

NGOs committed to 'full labour inclusion' of people with chronic diseases

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- **The guide prepared by these two organizations is aimed at companies and users in order to inform about the impact of chronicity on employment and the needs of these patients.**
- **In Europe, one in three people aged 16-64 have a long-term chronic disease or health problem**
- **Living with a chronic disease generates an emotional impact on patients and requires adaptations in the workplace.**

The Platform of Patient Organizations (POP) and the Malta Health Network (MNH), organizations that represent people with chronic disease in Spain and Malta respectively, have prepared the Guide “Managing people with chronic diseases in the work environment” with the aim of giving visibility to the situation of people living with a chronic disease and contributing to their full labour and social inclusion.

For this, they have developed this guide aimed at companies and employers that pursue the double purpose of: on the one hand, informing companies about the impact of chronicity on employment and the needs of these workers and, on the other, guiding them on the possible

adjustments to be implemented that contribute to favouring the inclusion of people with chronic disease in the workplace.

In Europe, one in three people aged 16-64 (active population) has a long-term disease or health problem. By gender, the percentage of women with disease is higher than that of men. Most people who have a lifelong disease are able and willing to work.

“Even so, being able to work is one of the biggest concerns and reasons for consultation with patient associations. It is a reality that unemployment or dismissal affects more people who have a chronic illness”, affirms the president of the POP, Carina Escobar. In addition, she adds that “developing in the workplace is a way to achieve a better quality of life, since feeling active and productive has benefits for physical and mental health. Companies, employers, and workers must find the best way for the person with the disease to develop their talent for the benefit of all”.

In this sense, from MHN, the president Gertrude Buttigieg highlights that “In times when there are difficult economic situations all over Europe, having people with Chronic conditions in the workplace is beneficial at all levels for the patients themselves as being gainfully employed, even on a part-time basis helps in their physical, mental and social life. For the employers themselves as the willingness of these patients to contribute to their place of work gives a better output for the companies and they do not have to seek to employ new people and loose the skilled and capable staff.”

Emotional impact

Living with a chronic disease is complex and requires adaptations in the workplace. “When the disease arrives, you think that life is no longer the same, that you will not be able to carry out the same activities, that you will request help from another person, that you will not be able to contribute to the well-being of your family, etc. This impact manifests itself more significantly if the disease gets worse or if there are moments of crisis,” Escobar points out.

Furthermore, it should be noted that “In an era when everyone speaks about rights and equality, being economically active and gainfully employed although one has a chronic disease gives the persons a sense of positive belonging in society and thus they feel valued in society and not a failure,” Escobar declares.

Health promotion in the workplace

According to the World Health Organisation, the health, safety, and well-being of workers very important for the workers and for their families, and also for the productivity, competitiveness and sustainability of companies. In this sense, it is necessary that society, companies/employers, and workers join forces to incorporate specific actions that protect people who have a chronic disease. Addressing chronic diseases in the workplace will lead to stronger economic growth, more profitable employment, reduced reliance on state benefits, reduce demands on healthcare systems, and increased productivity.

Work is the place where people spend a large part of their time, for this reason, “companies, employers and workers must seek the best way for people with chronic diseases to develop their talent for the benefit of all”, both organizations emphasize. To date, a diversity of resources and tools have been designed for companies and managers of workplaces to contribute to the promotion and improvement of health in work environments, as well as the prevention of diseases derived from work activity. . “These tools are essential to guarantee that people with chronic health conditions can maintain their employment under equal conditions or access to new positions in environments free of obstacles that could lead to abandonment or loss of employment”, conclude the POP and MHN.

Finally, both the POP and the MHN emphasise that patient organisations are an essential social and community agent in this society that work to accompany people with disease from diagnosis and throughout their life process. This implies developing actions that cover the set of needs and that complement the care received by public systems. These actions materialize in information and awareness services, training, social and psychological care, physical rehabilitation therapies or day and residential centers, among others.

Methodology

For the preparation of this guide, people with chronic disease, belonging to associations integrated in the Platform of Patient Organizations (POP) and in the Malta Health Network (MHN), have had the direct participation.

The information and recommendations contained in this guide have been extracted from 2 virtual focus groups held on May 30 and July 14, 2022 with people affected by different

pathologies or chronic symptoms residing in Spain and Malta, led by expert researchers. A total of 16 people affected by different chronic pathologies (8 in each focus group) participated in these sessions. They were recruited voluntarily and met the following criteria: having been diagnosed with one or several chronic pathologies; be between the ages of 18 and 66; be labourally active (working in paid employment, or actively seeking employment); and have work experience of at least 2 years.

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