



JUGGLING CARE AND DAILY LIFE

The balancing act of the rare
disease community

EURORDIS.ORG

Impact of rare diseases on well-being and mental health

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A decline in social and family life...

- **#1: Isolation from friends and family.**
 - 54% declare that it was caused or amplified by the rare disease
- **#2: Tension between family members**
 - 52% declare that it was caused or amplified by the rare disease
- **#3: Members of the family feeling neglected**
 - 46% declare that it was caused or amplified by the rare disease

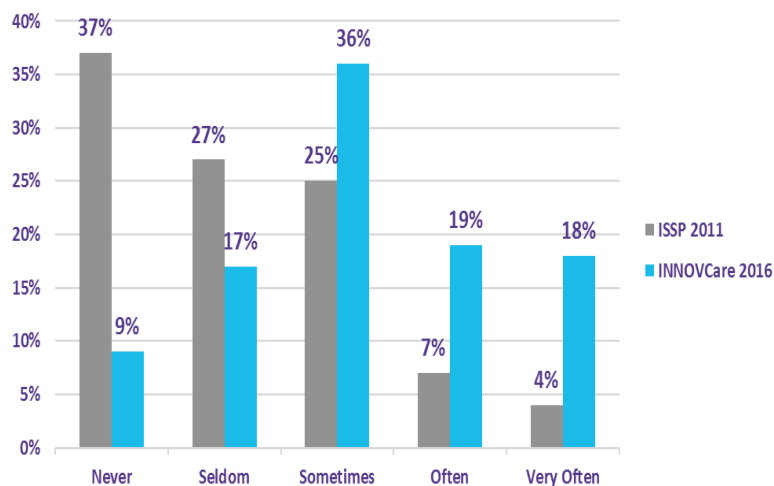
...But the family survives most of the time and its bonds can even be strengthened.

- Most families **stay together** while facing this situation:
 - Only 15% reported that a divorce or separation was caused or amplified by the disease.
- The disease can also have a **positive impact** on some families:
 - 45% declare that it has strengthened the family unit.

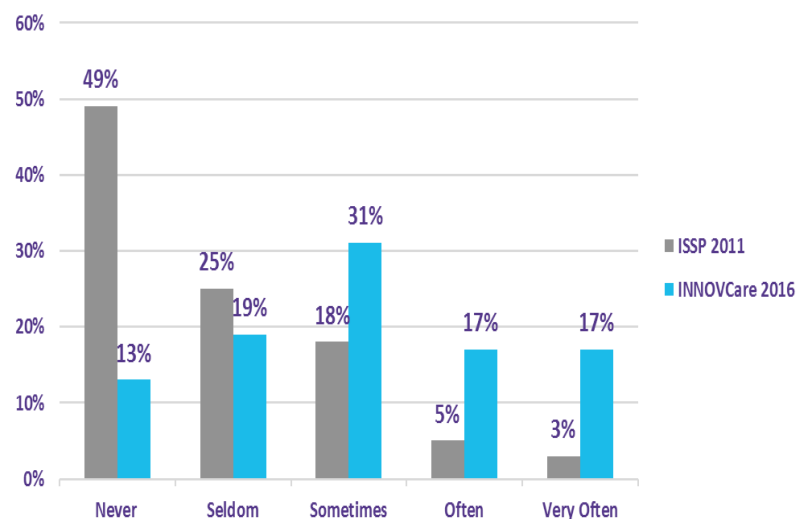
It is important to remember that, as difficult as it can get, a disease can also bring positive aspects.

Deteriorated mental health compared to the general population

In the past 4 weeks, how often have you felt unhappy and/or depressed ?



In the past 4 weeks, how often have you felt you could not overcome your problems?



- Rare disease patients and carers are **3 times** more likely to often feel unhappy and/or depressed than the general population
- Rare Disease patients and carer are **4 times** more likely to often feel they could not overcome their problems than the general population

The particularities of rare diseases are detrimental to the mental health of patients and carers

22% need respite care but do not benefit from any

Diagnostic wavering
Unappropriated health assessments
Lack of treatment
Endless explanations



Anxiety
Financial difficulties
Stress
Depression
Loss of confidence and self-esteem

38% need psychological support but do not benefit from any