



Impact of Rare Disease Quality of Life: What it means in real terms for PLWRD.

Theme 4 - Session 1

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ECRD – Vienna, 2018

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Rare diseases – some background:

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 we face

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**

Eurordis first Europe-wide survey on social impact of rare diseases highlights the challenges:



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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%20final.pdf

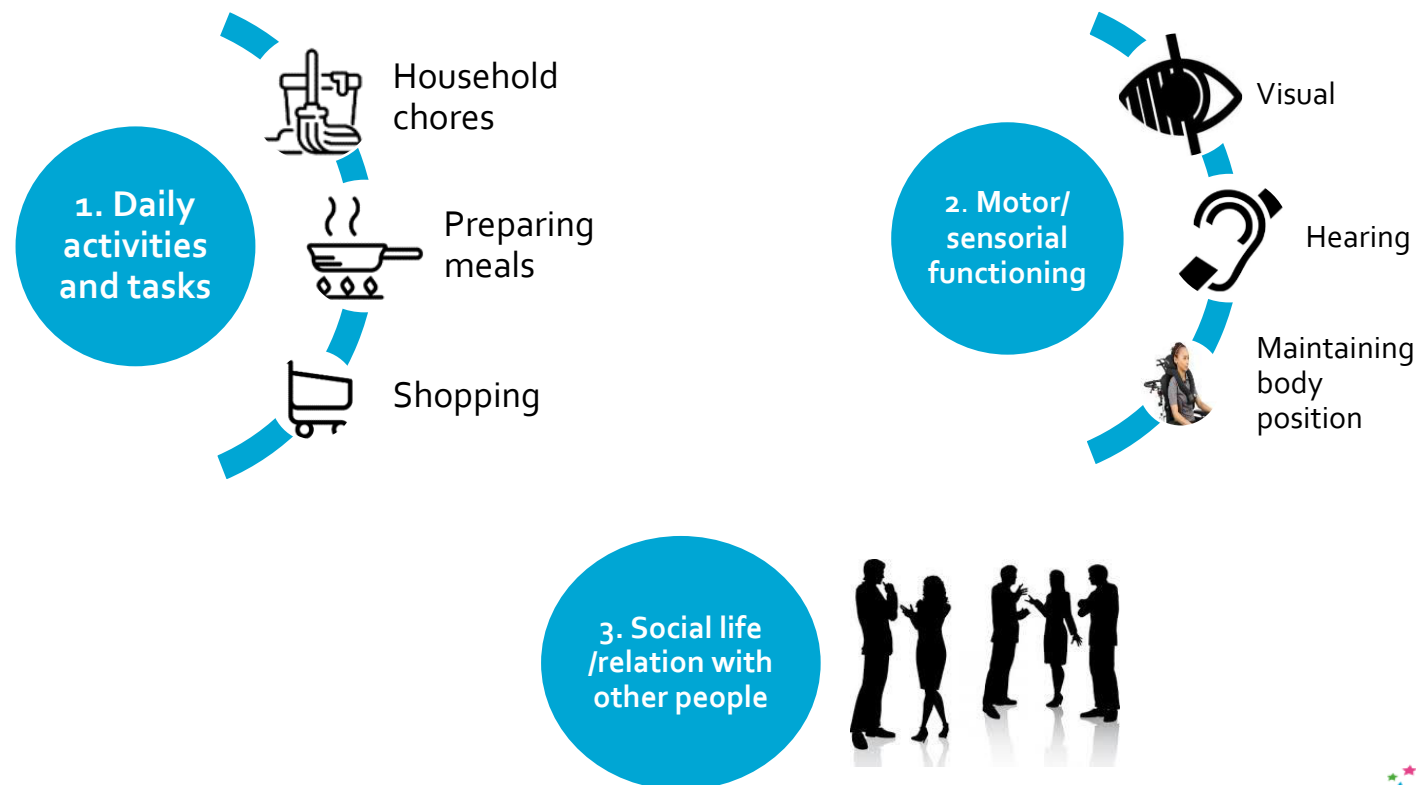
Summary of key results showed us what we already understood:

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”

Female, Spain



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

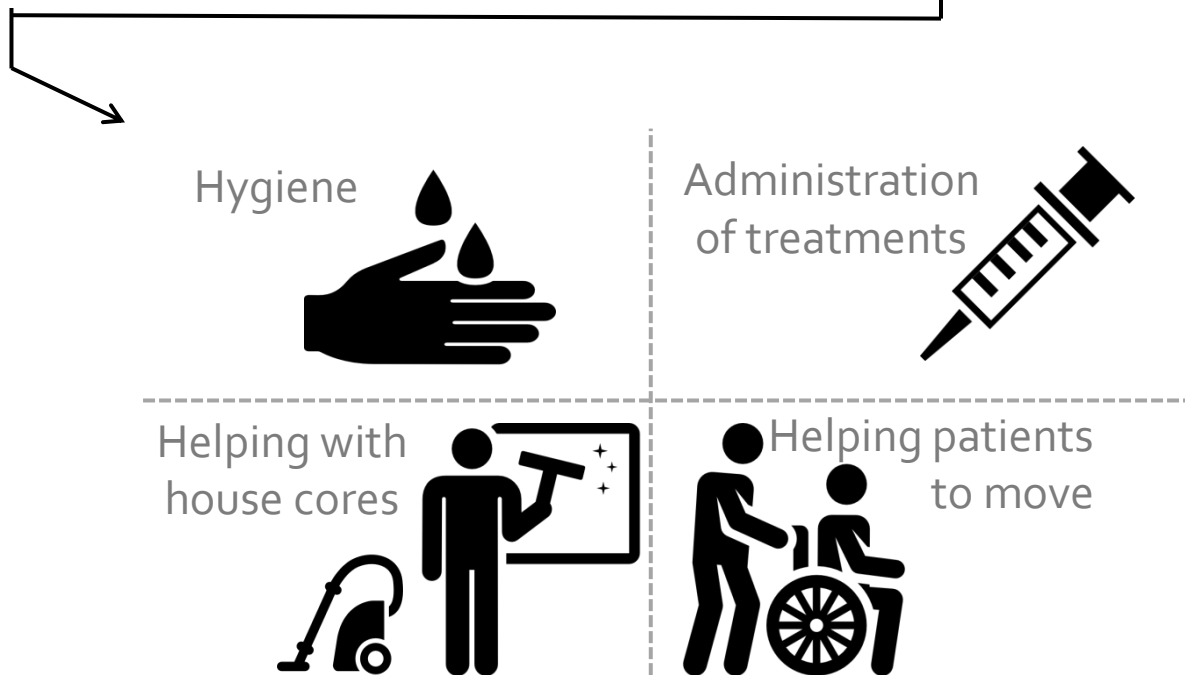
Illustrative photo. This presentation does not necessarily reflect the position of the person in this photo

Source: [EURORDIS Photo Contest](#)

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



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

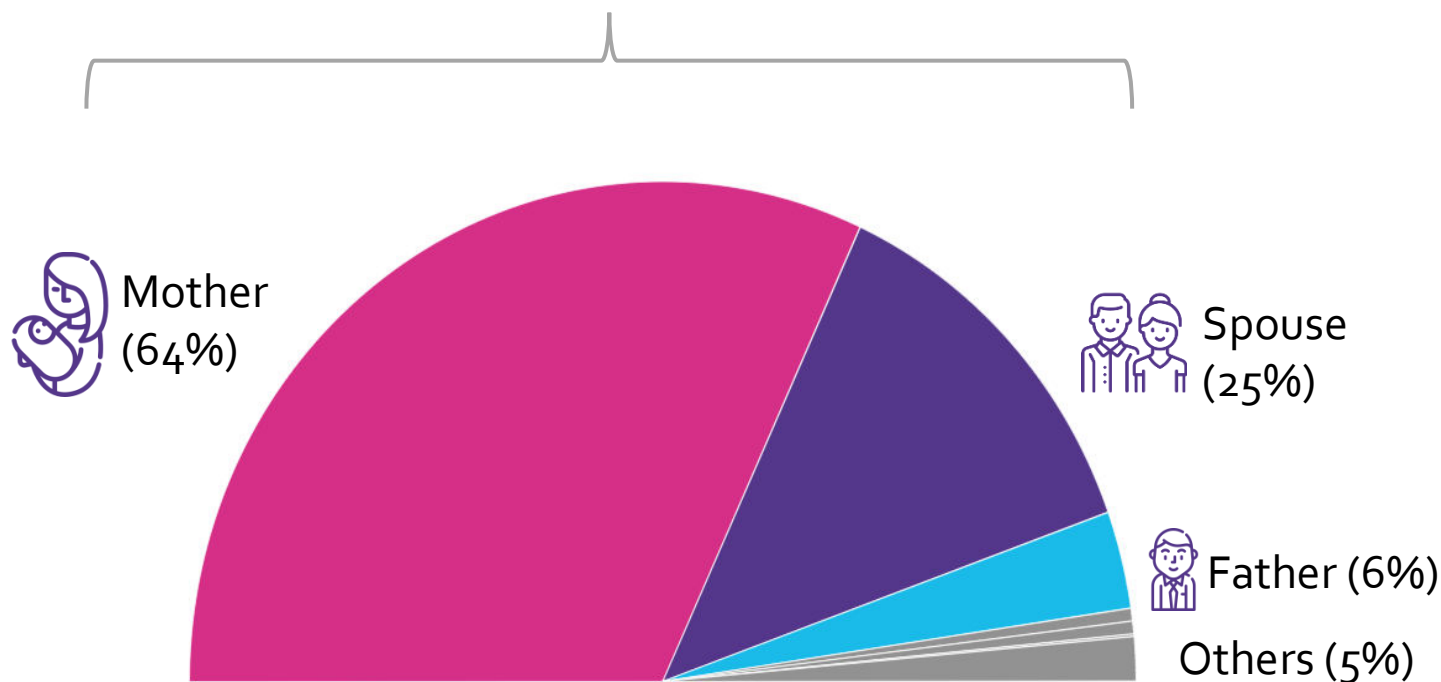
Organising care is time-consuming and hard to manage

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



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?

A burden that heavily falls on women

64% of rare disease patients carers
are **mothers**



25% of rare disease patients carers are
spouses (both genders)



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

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

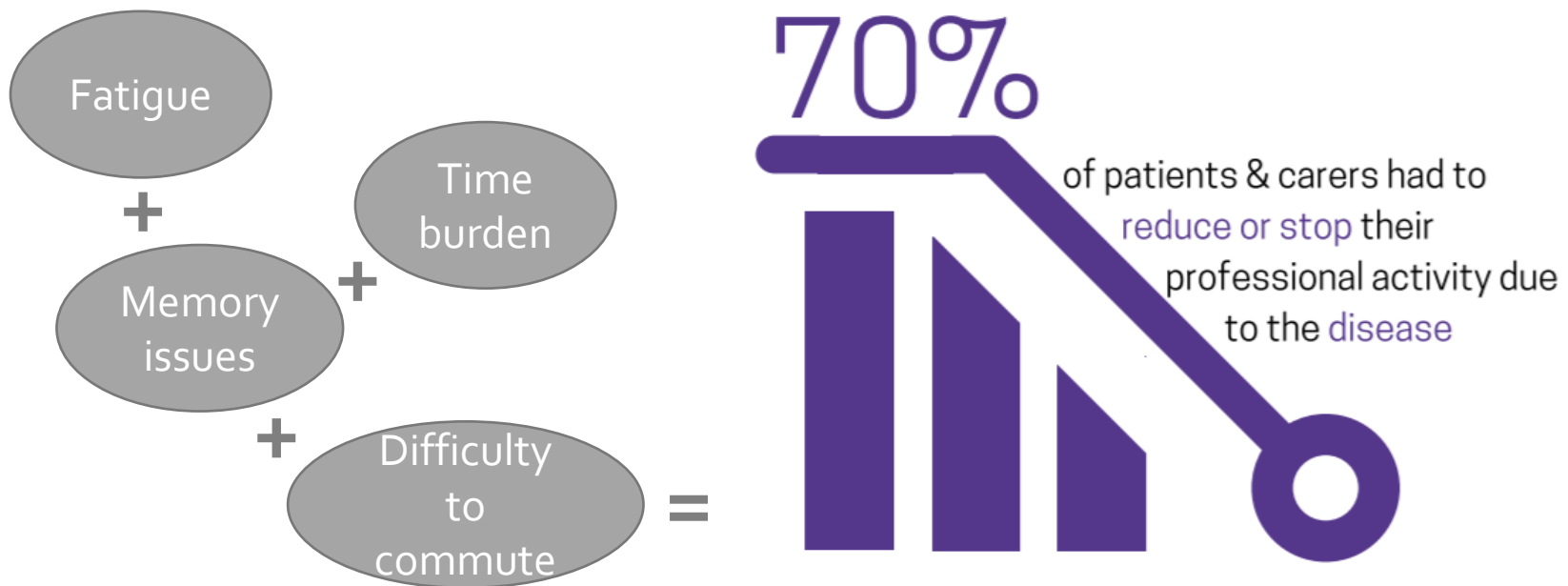
There are therefore often **waiting times** of around 6 months whilst dealing with each service or **waiting for service A to send your paperwork to service B.**

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

Female carer, France

3. Impact on work-life balance

Significant impact on professional life



“

With hyperacusis, tinnitus, hearing loss and dizziness, **I had to stop working as a teacher and reinvent myself.**

I currently work in an office and the **dizziness and hearing loss make my job very difficult.»**

Female, Luxembourg

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.**

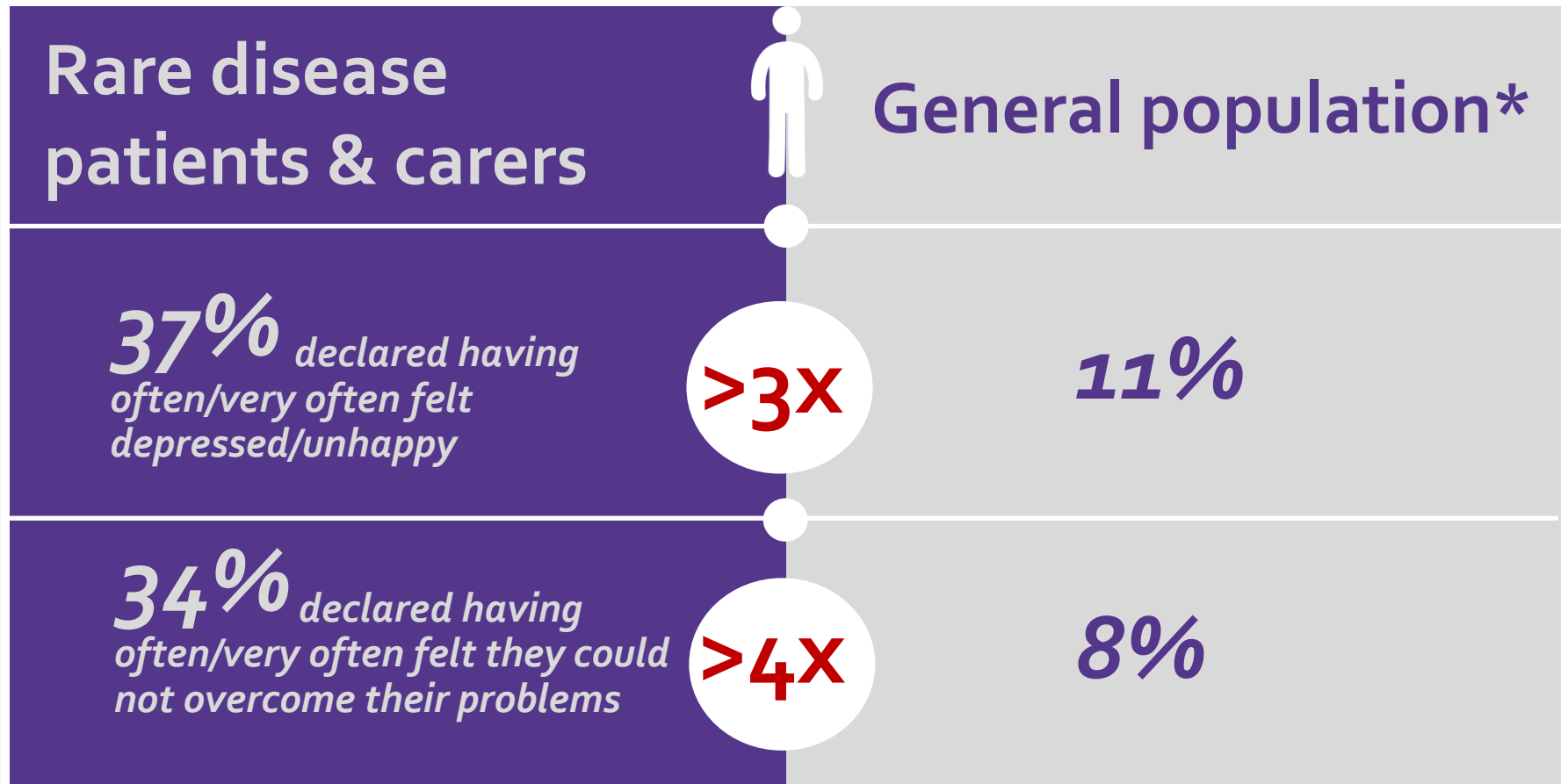
By asking a year **"non paid break"** (...) I received a **refusal from the employer.** So I decided to **give up my job** and stayed **unemployed for 4 years.**

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

Female, 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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Looking forward to hearing your
experience!

Thank you for your attention.

Avril Daly
Vice-President EURORDIS



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This project is co-funded by
the European Union
Call for Proposals VP/2014/008; ESF PROGRAM,
DG Employment, Social Affairs and Inclusion

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