Chronic progressive pathologies:
How to maintain people at work

From the disease of work to the disease at work
Extraprofessional pathologies

• Among the workers with extraprofessional pathologies: more and more workers with evolutionary chronic pathologies (cancer, HIV, hepatitis C, multiple sclerosis, diabetes...).

• Almost 20% of the working population is concerned, and this proportion should grow as the working-life time is extended, and as the workforce is ageing.

• These persons affected by chronic evolutionary pathologies do work, but the financial cost, the conditions and the impact of keeping them at work are most of the time underestimated or even unknown.

• Strong impact on work, particularly for women (4th european survey on working conditions).
The « discriminating organization » of work

- The pluri-pathology

- The "discriminating" organization of work
  - Effects on work of the pathology and its treatment

- The multidisciplinary approach :
  - Importance to combine the approach of patients’ associations and healthcare professionals
  - Coordinate actions and create dynamics between the different interlocutors : institutions, employers, healthcare professionals, …
The working conditions of women: less visible and objectivized than those of men

-
Impacts of evolutionary chronic pathologies and their treatment

• **Impact on the person:**
  
  – Tiredness
  – Job loss + difficulties to find another one
  – Difficulties in relation with the disease and its medical treatment (medication, concentration, irritability, tiredness…)
  – Stigmatization
  – Image given

• **Impact on the company:**
  
  – Absenteeism issues
  – Organisation of work
  – Sharing workload with other workers
  – Variable state of health of the person
Evolutionary chronic pathologies: specific effects on women at work

Women affected by this type of diseases have to face a **triple discrimination**:

- Woman / man (gender issues)
- Sick person / able-bodied person
- Disease (no acknowledgement) / disability (acknowledgement)
The approach based on work
Avoiding assumptions

Aims at avoiding the implementation of measures based on a wrong assessment of the activity that could create difficulties at every level (performance, health,…)

Another way to approach work:
the person affected by a chronic disease has to be considered as a common worker
A concrete example: a worker affected by multiple sclerosis

Isabelle M. works as a trainer in a Training institute

Degree of disability: 80%
- Progressive loss of sight: partially sighted person
- Sensory disorders of lower limbs: moves with difficulty
- Suffers from back injuries: problems with carrying heavy objects

Works as a trainer:
- Basic knowledges, job-hunting, socialisation, orientation

Works mornings – therapeutical part-time: Tiredness

Without help from her husband, Isabelle would not be able to work
Tasks that Isabelle needs to do to work

- Drive from her home to her workplace (25 km)
- Carry her business documents
- Get into the Training institute (16 steps to get to her floor)
- Door-to-door advertisement activities
- Prepare her course from home
- Organize the schedule for each trainee
- Move from a group of trainees to another
- …

Within the framework of the project, and using the approach based on her actual work, analysis of the working situations listed below:

- Driving from her home to her workplace
- Carrying business documents
- Getting into the Training institute
- Using IT tools
- Working from her home
Solutions found thanks to the « based on work » approach

• To drive from her home to her workplace:
  → Financial support (specific public founds allowance)
  → Her husband is now employed by a human-services company to drive her to work, park the car, help his wife to orientate herself, accompany her to the reception, prepare the courses, keep schedules, draft minutes

• To carry her business documents:
  → Purchase of a special carrier rolling bag

• To get into her office:
  → Moving to new business premises at street-level is under discussion with the present manager in Bordeaux
Solutions found thanks to the « based on work » approach

• To use the IT tools :

  → Purchase of specific equipment : a video enlarger, a special keyboard with large keypad, a protective equipment against high luminosity,…
  → Tools inside and outside the workplace have been synchronised

• To work from her home :

  → Acknowledgment and financial compensation of the hours spent on working from home
  → Consideration about the implementation of teleworking
  → Purchase of a specific seat adapted to Isabelle’s morphology (the same seat has been bought for her office)
People in charge of Isabelle

• **Medical environment**: company doctor, family doctor, specialists, functional physiotherapist, occupational therapist, social worker, nurse, …

• **Workplace**: employer, other employees, colleagues, H+S committee, unions, …

• **Institutions and social environment**: local authorities in charge of healthcare, patient associations, ARACT, her husband and relatives…

**All these people have to work together and have to be parts of the project management**
Conditions required for the approach to succeed

- Will and agreement of the worker affected by a chronic disease
- Will of the management within the company
- Implication of all the people involved in the action (company doctor, healthcare professionnals,…) to reach a common goal
- Considerations around organizational matters
Chronic progressive pathologies:
How to maintain people at work

Thank you for your attention