



Managing people with chronic diseases in the work environment

A practical guide for companies and employers



PLATAFORMA DE ORGANIZACIONES DE PACIENTES



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Introduction

Most people who have a life-long chronic disease are able and willing to work. Even so, being able to work is one of the major concerns and reasons why these people consult patient organizations. Unemployment or dismissal have a greater impact on people with a chronic disease.

Being involved in the workplace allows a better quality of life, since feeling active and productive benefits both physical and mental health. Companies, employers and workers must find the best way for the employee with chronic disease to develop their talents for the benefit of all.

A variety of resources and tools have been designed for companies and workplace managers to contribute to the promotion and improvement of health in the work environment, as well as the prevention of work-related diseases. However, the inclusion of people with chronic diseases in the workplace has not evolved to the same extent.

Therefore, it is necessary to create tools that favour inclusive working conditions to ensure that people with chronic health conditions can maintain their employment under equal conditions, as well as full marketplace accessibility in environments free from obstacles that could lead to dropping out of work or losing one's employment.



In this scenario, the Platform of Patients' Organizations and the Malta Health Network, non-profit organizations representing people with chronic disease in Spain and Malta respectively, consider necessary giving visibility to the situation of people living with a chronic disease and contributing to their full social and labour-market inclusion. To this end, they have developed this guide aimed at companies and employers.

The guide “The management of people with chronic disease in the workplace” has a dual purpose of: on the one hand, informing companies about the impact of chronicity

on employment and the needs of people living with chronic disease in the workplace and, on the other, guiding them on implementable adjustments to help promote the inclusion of people with chronic disease in the workplace.

More specifically, the purpose of the guide is informing companies and employers about:

The impact of chronic diseases in the workplace.

The needs of people with chronic diseases to achieve their inclusion into work teams.

The emotional and social impact produced by changes in the work environment as a consequence of chronic diseases.

The necessary tools to adapt and make work conditions and jobs more flexible to the particular needs of people with chronic conditions.

Methodology

This guide was developed with the direct participation of people with chronic disease, members of associations affiliated to the Platform of Patients' Organizations and the Malta Health Network (MHN).

The information and recommendations included in this guide have been extracted from two virtual focus groups carried out on May 30th and July 14th in 2022 with people affected by different pathologies or chronic symptoms living in Spain and Malta, facilitated by expert researchers.

A total of 16 people affected by different chronic pathologies* (8 in each focus group) who were recruited on a voluntary basis and met the following criteria participated in these sessions:

- Have been diagnosed with one or more chronic pathologies.
- Are between 18 and 66 years old.
- Are actively employed (working in a paid job, or actively seeking employment).
- Have at least 2 years of work experience.

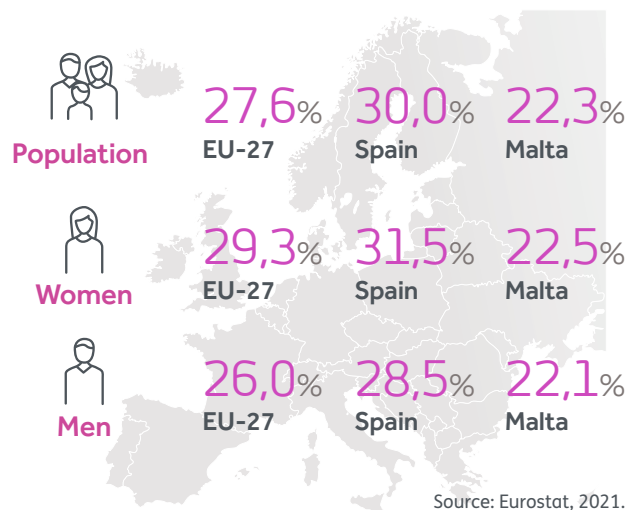
In addition, bibliography and official public sources have been consulted for the different sections included in this guide.

*Rheumatoid arthritis, metastatic breast cancer, chronic depression, type 2 diabetes mellitus, Crohn's disease, rare disease, epilepsy, multiple sclerosis, fibromyalgia, stroke, spinal cord injury, migraine, butterfly skin, multiple chemical sensitivity, bipolar disorder, HIV.

Chronic diseases and their impact on quality of life

In Europe, one in three people aged 16 to 64 years old (working population) has a long-term chronic disease or health problem. By gender, the percentage of women with a chronic disease is higher than that of men¹.

People with a long-standing chronic disease or health problem aged 16 to 64 years old (2021)



Source: Eurostat, 2021.

The World Health Organization (WHO)² considers chronic diseases as “those diseases that have a long duration (more than 6 months) and a slow progression, are not transmitted from person to person and are therefore considered to be non-communicable”. They are the result of a combination of genetic, physiological, environmental, and behavioural factors. The four most relevant types are cardiovascular diseases, cancer, respiratory diseases, and diabetes.

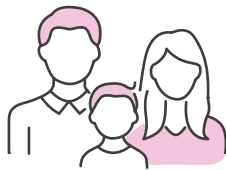
Chronic or not, any disease has negative effects. In a situation of chronicity, people and their families must live with these effects all their lives, if society as a whole and the health, social, educational or employment systems do not provide sufficient support.

Beyond health, having a chronic disease has an impact on all spheres of a person’s life: emotional, family, social and occupational.

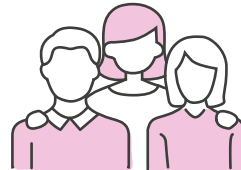
Chronic disease’s impact



Emotional



Family



Social



Occupational

The diagnosis of an illness generates an emotional impact on people. When the disease arrives, people tend to think that life will no longer be the same, that they will not be able to carry out the same activities, will need help from another person, will not be able to contribute to the family’s well-being, etc. This impact manifests itself more strongly if the disease becomes more acute, worsens over time³.

Being emotionally well also depends on the ability to maintain social and family relationships, as well as job stability.

The disease is experienced in the family unit. People with the disease and their families must learn to adapt family situations to the needs of the disease, for example, carrying out household chores, childcare or vacation planning. These changes can have an impact on the person, who tends to be more irritable with the family or think that they are or can be a burden to the family. If the disease involves moderate or severe disability, the family usually plays the role of caregiver.

30%

of people request information about the possibility of requesting legal permanent

20%

of queries belong to patients who do not want to lose their current job

The situation of chronicity also affects social relationships. Either because of the disease itself or because of the emotional impact it generates. People tend to go out less to avoid isolation due to their friends' planning activities without taking into account their needs or limitations.

Chronicity is a health problem that not only affects the clinical, emotional, and social level, but also has implications in the labour sphere because of the symptoms and functional limitations that can interfere work activities, professional development, and access to job opportunities.

Possible consequences on their work performance, such as layoffs or lack of adaptations or changes in the workplace are among the main concerns arising from people with chronic disease⁴.

An analysis of the queries received by the Platform of Patients' Organizations⁵ concludes that 30% of people request information about the possibility of requesting legal permanent disability, due to the impact of the disease on their ability to continue in their job. These are usually a result of symptomatology with an unfavourable prognosis and is not expected to improve over time. In these queries, patients express their inability to continue working and seek social protection.

Another 20% of queries belong to patients who do not want to lose their current job but need their limitations to be taken into account. Thus, they seek information on requesting an adaptation of the job or even a change of working position.

In any case, there is great concern about the possibility that the situation could lead to objective dismissal for being considered legally unfit for the job*.

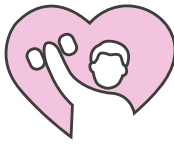
* Objective dismissal for being considered legally unfit for the job, in Spanish legislation, means when a person hired for a position and having performed it satisfactorily for a while, no longer has the skills or competencies to continue exercising it. The circumstances must originate from the worker, being beyond their control, after the trial period, true, permanent, and affecting the essential tasks of their work.

Health promotion in the workplace

According to a report by the World Health Organization⁵, the health, safety and well-being of workers are of fundamental importance for the workers themselves and their families, along with the productivity, competitiveness and sustainability of companies.

Implementing and developing health promotion programs in the workplace is beneficial for improving the work environment, corporate image, staff motivation and productivity.

Health promotion and chronic disease prevention programs in the workplace may include aspects linked to physical, psychological, and social well-being⁶ such as:



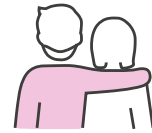
Physical well-being

- Physical exercise
- Nutritionist
- Healthy menus
- Reduction in tobacco and alcohol use



Mental well-being

- Healthy sleep
- Stress management
- Addiction control, including tobacco, alcohol and other drugs
- Fight against mobbing



Social well-being

- Volunteering
- Remote working
- Flexible hours work
- Internal cohesion

We recommend you consult the CHRODIS PLUS⁷ Workplace Toolkit, a toolkit for the promotion of health, well-being, and participation in the workplace.

[Access to the kit](#)

These programs are being implemented progressively, to a greater or lesser extent, depending on the resources available, but also on the values and corporate social responsibility of companies.



Similarly, it is necessary for society, companies/employers, and workers to join forces to incorporate specific actions to protect people who have a chronic disease. Addressing chronic diseases in the workplace will lead to stronger economic growth, more profitable employment, less dependence on government funds, fewer demands on healthcare systems and higher productivity.

Chronic diseases in the work environment

—○ Protection and benefits for employers and workers

There is no specific regulatory framework that covers the obligations and benefits of companies regarding people with chronic diseases. Nor do they have a specific protection framework in any area. The rights and obligations are the same as those of other employees, i.e., they can request leave for medical appointments, take sick leave and receive benefits during this leave.

At this point, it is worth noting the recognition of a disability requires administrative recognition, but an administrative recognition of chronicity does not exist. There is a relationship between chronicity and disability, but they are not the same. Many chronic diseases can also lead to disability, due to their evolution or their associated symptoms (multiple sclerosis, stroke, etc.); and some people with disabilities can develop chronic health problems as a result of their situation (cerebral palsy, etc.).

Both in Spain and in Malta, the regulatory framework that sets out the obligations and benefits of companies in this area is the “Disability/ Equal Opportunities Act”.

- In Spain, public and private companies with more than 50 employees must have at least 2% of their workforce conformed by people with disabilities.
- In Malta, the regulation applies to companies with more than 20 employees and the percentage of disabled people in the workforce must also be at least 2%.

In both countries there are alternative measures for companies.

- Spain: purchase of goods or services from a special employment centre or donate or sponsor actions to public utility associations or foundations whose objective is the employability of people with disabilities.
- Malta: annual contribution of €2,400 for each person with a disability who is to form part of the company’s workforce, with a maximum of €10,000.

In both countries, the hiring of people with recognized disabilities has social benefits for companies.

- Consult for Spain: Servicio Público de Empleo Estatal (Spanish Public Employment Service).
- Consult for Malta: Jobsplus.

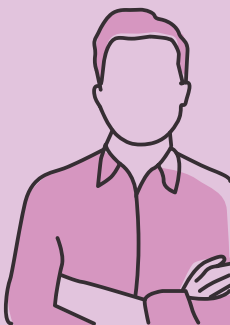


—○ Communication of the chronicity situation

Everyone should have an equal opportunity of employment access. When a person has a chronic diseases, they find themselves in a dilemma before a selection process. On the one hand, they want to maintain their right to privacy about their health condition and, consequently, is free not to report their health condition in the recruitment process. On the other hand, they strongly believe in their right to non-discrimination on health grounds and communicates it.

When the diagnosis takes place, there is a double life-impact, as the person must face what it means to live with a disease all their life, along with the uncertainty of communicating it or not and the possible consequences that may follow.

The main concern is losing their job, as well as having difficulties attending medical appointments. In addition, most of them also face the stigma that may arise from the lack of understanding of their situation by co-workers.



“I attended countless job interviews where I was not hired, because in order to explain why I didn’t have a driver’s license I had to tell my diagnosis.”

(Person with epilepsy and bipolar disorder)



“After communicating my diagnosis to my company, they did not consider adapting the position and directly fired me days after requesting a sick leave.”

(Person with lupus)

Ultimately, the communication of a chronic disease or condition can have a significant impact on the employment situation of the people who suffer from it, for various reasons:

Difficulties accessing employment when the communication of the diagnosis is mandatory during the selection process because the pathology may interfere with job performance.

Voluntary resignation from employment due to the limitations and consequences of the disease in the workplace or the lack of adaptation of the position (symptoms, incapacity for work / disability...).

Difficulties in requesting the necessary permission to attend follow-up medical consultations.

Reduced work productivity or performance as a result of the symptomatology and impact of the disease.

Dismissal due to the inadequacy of the job position to the particular needs of employees with a chronic pathology, which prevent adequate job performance.

The day to day at work

People with chronic disease face challenges in their daily work activities hindering their disease management (symptoms, outbreaks or treatments' side effects) and can have a negative impact on job performance and on the relationship with employers and co-workers.

Lack of empathy and knowledge from companies and employees on the reality and needs of people with chronic disease, which often results in:

- Trivialization of the impact of chronicity on work performance, especially regarding pathologies with invisible symptoms (such as fibromyalgia and migraine, among others).



“Some colleagues ask me how is it possible to be on sick leave because of a headache.”

(Person with chronic migraine)

- Lack of understanding of the social and medical requirements in workplace adaptations.



“My co-workers don’t understand that I can be very tired after only two hours of work.”

(Person with fibromyalgia)

Colleague rejection of people with infectious conditions, such as HIV, because of the stigma and fear associated with it.

Patronizing attitudes that lead to infantilization of those living with a chronic disease by their work environment, and specifically in the case of people with physical disabilities.



“When you are a subject with full rights to receive care, it is very complicated to be accepted as a whole person, capable of doing things, even if it is with help.”

(Person with spinal cord injury)

Lack of training of managers and employers on workplace adaptations for people with chronic health’ specific needs.

Architectural barriers (deficit of workplace adaptation and accessibility) usually faced by people with functional diversity, preventing them from applying for certain jobs.

Lack of adjustments to the job and working conditions, often leading to a reduction in work performance and worsening health of the people affected.



“By making my schedule more flexible, I could perform my job without any problems, because I feel better in the morning”

(Person with fibromyalgia)

Emotional impact

The chronic disease itself, as well as the impact it generates in the workplace affects the emotional state of people who live with it and may appear in the form of frustration, worry, anxiety and guilt:

Frustration as a consequence of the impossibility or develop day to day work activities, as along with the need to depend on the assistance of third parties to perform certain work tasks.



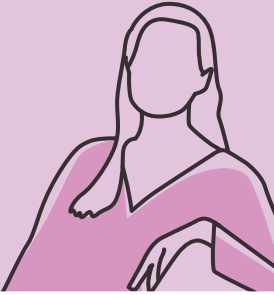
“I’ve had to accept that there are certain tasks that I will no longer be able to do, even if they are the ones in which I have the most experience. I have even considered quitting my job.”

(Person with chronic migraine)

Concern on the reorienting the professional career and accessing new work sectors.

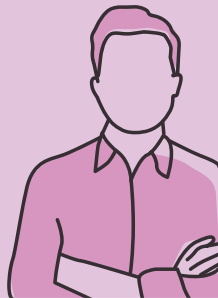
Anxiety about the consequences of communicating the diagnosis in the company and about the lack of adjustments preventing personal fulfilment through work, often trivialized in work environments.

Guilt for requiring days off work or for having a lower work performance, aggravated by the lack of empathy, and understanding from co-workers and employers about their special needs.



“Hiding the diagnosis and its consequences from the company created a lot of anxiety for me. I was forced to keep lying so that I could go to medical appointments.”

(Person with cerebrovascular disease)



“I cannot work normally due to the lack of adaptation of my working conditions to my disease. I depend on the voluntariness of my colleagues if I want to develop professionally.”

(Person with multiple chemical sensitivity)

Thus, people affected by chronic health problems often require psychological care as a result of the impact of the disease.

On the other hand, the lack of adjustment in the workplace leads to a worsening of the symptoms in different pathologies (such as pain, fatigue, difficulty concentrating, etc.), which can repercuss not only on work activities, but on the ability to participate in leisure activities and social interactions.

Companies and employers can contribute, with specific actions or plans, to a better talent management. Having multidisciplinary work-oriented programs for people with chronic diseases reduces sickness absence. In addition, cognitive-behavioural intervention programs have shown positive results on work performance and sick leave reduction. Coaching has also been proved to be effective in self-management of illness and improving perceptions of work ability and fatigue⁸.

The role of companies and employers managing people with chronic health needs

The workplace is where people spend most of their time. Consequently, work directly affects people's health, which in turn affects worker productivity. It comes to no surprise that companies want to promote a healthy lifestyle and contribute to improving health among their workers. The survival of companies and by extension the economy of countries depends on a motivated and healthy workforce.

When workers have chronic health needs, employers and human resources managers are responsible in making the inclusion of these people in their work environment effective. To make this possible, it is necessary to transform the way companies address chronic health needs in their work teams.

● Advantages for employee with chronic disease

- Positive impact on their emotional health, as they feel valued and cared for by the company. It can also improve their disease.
- Economic advantage for the worker, lessening income reduction. Economic stability is, in turn, a contributing factor to their quality of life.
- Improves the beginning and development of their professional career without obstacles.
- Generates confidence, ensuring that a chronic disease is not always a barrier.

● Advantages for companies

- Generates a positive work environment in which employees enjoy their work and are more motivated.
- Reduces absenteeism and sick leave, fewer workdays are lost.
- Gains a competitive advantage through a boost in productivity.
- Retains the talent (experience and knowledge) of employees with chronic disease.
- Reduces health care costs and avoids costs for dismissal and for hiring and training a new candidate.
- Avoids legal costs of potential litigation with workers.
- Generates a more responsible and aware image of the company with groups at risk of social exclusion.
- Increases workers' commitment to the company's values.

Proposals to improve the management of people with chronic disease

Taking care of workers' health is not conditioned to the size, resources or type of company. The following proposals can be applicable to self-employed people who hire other people, to SMEs and to large companies.

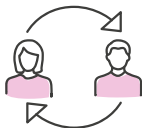
Just one of this measure can be developed, some of them might already be in place, gradually incorporating others. The main goal is to establish a health care policy, including chronic diseases.



Raise awareness with talks and briefings to employers on most prevalent diseases. Patient organizations can be an ally in this activity.



Integrate the figure of an expert chronic mentor or tutor to promote communication between employers and people with chronic diseases. This position can also be assumed by the employer or another worker.



Encourage position adaptations, for employees with difficulties in their day-to-day job but could play another position in the company.



Implement work flexibility measures such as remote working, flexible working hours or extra breaks on the working day.



Allow reductions of working hours, for people with performing their job because of their diseases.



Establish technical adaptations in work conditions: space, lighting, acoustics, equipment, and furniture.



Eliminate physical and architectural barriers that hinder mobility.

How to start

STEP

1

Identify who needs help.

Human resources (HR) departments must help their workers with chronic health needs. In cases of non-visible chronic diseases, if the worker has not communicated it, it is difficult to anticipate their needs, but this is not the case when a worker has been absent for a long time on a sick leave.

STEP

2

Improve communication.

As previously stated, some workers with non-visible chronic diseases hide their disease in fear of consequences (dismissal or stigmatization). Employers or HR managers should generate spaces of trust and sincere communication with their workers, helping them talk about their condition.

For example, when a worker is on sick leave (long or regular sick-leave), the company should contact them on writing, by telephone or in person. It is important to show interest and build trust in their employers. A climate of trust and honest communication will facilitate collaboration between the company and the employee.

STEP

3

Meet privately and communicate the company's intentions.

Hold a private meeting with the employee outside of work to address chronic health needs. The objective is to inform about the company's policies on chronic health needs and cooperate with the worker in defining implementable actions to address their needs. Above all, it must be ensured that the employee consents to these aspects regarding their privacy.

STEP

4

Assess specific health needs.

If the employee consents and cooperates with the company in addressing their chronic health needs, the goal is to assess the extent of their diseases. To this end, the company can offer a medical assessment to help establish the impact of the disease in work performance (provided that the protection of personal data is not violated). A medical assessment can help the company define actions that meet their specific health needs.

STEP

5

Define an action plan.

The company and employee can define and agree on a support program for the chronic disease management in the workplace. This program should clearly convey the agreements and commitments of both parties.

STEP

6

Review the implementation of the plan.

It will be necessary to pay attention to the worker's health to see if it has improved with the implemented actions. This will require periodic meetings or interviews to obtain valuable information on progress and or difficulties.

Role of patient organizations

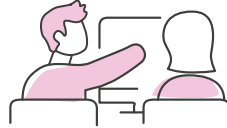
Patient organizations are an essential social and community agent in society. Founded by patients themselves and their families, they support patients from the diagnosis and throughout their life process. This implies developing actions covering all the needs and complement care received by public systems. These actions take form of information and awareness-raising services, training, social and psychological care, physical rehabilitation therapies or day and residential centres, among others.

In addition, patient organizations carry out other necessary actions that help people with chronic diseases to achieve a good quality of life in all areas: physical, emotional, social, and occupational.

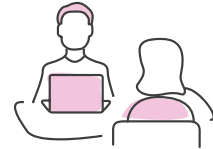
In the workplace, many organizations offer information and counselling services to companies and employers:



Information and awareness days on chronic diseases for employers and employees.



Counselling employees on communicating the diagnosis to the company.



Advice employers on workplace adaptation.

The Platform for Patients' Organizations (POP) is integrated by 35 state-level patient organizations in Spain for the following diseases or chronic health conditions:

- Autism spectrum disorder
- Oncological diseases
- Immune-mediated inflammatory diseases
- Neurological diseases
- Rare diseases
- Cardiopathies and other circulatory diseases
- Kidney disease
- Liver disease
- Kidney, liver, lung, and heart transplant recipients
- HIV/AIDS
- Spinal cord injury
- Brain damage
- Celiac disease
- Respiratory diseases

The Malta Health Network (MHN), brings together 40 health related organisations including patient organizations representing the following diseases:

- Attention Deficit Hyperactivity Disorder
- Breast Cancer
- Arthritis & Rheumatism
- Congenital Heart Conditions
- Epilepsy
- Coeliacs
- Crohn's and Colitis
- Mental Health
- Congenital Hearing Loss
- Colorectal Cancer
- Dementia
- Diabetes
- Eczema
- Acquired Heart problems
- Obesity
- Osteoporosis
- Multiple Sclerosis
- Rare Diseases
- Transplanted people

If you need help you can contact POP or MHN or directly one of its member associations. Information is available on their websites:

plataformadepacientes.org

maltahealthnetwork.org

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Applicable regulations

Spain

- Royal Legislative Decree 1/1994, of June 20, which approves the Consolidated Text of the General Law on Social Security.
- Royal Legislative Decree 1/1995, of March 24, which approves the Consolidated Text of the Workers' Statute Act.
- Act 62/2003, of December 30, on fiscal, administrative and social order measures.
- Act 3/2012, of July 6, on urgent measures to reform the labor market.
- Act 13/1982, of April 7, on the social integration of the disabled. ("BOE" 103, of 4-30-1982).
- Act 51/2003, of December 2, on equal opportunities, non-discrimination and universal accessibility for people with disabilities (LIONDAU) – amended by Act 26/2011, of August 1, on regulatory adaptation to the International Convention on Rights of Persons with Disabilities.
- Act 3/2012. BOE. N.162, July 7th of 2012. Page 49113-49191. Ref. BOE-A-2012-9110.
- Royal Decree 364/2005, of April 8, which regulates alternative compliance on an exceptional basis with the reserve quota in favor of workers with disabilities.
- Royal Decree 86/2015, of June 2, on the application of the 2% reservation fee to people with recognized disabilities.
- Royal Legislative Decree 1/2013, of November 29, which approves the Consolidated Text of the General Act on the rights of people with disabilities and their social inclusion.

Malta

- Persons with Disabilities (Employment) Act. Ch. 210.
- Employment and Industrial Relations Act. Ch. 452.
- Equal Opportunity (Persons with Disabilities) Act. Ch. 413.
- Employment and Training Services Act. Ch. 343.



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