



Request for advice in response to a citizens' initiative

At the request of the Minister of Health, Welfare and Sport, the Health Council has mapped out the state of scientific knowledge about fibromyalgia. The request was prompted by a debate in the House of Representatives about a citizens' initiative. The advisory report has been drawn up by the Committee on Fibromyalgia. This Committee has reviewed the scientific literature and held a hearing with representatives of relevant organisations, including patient organisations, and people who suffer from fibromyalgia or who are involved in the care of someone with fibromyalgia.

Diverse and variable symptoms affecting a few percent of the population

Fibromyalgia is characterised by chronic pain throughout the body in combination with other physical, cognitive and/or emotional symptoms. Fibromyalgia is therefore more than having chronic pain. The symptoms and their severity can differ from person to person and vary over time in an individual. While fibromyalgia typically follows a prolonged course, reduction in symptoms and improvement in functioning are possible.

Estimates of the prevalence of fibromyalgia vary in the scientific literature. That variation appears to depend in part on how fibromyalgia is diagnosed. Based on studies carried out in several parts of the world, it is estimated that almost 2% of the general population has fibromyalgia. The Committee assumes a similar estimate for the Netherlands.

An important health problem that deserves recognition

The symptoms experienced by people with fibromyalgia can have a significant impact on their well-being and functioning. When people are limited in their daily activities due to fibromyalgia, they can lose work and social contacts leading to sadness and feelings of loneliness. The lives of partners or families of people with fibromyalgia can also be affected by the symptoms.

Due to the potential severity of the symptoms and their impact on quality of life, the Committee views fibromyalgia as an important health problem that needs to be recognised. According to the Committee, recognition means taking the symptoms and their impact seriously and approaching people with fibromyalgia with an open and unprejudiced attitude.

The Committee also considers the provision of proper care to be an important form of recognition.

Causes and factors that influence the course are not fully understood

It is not fully understood what causes fibromyalgia and influences its course (how the symptoms develop). The current prevailing view in the scientific literature is that there is no single cause for the onset and persistence of fibromyalgia, but that several biological, psychological and social mechanisms and factors play a role. This view is also reflected in the latest version of the international classification system ICD (International Classification of Diseases) and is in line with the biopsychosocial model. This model posits that, for any health problem, consideration must be given to biological, psychological and social factors (see figure 1).

The scientific literature describes various mechanisms and factors that may play a role in the onset and persistence of fibromyalgia.

The Committee emphasises that these are theoretical models. The current dominant theory is that the onset and persistence of pain arise from central sensitisation. Central sensitisation refers to the phenomenon of amplified neural signalling due to changes in the central nervous system, which can lead to pain hypersensitivity. The central sensitisation model can also potentially explain some symptoms other than pain.

The biopsychosocial model posits that, for any health problem, consideration must be given to biological, psychological and social factors.

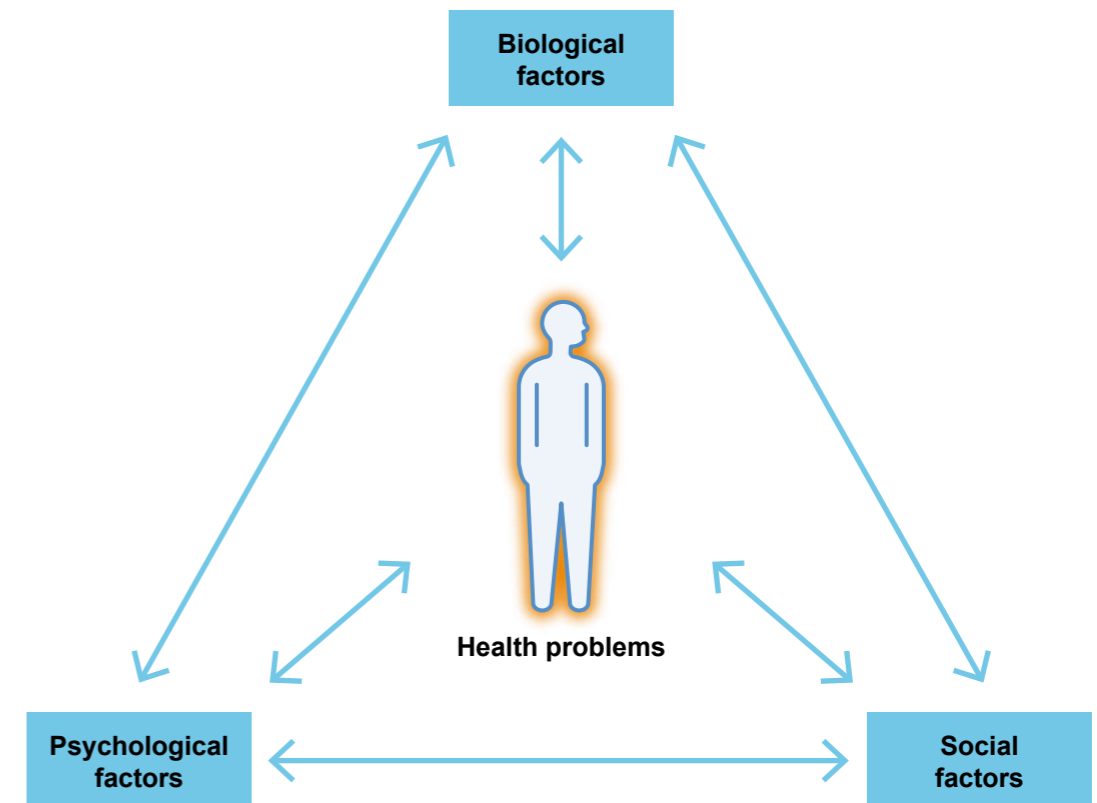


Figure 1 Diagrammatic representation of the biopsychosocial model

Several mechanisms and factors associated with the onset of fibromyalgia could also be a *consequence* of this. In all likelihood, there is a dynamic and complex interplay in which the various mechanisms, factors and manifestations of fibromyalgia can be interrelated and interact with each other. This process can differ from person to person.

Diagnosis based on criteria *and* a comprehensive biopsychosocial analysis

Fibromyalgia should be diagnosed by a physician. There are no measurable biological indicators that can be used to reliably diagnose fibromyalgia. The physician should make the diagnosis based on an assessment of the symptoms (using diagnostic criteria) and the results of a comprehensive biopsychosocial analysis.

There are a number of diagnostic criteria that can serve as an aid when making a diagnosis. The Committee prefers the ACR-2016 criteria, in part because the most clinical and scientific experience has been gained with these criteria compared to other recent diagnostic criteria (the AAPT criteria).

The biopsychosocial analysis is carried out through interviews with the patient, with or without the use of questionnaires, targeted physical examination and, if necessary, additional investigations. The analysis is important in order to assess whether the symptoms can be explained by a health problem other than fibromyalgia. The analysis is also important to identify factors from the various biopsychosocial dimensions that play a (primary) role in the onset and persistence of the symptoms, the impact of the symptoms on the patient's daily life and what request for help exists. The aim is to gain insight into possible starting points for management and treatment.

The diagnostic process can be lengthy. In addition to the complex symptom pattern of fibromyalgia, other factors such as a lack of knowledge among physicians of diagnostic criteria and insufficient application of the biopsychosocial model could play a role. For timely diagnosis, it is important that health care professionals identify and recognise the symptoms associated with fibromyalgia and take these symptoms seriously (and if they are not physicians themselves, that they refer the patient to a physician for diagnosis). Physicians who come into contact with people who may have fibromyalgia should be well-versed in the ACR-2016 criteria.

Differences between physicians in assessment of work ability

Fibromyalgia can adversely affect a person's ability to work. Some people also experience a lack of understanding at work. According to the Committee, things that can help to ensure a good balance between workload and work capacity are adjustments to the (organisation of) work and understanding and support from colleagues and the employer.

If a work disability assessment needs to be carried out in the context of certification of work disability benefits, people come into contact with the Employee Insurance Administration Agency (*Uitvoeringsinstituut Werknemersverzekeringen*, UWV). Differences between insurance physicians in the assessment of work ability are sometimes perceived as arbitrary. A possible explanation for these differences is that insurance

physicians interpret the medical disability criterion (*medisch arbeidsongeschiktheids criterium*, MAOC) differently. The manner in which the criterion should be applied during the work disability assessment is described in the medical disability criterion (MAOC) guideline.

The essence of this guideline is laid down in the *Schattingsbesluit arbeidsongeschiktheidswetten 2000*. According to the MAOC guideline, the laws and case-law of the Dutch Central Appeals Tribunal (*Centrale Raad van Beroep*), a physical or psychological cause of the symptoms does not always have to be established. It is not always necessary to prove which disease or physical abnormality caused the person to become unable to work. If no clear physical or psychological cause can be established, it can be assumed in some cases that a person is not or no longer able to work or work at full capacity due to a consistent and coherent set of disorders, limitations and disabilities. The Committee finds that insurance physicians, in general and therefore also in the case of fibromyalgia, should focus on functioning and limitations, and less on the cause, when carrying out a work disability assessment.

Personalised care through a biopsychosocial approach

There are currently no specific interventions to prevent fibromyalgia. It is also unclear whether early diagnosis has a positive impact on the course of fibromyalgia.

The Committee believes that a person-centred and biopsychosocial approach is a vital precondition for good care and optimising quality of life – for all health problems, hence also for fibromyalgia. According to the Committee, it is essential that management and treatment are tailored to the results of the biopsychosocial analysis. This approach is central to the Care Standard for Chronic Pain (*Zorgstandaard Chronische Pijn*), which according to the Committee can guide health care professionals in shaping the management and treatment of people with fibromyalgia. In the care standard, also elements are addressed that the Committee deems essential for the management and treatment of people with fibromyalgia. These are: information and (pain) education, self-management support, attention to work and support in optimising daily activities and participation.

Various interventions, both non-pharmacological (without medicines) and pharmacological, have been studied in people with fibromyalgia. The Committee has reviewed the scientific evidence of the effectiveness/ efficacy of interventions based on recommendations of the European League Against Rheumatism (EULAR, now the European Alliance of Associations for Rheumatology) and the National Institute for Health and Care Excellence (NICE). This shows that some interventions are reported to have a beneficial effect. The Committee explicitly states that the overall evidence is generally weak. It is also often unclear whether the effects are long-lasting. Moreover, no single intervention is effective for all people with

fibromyalgia and no general statement can be made about which intervention can best be used for a specific symptom or combination of symptoms. It is also unclear which patient characteristics can predict therapy response. The Committee is of the opinion that practitioners should be aware of the EULAR and NICE recommendations. Depending on the patient's situation, personal needs and goals (as revealed by the biopsychosocial analysis), they can consider a specific intervention that has received a positive recommendation from EULAR and/or NICE. The Committee makes an exception for tramadol and cyclobenzaprine: it advises against the use of these drugs.

Due to possible side effects of pharmacological interventions and a potential risk of dependence, it is important, in principle, to focus first on information and (pain) education, and on non-pharmacological interventions.



Greater knowledge required: important steps to be taken in scientific research

Much remains unclear about fibromyalgia. Although the lack of clarity is to some extent inherent to the complex nature of fibromyalgia, the Committee believes that important steps need to be taken in scientific research. Due to limitations in the research conducted to date, the Committee believes it is important that well-designed scientific research is carried out into existing interventions, with a specific focus on investigating long-term effects. In addition, it is important for the development and design of treatments that more knowledge becomes available on what causes the onset of fibromyalgia and what factors influence its course. In general, the Committee considers it important that research has an integrated approach; in principle, attention should always be paid to all dimensions of the biopsychosocial model.

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