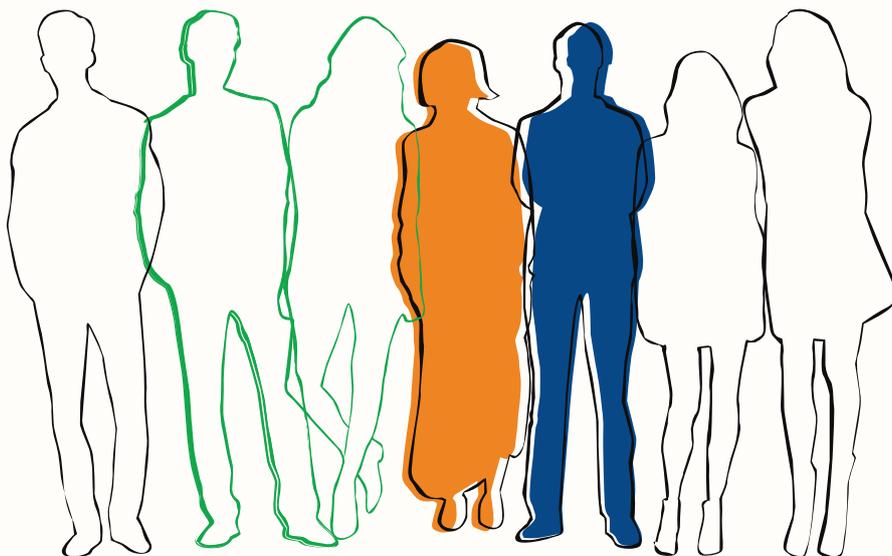


# INCLUSION OF PEOPLE WITH CHRONIC DISEASES IN THE WORKPLACE



How to foster  
inclusive work places

# 1. People with chronic conditions, employment and discrimination

## What is discrimination in the workplace?

**Discrimination** occurs when one person is treated less favourably than another is, has been, or would be treated in a comparable situation, based on a particular characteristic they hold or when an apparently neutral provision, criterion, or practice would put one person at a particular disadvantage compared with other persons.

**Stigma** occurs when certain differences (or imagined differences) are labelled or pointed out and given negative associations.

In the EPF project EMPATHY “Europe Meets Young Patients”, funded under the Youth in Action Programme, young patients identified discrimination and stigma in education and the workplace as important obstacles they face, regardless of their nationalities or conditions.

### Facts and figures:

**Diabetes:** In 2013, The French Federation of Diabetes Patients carried out a survey that showed a person living with diabetes is **4 times more likely to be excluded from their working environment** due to their condition. Ignorance and a lack of understanding of diabetes has been identified as a root cause of discrimination and as the principal obstacle for the employment of people with diabetes.

**Chronic pain** and neurological conditions: Current evidence shows that only **4 in 10 people with chronic pain say they receive enough support from their employers** to manage their job. Chronic pain results in more than 500 million sick days in Europe, costing the European economy more than €34 billion.

In a recent survey of German patients with myasthenia gravis (a neurological condition), 8% reported it impacted their choice of job, 21% experienced hardships in their job, and 28% were forced to retire early.

**Musculoskeletal disorders:** Over 40 million EU workers have musculoskeletal disorders caused by their work; representing almost 50% of all absences from work of three days or more.

**Rare diseases:** In the EURORDIS Care Survey which targeted 12 000 families from 23 countries (2002-2008), 1/3 of the respondents reported that a patient in their family had to reduce or stop professional activities due to the disease; an additional third reported that one member in the family had to reduce or stop professional activities to take care of a relative with a rare disease.

In the ENSERio Study performed in Spain (2009) – 32% of patients reported they feel discriminated against in the labour market, either when searching for a job (17%) or in their current job (15%).

**Mental health:** Work-related stress is the second most reported work-related health problem in Europe. Around half of European workers consider it to be common in their workplace. Unrecognised mental ill health which does not result in sickness absence is much more costly than days lost through people taking time off work. 79% of European managers are concerned about stress in their workplaces but less than 30% of workplaces in Europe have procedures for dealing with it.

“When I went to see them, I sat there, and my head was totally twisted to the left. The health insurance officer gave me a cold look and said to me, “If you turn your left side of your body towards the desk you can write on the computer”. My eyes filled with tears, I remember feeling so hurt and misunderstood. She doesn't know anything about what it feels like not being able to control your movements the way you want, I thought. There is nothing else I would like than being able to hold my head straight and go to work.”  
(Swedish patient with cervical dystonia)

## 2. Patients' experience of discrimination in the workplace

- In the workplace, people with chronic conditions often face **low levels of awareness about living with and managing a chronic condition** from their employers.

- Employers often **underestimate the abilities of people with chronic conditions to continue working**, resulting in stigma, while work can be very positive for the recovery process of a person with mental ill health for example. They may have (unfounded) concerns about costs, productivity, and absences.

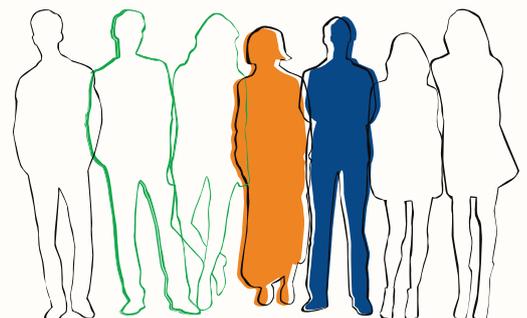
- **Because of negative perceptions**, people with chronic conditions may not **disclose** their condition or may not ask for the necessary **adaptations**. Disclosing the illness is often sensitive for people with chronic conditions as there is stigma attached to chronic conditions and lack of awareness that people with chronic conditions can continue to work. Chronic conditions may also sometimes be considered as a private matter by people with chronic conditions or/and employers. In the context of mental health, the fact of not disclosing can also lead to the mental health problem getting much worse and may eventually lead to a longer sick-leave absence as well, to the detriment of as well the employee and the employer. The work place should allow for a climate where mental health can be discussed in a safe environment.

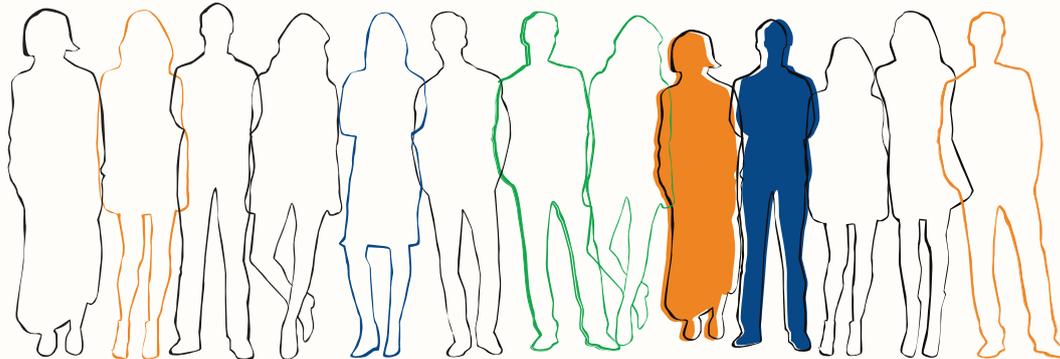
- Disclosing the condition to the employer may open the rights of people with chronic conditions to **accommodation and appropriate adjustment**. Article 5 of the EU Employment Equality Framework Directive specifies that employers must take appropriate measures where needed in a particular case, to enable a person with a disability to have access to, participate in and, advance in employment, or to undergo training.

- People with chronic conditions may face **stigma and discriminatory** attitudes from employers or colleagues, such as inappropriate disclosure of their condition, lack of support when returning to work after sick leave, or even difficulties after a long-term absence (e.g. some people with chronic conditions are “side-lined”).

People with MS often have difficulties due to the fluctuating nature of the condition and employers wanting certainty (even though there is no such thing!) without preparing the business to effectively manage absence.”  
Patient representative, Multiple Sclerosis

The Eurofound study on employment opportunities for people with chronic conditions shows that they may have more difficulties obtaining training opportunities and promotion.





- People with chronic conditions can face discrimination during **interviews** if they disclose their condition. They may be discriminated against through mandatory medical examinations. There is a misconception that they may be unable to work, when they may be, sometimes with only minor adjustments.
- **Returning to work after a sick leave** has also been flagged as important by patient organisations, and it was documented by the OECD. In 2014, the French Cancer League indicated that 2 years after diagnosis, 1 in 3 people lose or quit their job, mostly due to discrimination and stigma or simply due to a lack of return to work policies. Having a sound return to work procedure is essential for employees after a long-term absence, helping to prevent prolonged sick leaves, lower job quality, or even long-term unemployment. Flexible solutions like part-time sick leave implemented in Sweden, have been flagged as beneficial by patient organisations.
- Patients' health status and their difficulties to remain at work may affect the working situation of their family **carers**. Caring may lead to difficulties balancing paid work with care responsibilities.
- With **adequate support** people with chronic conditions can work, resulting in a hugely improved quality of life that minimises the negative financial impact of chronic illness and the risk of social exclusion. For people with chronic conditions and informal / family carers, the value of staying at work goes beyond providing financial stability.

“ MP has so many medical appointments, and therapy sessions each week that I had to stop working. I have only 4 hours free to come back home, do the cleaning, cook, go to supermarket, deal with the infinite bureaucratic processes that we have to deal with to get a special school and special social assistance and support. Then, I pick him up again, come back home and accompany him in all the exercises his therapist has given him. I go to bed exhausted and I don't get a lot of help at home. I'm an architect, I loved my work and I miss it a lot! At this moment, it is impossible for me to find a job

Sandra, mother of MP, 3 years old, living with Congenital Disorder of Glycosylation, Spain (provided by EURORDIS)

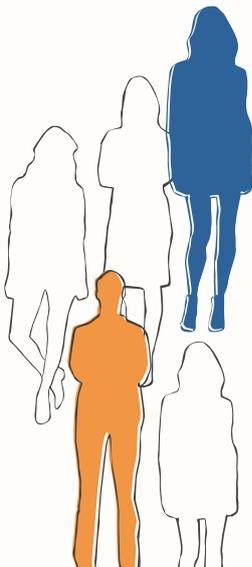
# 3. The business case for inclusive workplaces

## Inclusive work places - what are the benefits for employers?

Employers benefit from preserving their employees' capacity to work and retaining their staff, thus reducing the associated cost of health insurance and maintaining the productivity of their workforce.

For employers, the benefits of hiring and retaining employees with chronic conditions are multiple:

- it shows the employer **values diversity and inclusion**, which are part of a well-functioning company.
- It results in **higher motivation and commitment** of the employees and better productivity.
- It ensures that the company **retains skilled** staff and spares additional costs of recruitment and training.
- Inclusive hiring policies show the company is taking **responsibility for its impact on society** and according to the European Commission, such policies provide important benefits to companies in risk management, cost savings, access to capital, customer relationships, HR management, and their ability to innovate.



## How should employers create and foster inclusive and supportive workplaces for people with chronic conditions?

- By implementing policies for **prevention, workplace adjustment, accommodations, and return to work**, building on existing good practices. More research in this area is needed in the EU and good practices should be evaluated with the participation of relevant stakeholders, including people with chronic conditions.
- By **encouraging work-life balance and flexible working hours** as part of workplace accommodations. Flexible working arrangements in favour of employees are directly related to a higher commitment from and lower stress for workers and, consequently, indirectly decrease the costs that companies and employers may incur due to work-life conflict.
- By implementing policies aiming at ensuring **equal treatment in employment should involve patients** and their organisations in order to ensure they meet patients' needs.
- By implementing measures towards creating **inclusive work places**, offering an enabling environment for discussing benefits of diversity and health, including mental health; as well as awareness-raising for society at large.
- By providing **training on equal treatment in employment and non-discrimination** at the workplace of all staff.

According to the UN Convention on the Rights of People with Disabilities (UN CRPD), which has been ratified by the EU and 27 MSs, "**Reasonable accommodation**" means necessary and appropriate modification and adjustments not imposing a disproportionate or undue burden, where needed in a particular case, to ensure to persons with disabilities the enjoyment or exercise on an equal basis with others of all human rights and fundamental freedoms.

**Examples** of such adjustments could include:

- shorter or flexible working hours
- ensuring easy access to the building and/or office
- working from home
- allowing time for medical appointments
- offering another position within the company (accompanied by training for the new position)
- unlimited toilet breaks

· By offering **professional reorientation** for people with chronic conditions who cannot continue to work in their current job because of their health status;

· By participating in **case reviews or discussions** involving the employer, the employee, and external advisors (medical, insurance, health and safety officers...) which would be crucial for people with chronic conditions who may need to retire early or quit work due to their condition;

· By encouraging Member States to provide **one-stop-shop websites to inform employers and employees** about the rights of people with chronic conditions at work. Employers need more information regarding the types of reasonable adjustments that can be made to support people with chronic conditions to stay in work. This will help reduce the number of people with chronic conditions leaving employment as a result of functional limitations and to help overcome any discrimination that may be experienced in the workplace;

· By instilling policies which **maintain employability and adaptability**, which are among the most effective ways of enabling the extension of working lives and supporting internal and external flexibility for workers. This has three interlinked facets: Maintaining high levels of motivation; Safeguarding health and safety at the workplace and Ensuring productivity and adaptability by updating skills throughout an individual's working career.

· By benefiting from support schemes available to employers, such as the European Social Fund (ESF) which can provide **funding towards the costs of modifications or special equipment** that will allow a person with a condition to take up an offer of employment or to remain in employment. These funds are often not used. Employers must campaign to ensure Member States understand and implement employment policy - highlighting availability of EU Social Funds to retain, rehabilitate and reintegrate people with chronic conditions and caregivers. Furthermore, in some EU countries there are a number of **support schemes available to employers** if a member of staff acquires a chronic illness or disability or if a new staff member is hired who has a chronic illness or disability.



# 4. Get inspired

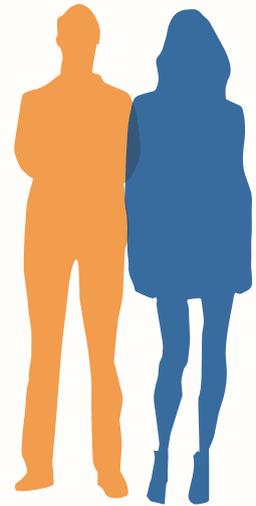
## Good practices

In 2016, the European Agency for Safety and Health at Work - **EU OSHA**, carried out a study on 'Rehabilitation and return to work: Analysis report on EU and MSs policies, strategies and programmes'. The results of this study - which highlights a number of elements around why certain national systems for rehabilitation and return-to-work are more successful than others - should be further disseminate and promoted.

In the context of its 2016-2017 campaign on health workplaces for all ages, EU OSHA has developed a healthy workplaces good practice awards initiative to highlight leading examples of organisations actively managing safety and health at work in the context of an ageing workforce. This publication is available in all EU languages.

There are many examples of good practice which could be applied more widely in Europe. Below are some existing examples.

- In **Austria** there is a programme called 'fit2work' which is a free-of-charge consulting service for employees whose job is endangered due to health problems; or for persons who have difficulties finding employment due to their health condition. The aim of the programme is to prevent morbidity and disablement and thus an early exit from the labour market. The programme is open for individuals in work, for the unemployed and for companies. This is an example of excellent practise which could be increased across Europe.
- In **Austria's** sickness funds and employers insurance's 'Social Coaching' programme employs a high number of people with chronic illness. Three main activities are offered to manage resulting challenges: return-to-work talks, evaluation and adaptation of the workplace. These measures are not only limited to people with physical disabilities but were also created for people with mental problems or employees who had stayed absent for a longer period of time due to long-time sickness.
- The Workplace/ Equipment Adaptation Scheme in **Ireland** allows an employer to get a grant towards the cost of adapting the workplace or buying equipment. The Employee Retention Grant Scheme can help to retain an employee who has acquired an illness, condition or impairment that affects their ability to carry out their job. The Disability Awareness Training Scheme is open to all companies in the private sector. Disability awareness training can help your staff provide the best service to customers or clients with disabilities and ensures that they also develop and maintain good working relationships with colleagues with disabilities.



Data from the European Working Conditions Survey 2010 suggests that **employment rates of older workers** and their perceived ability to stay working up to the age of retirement are **sensitive to indicators of adaptation in the workplace**, including strong health and safety provisions. In addition to existing requirements for employers to carry out risk assessment and to address any physical or psycho-social health risks, some Member States (e.g. Finland, France, Ireland, Portugal, UK) have also acted to develop **comprehensive systems to support such health and safety strategies**. However, such policies, as well as supports for workplace adaptations remain under-developed. The same is true for public supports to adapt workplaces to meet the requirements of workers with diminished work ability..

- **Finland** offers all employees with long-term illnesses the opportunity to work part-time.
- **'Place and Train models'** such as individual placement or support for persons with more severe mental health problems, is consistent with a social work perspective, which rapidly place people with mental health problems in real-world settings, so they can experience the benefits, as well as the challenges of these situations, and then provide the necessary training and support to successfully maintain these placements. Th place-train approaches can help people with serious mental illness attain many of their work and housing goals without increasing the frequency of relapse.

- The German car manufacturers BMW employed a research team to collect information from a group of employees on all the aches and pains they experienced on the job, as well as suggestions on how conditions might be improved to reduce or eliminate these. None of the innovations were huge: they included items such as softer flooring, adjustable worktables, easy exercises and lighter work shoes. The health implications were, however, dramatic. Absenteeism due to sick leave dropped from 7% to 2%. The company also benefited financially. Although the speed of the line was reduced by one-third, productivity increased by 7% and had an almost zero error rate. BMW is rolling out the changes – and researching new ones – across all its Bavarian plants.
- At BOGESTRA, **public transport sector in Germany**, health management is integrated into wider organisational management to ensure that working conditions and processes are designed to minimise health and safety risks. The key priorities are prevention, early detection and reintegration. As part of this process, strong emphasis is placed on the ongoing improvement of workplace design. This includes, for example, the involvement of drivers in the design of new transport vehicles to ensure that drivers' seats offer the greatest possible comfort and flexibility. In recognition of the fact that certain jobs are difficult for individuals to perform over a working lifetime and up to retirement age, BOGESTRA has developed the concept of “dual jobs” which allow individual employees to combine their job with other tasks in maintenance or administration if – for health reasons – they are unable to perform their primary job on a full-time basis.

## Further guidance for employers

- The European Multiple Sclerosis Platform (EMSP) has developed a **practical toolkit for employers** which guides businesses to enhance or build their policies in terms of recruitment, attendance management and return-to-work procedures.
- Mental Health Europe (MHE) has developed: an **infographic on positive mental health in the workplace**, which looks at how to foster mentally healthy workplaces; a **video on reasonable accommodations** and the UN CRPD; and a **toolkit on article 27 of the UN CRPD**.
- The European Men's Health Forum (EMHF) **guide for men about working with cancer**. A video is also available.
- EPF has developed a **position paper on equal treatment for patients in education and employment**, which aims to engage important stakeholders, including employers, to break down the barriers that people with chronic conditions encounter on the labour market.
- The Fit for Work global alliance has developed an **Early Intervention toolkit** and **publication** which explores the benefits of Early Interventions which help people with chronic illness remain in work.
- FitForWork UK has developed an **online platform with advice for employers**, containing information about health at work including workplace adjustments, as well as a helpline.
- The International Labour Organization (ILO) has developed a **practical guide on promoting diversity and inclusion through workplace adjustments**, which includes tips for how to address mental health in the workplace and disclosure of mental health problems.
- The European Network for Workplace Health Promotion (ENWHP) has developed a **guide to good practice on promoting healthy work for workers with chronic illness**, primarily aimed at employers and managers who are faced with the challenges and opportunities of managing workers with chronic illness and supporting them to stay at work; or to assist in the process of returning to work after a period of absence. ENWHP has also developed a **campaign on promoting healthy work for employees with chronic illness and collection of models of good practice**.
- The UK Trade Union Confederation has developed a **guide** for workplace representatives **on the health and safety of older workers**.

