



JUGGLING CARE AND DAILY LIFE

The balancing act of the rare disease community



A EURORDIS INITIATIVE



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The challenge of working while living with a rare disease

Sandra Courbier, EURORDIS

The difficulty to combine rare diseases and work life

“The worse time, was the time we were looking for a diagnosis. (which took roughly 6 years). It was also the time I had two young children. By asking a year "non paid break" (to pursue my diagnosis journey and to take care of my children, one of them also having similar symptoms) I received a refusal from the employer. So I decided to give up my job and stayed unemployed for 4 years. At least I had the time to find out exactly what disease I had enough energy to take care of my children. Strangely, feeling stronger after the diagnosis and the information about the disease (which my husband I and I sought by ourselves), I decided to pick up work again. One year: part-time and thus earning half as much as before. Later on and until now: working less then a part time and earning even less; but the job is my dream job and I still have a husband who is the main "breadwinner". That's how we manage to make ends meet.»

Female, Luxembourg

- high absence rate at work: 58% were absent more than 15 days a year
- having to make the decision to leave or reduce employment: 13% of parents faced it
- facing the fact that the child is starting school later than average: 23% of parents face it
- difficulty in accessing higher education: 19% declare reported these difficulties

Most rare disease patients remain employed but the disease decreases employment quality

Decrease of employment quality

- 35% part time compared to 17% in the general population
- Interrupted careers

Less fulfilling job careers

- 76% were limited their professional choices
- 67% were limited in being promoted

“ I was studying for a degree in software engineering, and spent a year in industry after the first two years at university. By the end of that year, my mental and physical health both had collapsed and I had no choice but to suspend my studies and move back to my parents' because I wasn't well enough to work or cope on my own. I spent three years applying for every job I thought I had any chance of doing, and over that time went from ambulatory, to a stick, to crutches, and then to a manual and then a powered wheelchair. Every time my disability got more obvious, the look of "oh. you're wasting my time" when I went to an interview got more obvious.»

Other gender, United Kingdom

An unsatisfied request of flexible employment practices

Is/was your current/last work environment specially adapted for you, in terms of:

