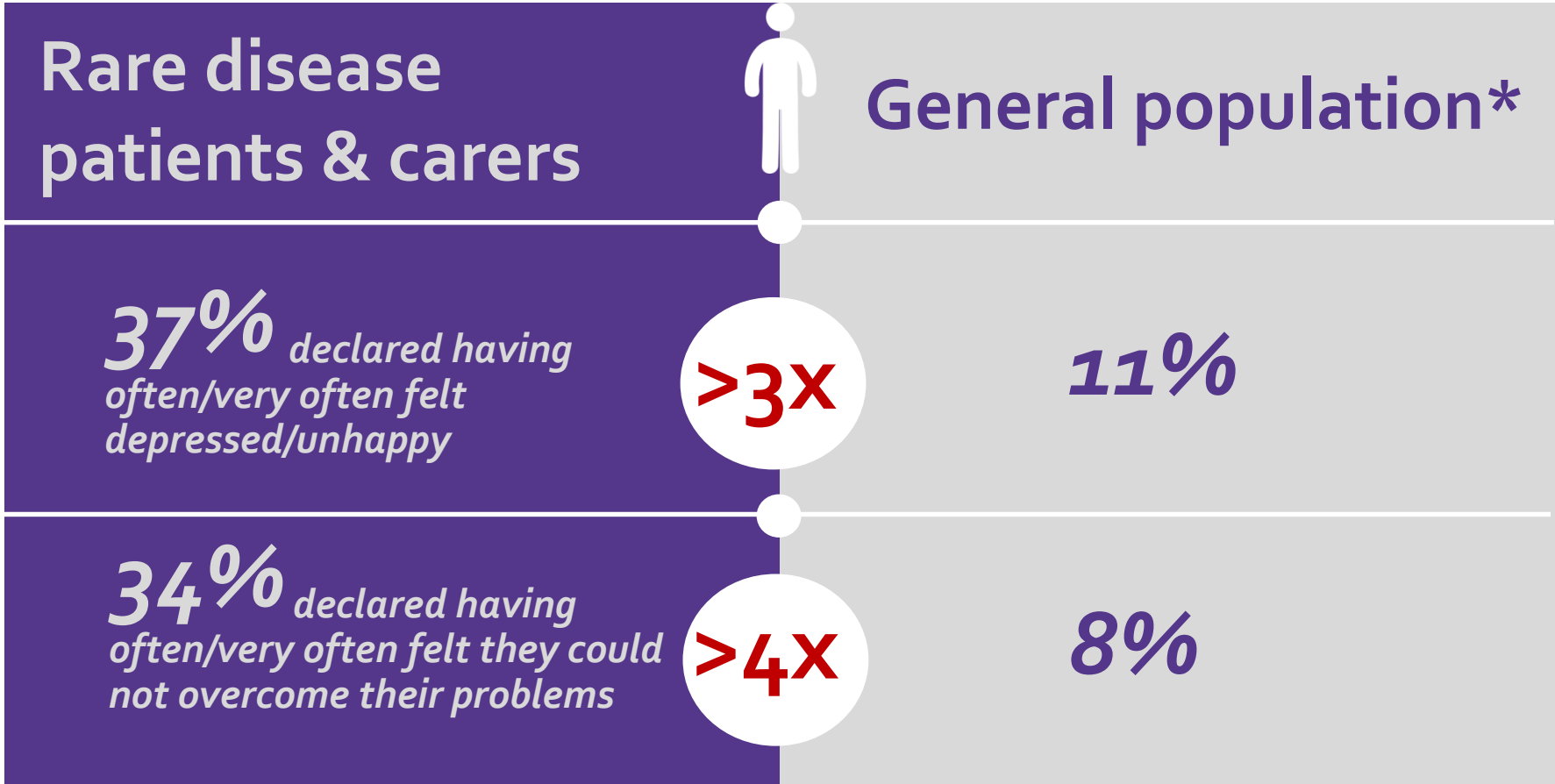
By asking a year **"non paid break"** (...) I received a **refusal from the employer.** So I decided to **give up my job** and stayed **unemployed for 4 years.**

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

*Woman, Luxembourg*

# 4. impact on the mental health of patients and carers

# Deteriorated mental health compared to general population



\* 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**

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This survey was carried within  
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[www.innovcare.eu](http://www.innovcare.eu)



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**Thank you for your  
attention.**

**Avril Daly**

**Vice-President EURORDIS**

**EURORDIS.ORG**

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