



## Chronic progressive pathologies : How to maintain people at work

From the disease of work to the disease at work



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## 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

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# 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 funds 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 professionals,...) to reach a common goal
- Considerations around organizational matters



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Thank you for your attention