Chronic pain is a huge problem; not just because of its debilitating effects on those afflicted but also because of the associated stigma, writes Jeroen Lenaers.

In recent years, a great deal of work has been done on the serious issue of chronic pain and the societal impact that it has. Approximately 20 percent of the adult population in Europe is affected.

During the previous term, I had the honour of being vice-chair of the Brain, Mind and Pain interest group in the European Parliament.

It served as a platform to bring together various MEPs, stakeholders and, most importantly, patients themselves.
This shared commitment resulted in concrete policy recommendations and amendments and the drafting of a Written Declaration, signed by colleagues from a variety of political groups.

It called upon the Commission to intensify its efforts to improve access to employment for those affected by neurological disorders and chronic pain conditions.

The European Pillar of Social Rights now specifically recognises that workers have the right to high level protection of their health and safety at work – crucial for workers with chronic pain.

“The debilitating symptoms and side effects of treatment can make it difficult to find and then remain in employment”

Let’s hope that our efforts result in more concrete Commission proposals. Creating awareness about this topic remains key for improving the situation of the many Europeans suffering from this condition.

We must ensure that policymakers and the public are aware of the consequences on work-life balance, on the way people are able to fulfil their jobs and the impact of this pain.

Those affected by neurological and chronic pain disorders face a ‘double disadvantage’ in terms of access to employment and education.

The debilitating symptoms and side effects of treatment can make it difficult to find and then remain in employment.

In addition, those successful in finding jobs need to contend both with their condition as well as the associated stigma and social biases. Pain also has a great economic impact on society.

The estimated direct and indirect healthcare costs in Member States for chronic pain disorders is 2-3 percent of GDP – more than €400bn annually.

I became aware of the disrupting effects of living with chronic pain in 2014, before I was elected to the European Parliament.

Pain Alliance Europe set up an awareness campaign in the European Parliament by bringing a pain simulator box. People were asked to put their hands in the box for a minute in order to experience how chronic pain feels.

“The fight against the disruptive social effects of chronic pain starts with ourselves”
When I tried it, it gave me a burning sensation – clearly unpleasant but fortunately it only lasted a minute. However, for those suffering from chronic pain, it often lasts a lifetime.

The experience and the explanation and information from Pain Alliance Europe impressed me and I became more aware of the difficulties of dealing with day-to-day chronic pain.

It was also instrumental in my decision to join the Brain, Mind and Pain Interest group. During my work in Parliament’s Employment and Social Affairs committee, I also paid extra attention to the effects of European policy on people with chronic pain.

With the new parliamentary term already underway for more than half a year, I am glad to see that various interest groups like Pain Alliance Europe (PAE), the Societal Impact of Pain (SIP) Platform and others continue their important work.

Their work is vital in keeping the public and policymakers informed and reminding them of their important social and political responsibility vis-a-vis chronic pain patients.

However, much more work is required, particularly on stigma in the area of pain. Results from the PAE’s 2019 survey show how significant this problem is.

The 6069 responses from 28 European countries show the immense effect of stigma on chronic pain sufferers. For example, more than 64 percent of the respondents experienced daily stigmatising reactions or behaviour in their work environment.

Similar reactions are also reported from family and friends (more than 55 percent) and even within healthcare environments (more than 50 percent).

Furthermore, most respondents estimated their quality of life was only half of what they had before the onset of their chronic pain.

Additionally, one-third reported that they avoid social situations because of embarrassment. These results should make us feel more committed to move forward.

It is a challenging task to reduce stigma, because chronic pain is usually invisible to others and those with chronic pain are reluctant to disclose for fear of stigmatisation.

Part of the solution could be to make the societal impact of pain a priority in the health systems of all EU Member States.

This may be achieved by making chronic pain a vital part of the education of healthcare providers and others engaged in dealing with persons suffering from chronic pain.

Patients should also learn how to talk about their suffering with their family and friends to improve their understanding. Improved pain care policies could also improve cost-effectiveness - highly welcome given the immense economic impact.

Finally, I would like to emphasise that there is also a great responsibility for all Europeans to speak up whenever they hear negative comments about persons with chronic pain.

They should be helpful and show empathy; the fight against the disruptive social effects of chronic pain starts with ourselves.

About the author
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