

THE SOCIO-ECONOMIC IMPACT ON THOSE LIVING WITH BRAIN, MIND AND PAIN DISORDERS

About BMP Disorders and the BMP Interest Group

Brain, Mind and Pain (BMP) disorders encompass both neurological and chronic pain disorders, impacting approximately 370 million people [1,2] and causing enormous suffering and disability. BMP disorders can interfere with a person's quality of life and general functioning, but unfortunately, they are not widely recognised or understood by the general population. This lack of public awareness of BMP disorders contributes to the stigma and the associated isolation and discrimination, which affects the daily lives of people living with BMP conditions, their families and carers.

The [BMP Interest Group](#) is an initiative of the European Federation of Neurological Associations and Pain Alliance Europe, seeking to improve the quality of life of all those living with BMP disorders across the EU, as well as their families and carers.

The impact of BMP disorders on employment

The prevalence of chronic diseases and disabling conditions, such as BMP disorders, has been growing in the European Union over the past decade due to an ageing population. In addition, **more than one-third of the employable European population has a chronic illness** and two out of three people reaching retirement age have two chronic diseases [3].

For people living with BMP disorders, **these conditions also bring barriers to employment and professional development**. This has a **significant impact on their salary, financial situation and level of seniority reached within an organization**. For example, 1 in 4 people with chronic pain reported that their condition impacted their employment, with an average loss of more than 3 weeks of work each year due to their pain [4]. One international survey found that two-thirds of respondents had a lower income due to the impact of chronic pain, and from this proportion, approximately 44% reported that their income had dropped by at least 50%. For these people, **the disability allowance is usually their primary source of income together with their early retirement pension due to chronic pain**. [5]

BMP disorders are associated with recurring sickness absence and work impairment, which can lead to increased stigma in the working environment. Unfortunately, more than 64% of chronic pain patients declared that they experienced stigma at work, 67% from work colleagues and 64% from managers. [6] In another study, almost half of BMP patients declared that they felt uncomfortable discussing their condition with their colleagues (39%) or manager (40%). When BMP patients decided to disclose their condition, their managers' reaction was not positive in a fifth of the cases (18.5%). Therefore, many employees prefer not to disclose it, and are concerned that they will lose their job or fear they might be humiliated or made fun of. [7]

The increased stigma in the workplace, together with their physical impairment, is also a main reason why people living with these conditions have **difficulties retaining a job or returning to work after a long period of absence**. The stigma ultimately impacts their overall employment prospects. For example, about 40% of people living with chronic pain had to change their employer because of their condition. [5]

A CLOSER LOOK INTO THE IMPACT OF MIGRAINES ON EMPLOYMENT

Migraine is the second leading cause of disability in the world, with a significant impact on the employable population. The disease is most troublesome during a person's most productive years (late teens to 50s), so a large share of people suffering from migraines still participate in paid work. A study of 12,545 migraine patients in 16 countries found that half of the participants felt that their ability as a professional was affected by migraine. 16% say it prevents them from applying for a job, while 1 in 8 respondents say the disease has prevented them from accepting a promotion. At the same time, more than half are hiding their migraines from their employer so that it does not have a further impact on their professional relationships with colleagues and managers. [8]

A disproportionate burden of care

In Europe, **80% of care work is still provided by informal carers**, with women providing approximately two-thirds of care. The economic value of unpaid informal care in the EU - as a percentage of the overall cost of formal long-term care provision - varies from 50% to 90%. [9] However, this estimate does not include short-term or irregular care, which means that the economic value of informal care is much higher.

Caregiving responsibilities can significantly limit work participation, productivity and opportunities for job advancement. For example, in the case of women caring for patients with dementia, research found that about a third of carers end up reducing their working hours or are compelled to give up their job [10]. This has **serious socio-economic consequences, including financial loss due to reduced income and financial difficulties in old age because of lower pension benefits.**

Caring for a loved one is a responsibility that also has an **enormous impact on carers' personal lives, relationships and mental wellbeing.** A poll among carers for people with multiple sclerosis has shown that 50% of those surveyed felt that people around them do not truly understand what it means to care for someone, contributing to their isolation. Moreover, the survey found that almost half of carers (41%) suffer from either severe or high stress levels often or all the time. [11]

With so much of their time focused on looking after someone else, **caring responsibilities tend to take a toll on the physical health of those providing care.** Carers often prioritize the needs of others and delay their own healthcare needs, which can result in poorer healthcare outcomes or harmful habits and lifestyles, such as smoking, inadequate food or disruptive sleep patterns. [11] For those carers that are still in employment, this can lead to productivity losses, increased job turnover and additional direct healthcare costs, which can ultimately impact their financial situation.

The impact of the Covid-19 pandemic on people living with BMP disorders and informal carers

The Covid-19 pandemic poses significant challenges for people living with BMP disorders and those that care for BMP patients. For patients working in essential services, going to work has meant exposing themselves to a virus that disproportionately targets those with underlying health conditions.

Typically, **people with chronic conditions, such as BMP disorders, are at a higher risk of unemployment.** [13] There is a further risk that this trend will increase because of the pandemic, and **BMP patients are already concerned that they will not be able to afford healthcare costs** associated with their conditions as they will lose some or all of their income.

The pandemic has also had a **significant impact on the socio-economic situation of carers for people living with BMP disorders.** In one survey, 54% of carers for those living with a long-term illness, physical disability, or cognitive/mental condition declared that the pandemic has worsened their financial situation, stating that one of the reasons is the insufficient financial support provided by the government or social services for caregiving expenses. Moreover, 62% of employed carers are concerned they will lose their job because of the time commitment needed as a carer. In addition to the financial strain, carers' career prospects are deeply impacted, impeding their economic opportunity. As a result, 9 in 10 carers for those living with neurological and other cognitive/mental health disorders would like for the health and social services /care system to do more to support them as carers. [14]

A CLOSER LOOK INTO THE IMPACT OF SPASTICITY ON EMPLOYMENT

Spasticity is one of the most common and disabling conditions associated with many neurological diseases in adults, such as stroke or traumatic brain. The condition induces multi-level disability related to muscle stiffness, including impaired walking and hand use, pain, disfigurement and contractures. An international survey assessing the burden of spasticity on patients' lives found that 98% of them struggle with carrying items, impacting their professional lives. At the same time, almost half of patients (44%) do not work or work part-time because of their condition. The condition also impacts carers, and almost a third of caregivers (29%) do not work or work part-time to be able to take care of their loved ones. [12]

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