



**The course of the illness for ME patients in Norway:  
What are the typical courses of the illness,  
and what worsen or improve them?  
*English Summary*<sup>1</sup>**

**By Trude Schei and Arild Angelsen, the Norwegian ME Association<sup>2</sup>**

**March 2021**

*The knowledge about the course of the illness and prognosis for ME patients is deficient. This report is based on a patient survey among 5 822 ME patients in Norway. It provides critical insights that should form the basis for the understanding and approach to the illness, and how ME patients are met and treated by the healthcare service, the welfare administration and the educational system. The oft-assumed typical course – a gradual improvement over time – characterizes only 12% of the respondents. Large fluctuations, or fluctuations with gradual deterioration, are the two most typical courses of the illness. Activity regulation (pacing) is by far the most important positive factor for improvement, whilst too high level of activity is the most frequently reported negative factor. The healthcare service is mentioned 56% more frequently as a negative factor than as a positive factor for the course of the illness. The approach taken by parts of the healthcare service, the welfare administration and the educational system contributes to a worsening of the illness for many patients. While there is a need for more knowledge, even more important is to use the knowledge we already have to offer support and assistance that is adapted to the patients' needs and which is based on an understanding of the course of the illness and the factors affecting it.*

---

<sup>1</sup> The full report (Schei and Angelsen 2020), written in Norwegian, is available here: <https://www.me-foreningen.no/ressurser/me-foreningens-rapporter/sykdomsforlop-for-me-en-brukerundersokelse/>

<sup>2</sup> [trude.schei@hotmail.com](mailto:trude.schei@hotmail.com); [aangelens@gmail.com](mailto:aangelens@gmail.com)

## **0 The survey**

There are few good studies on the course of the illness and the prognosis for patients diagnosed with ME (ME/CFS). To improve the knowledge base, the Norwegian ME Association conducted a patient survey to: (i) identify typical courses of illness, and (ii) map the factors that have contributed positively or negatively to the development of the illness over time. The survey was online, anonymous, limited to one answer per IP address, and open between 07.02.2019 and 12.04.2019. It consisted of 11-13 structured questions and two open-ended questions about the respondent's experience on factors that have had a positive or negative impact on their illness. A total of 5 822 complete responses were received, more than 800 more than there were members of the association. This indicates that between 29% and 58% of ME patients in Norway answered the survey, and it is, as such, the most comprehensive survey of ME patients' experiences. 86% of the respondents were women. Most were between 20 and 60 years old, with those between 40 and 50 years making up 30% of the respondents. 7% were below 20 years.

This study targeted both current ME patients and people who have recovered from ME. However, we do not know to what extent we have covered those who are (almost) recovered today. We cannot, therefore, use the answers to estimate the proportion of ME patients who will recover, or to give forecasts and probabilities for different courses. Nevertheless, the overall picture matches well with the ME Association's experiences and the five previous patient surveys. Close to 6 000 respondents provide a solid data source on broad experiences with the disease and the factors that determine the course. The findings are important corrections to several misleading notions about ME, the course of the illness and critical factors, notions which are often based on a much thinner empirical basis than this study. We summarize the results and recommendations in ten points.

## **1 ME is a chronic disease**

ME is a chronic disease, which indeed is embedded in the related term "Chronic Fatigue Syndrome – CFS" (we use CFS as a broader term for long-term fatigue, and not necessarily with Post Exertional Malaise - PEM). More than half of the respondents have been ill for more than ten years, and many will have to live with the disease for the rest of their lives.

Many actors within the healthcare system and welfare administration have unrealistic expectations about ME being a short-term disease that "burns out". This is especially true for children and adolescents, where unrealistic expectations of imminent improvement create major problems. When there is no improvement, the patient is often blamed. This, and the lack of knowledge about the risk of prolonged deterioration due to excessive activity, leads to the

patients being subjected to activities they cannot tolerate. It lays the foundation for vicious circles and long-term deterioration.

## **2 Many are moderately ill, and that is serious**

The Norwegian national CFS/ME guidelines describes four degrees of the illness: mild, moderate, severe, very severe (Helsedirektoratet 2015). There are no representative Norwegian studies for how ME patients are distributed between different degrees. The answers from this survey point to moderate ME being the most typical, and close to 6 out of 10 (57%) of the respondents say they are in this category. 1 in 4 (25%) state that they have a mild degree, although there may be reasons to believe that a lower proportion in the group “mild ME” have responded to the survey. 15% say they have a severe degree, while 1% have a very severe degree of the illness.

The different terms for degrees of ME may, however, be misleading. For example, mild degree implies that the activity level is reduced by at least 50%. At a moderate degree, the patient is largely housebound, and spends several hours a day on the couch or in bed to rest. Moderate ME is a serious illness that, for the most part excludes having paid work, severely limits social activities, and makes patients depend on assistance from family and friends for daily chores.

## **3 Large fluctuations or deterioration are the typical courses of illness**

Many actors in the healthcare system describe a course of the illness with initial fluctuations and a gradual improvement. Such a course is possible but is only characterizing a small minority (12%) of the respondents. The two most typical courses are large fluctuations all the time (29%) and fluctuations in the beginning, followed by a gradual deterioration (25%), as pictured in Figure 1. Almost three times as many respondents report that they are now in deterioration as opposed to improvement.

We do not know to what extent the serious patterns reported are due to, for example, biological factors or external influences, such as imposed activities (by the welfare administration or schools) or expectations from family and friends. In the free text answers, the respondents describe that high levels of activity or stress are factors that negatively affect the course of the illness. These two factors are associated with mistrust from others on the validity of the disease, problems with getting a diagnosis, incorrect advice about activity after onset, pressure about high activity from the employer, the school or the welfare administration, and concerns about finances. The answers clearly point in the direction that the healthcare service, the welfare administration and the educational system expose a large number of ME patients to stresses that contribute to permanent deterioration.

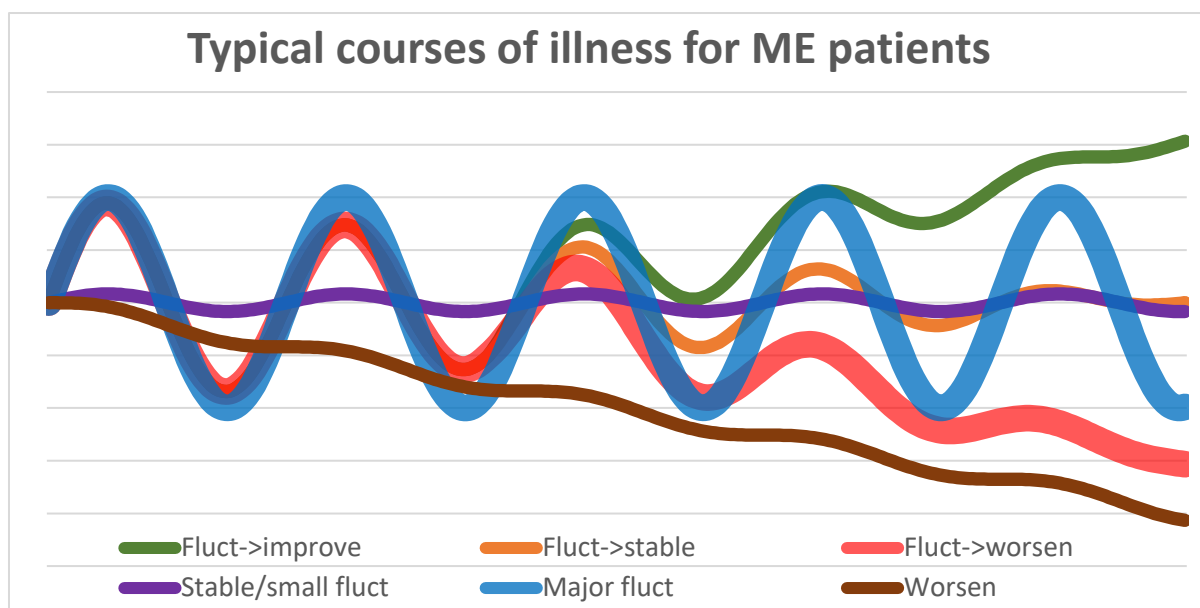


Figure 1: Typical courses of illness among ME patients (n = 5 724).

#### 4 Recovery occurs, but unfortunately far too rarely

Just over 2% of respondents state that they have recovered from ME. Again, this is not a follow-up study with a representative sample of those who have become ill. However, the number is not surprisingly low. A literature review from 2005, based on studies using broad CFS criteria, estimated that ca. 5% recovered completely (Cairns and Hotopf 2005).

Various media reports about ME patients who have recovered after various treatments are very unrepresentative for the population of ME patients. Recovery occurs, and should certainly be welcomed, regardless of cause and treatment. The problem arises when anecdotes are generalized without research documentation or being based on broad patients' experiences, both in terms of incidence and what constitutes effective treatments. This concerns, in particular, different forms of cognitive treatments. While the direct relevance to the everyday lives of the vast majority of ME patients is limited, the media and public debate is nevertheless important because it illustrates two diametrically different views on ME. The answers in the survey clearly indicate that the lack of understanding and respect for the disease that many patients experience can be linked to a widespread psychosomatic approach to ME.

#### 5 A peak in new cases in 2009 (swine flu)

The answers show a large increase in the number of new cases of ME in the period up to 2009, where we see a peak that coincides with the swine flu epidemic. Other studies have shown the risk of getting ME was doubled among those that have had the swine flu, whereas there was no increased risk among those that have received the swine flu vaccine (Magnus et al. 2015).

There is a new peak in 2011, then we observe a decline. We do not know whether the decline seen in Figure 2 in new cases is real or not. One plausible explanation is the fact that it normally

takes a long time from onset of the illness to diagnosis. Among the respondents who answered that they were still under examination, the median time from onset to the time they answered was five years.

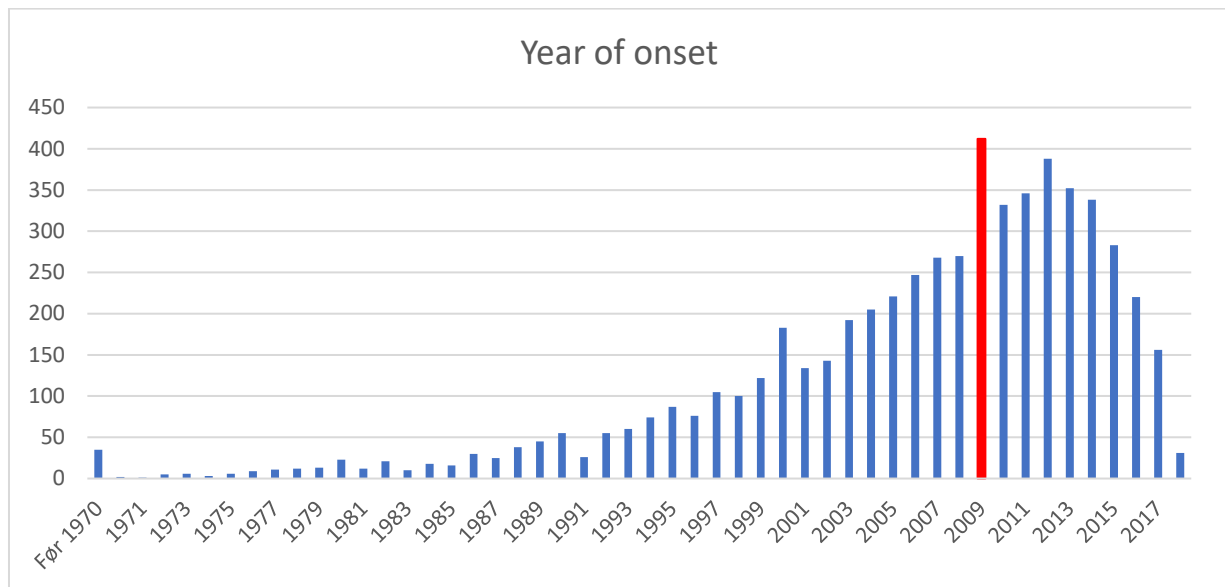


Figure 2: Year of onset of illness (n = 5 822).

## 6 Severe illness associated with early onset of illness

Both this study, previous patient surveys (Schei, Angelsen, and Myklebust 2019) and research (Lacerda et al. 2019, Chu et al. 2019) show that in the (very) severely ill group of ME patients, a higher proportion became ill before the age of 20. In this survey, more than half of those who are very severely ill reported that they became ill before they turned 20. Thus we find a statistically significant correlation between an early onset and having a severe or very severe degree of ME, as illustrated in Figure 3. We do not know why, and this is clearly an area where more research is needed. One plausible hypothesis is that the correlation is, at least in part, related to erroneous advice and excessive emphasis on activity early in the course of the illness. Both user experiences and research indicate that too high a level of activity early in the process can lead to a more severe course of the illness (Schei, Angelsen, and Myklebust 2019).

The findings of this study should have strong implications for how ME patients are met by the healthcare services, the welfare administration, schools and municipalities. Activity beyond the patient's energy envelope may not only cause short-term PEM, but also long-term exacerbations. A patient survey among children and adolescents with ME showed how they are often pushed to a level of activity beyond their tolerable limit (Bråthen 2016).

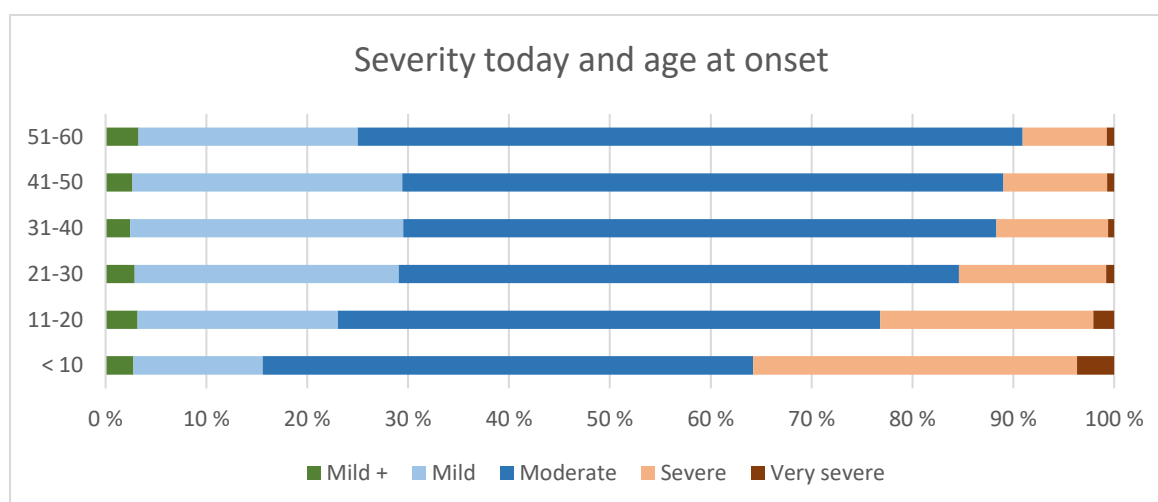


Figure 3: The association between severity of illness today (x-axis) and age at onset (y-axis) ( $n = 5\,548$ ).

## 7 Activity adjustment is the most important “medicine”

One of the clearest conclusions from this study is the significance of the activity level for the course of the illness. Almost 2 800 free text responses state that regulation of activity levels contributes positively to the course of their illness, while more than 3 100 responses describe in various ways how activities outside their individual energy envelope contributes to a worsening of the illness. Excessive activity is not just about physical activity; major emotional strains and stress are also perceived as negative, and are often described in connection with mistrust from the healthcare services and the welfare administration, from family members who do not believe in ME, from marital breakdown or death in the family, or from uncertainty about finances and welfare benefits.

Coping strategies such as activity pacing and energy management are therefore by far the most important measures for a good outcome. These strategies are concerned with finding a balance between activity and rest, rationing the use of energy, and finding optimal energy-saving ways to perform activities (O’Connor et al. 2019). A major goal is to stabilize the illness and possibly achieve improvement in the form of lower symptom burden and better functional capacity over time. Although many experience the opposite, this survey also indicates that much can be done to influence the course of the illness in a positive direction. Activity adjustment is enabled by accepting the illness, listening to one’s body and taking care of oneself, having the opportunity to manage everyday life to adjust daily activity levels according to a fluctuating symptom burden, receiving support from family and friends, being believed by the healthcare service and welfare administration, and having a secure financial situation. Only 6 (0.1%) of the respondents report that they have become worse due to inactivity.

Any guidance, recommendations or non-drug treatments for ME patients that are *not* based on the patients’ energy envelope and the need for activity regulation risks doing more harm than good.

## **8 The healthcare service contributes to both health and (even more) to ill-health**

The respondents' views on, and experiences with, the healthcare system are divided, as we have seen in all other patient surveys (e.g. Schei, Angelsen, and Myklebust 2019). The survey had 56% more responses stating that the healthcare services have been a cause of health deterioration rather than improvement. It would be difficult to find any other patient group where patients consider the healthcare service to have contributed more to the continuation or deterioration of the illness than to the improvements or recovery. This should be of great concern to the health authorities, and ought to lead to a radical change in the way ME patients are received and treated.

The reasons why the healthcare service becomes a negative factor for the course of the illness are several: mistrust of patients and their description of symptoms, lack of knowledge about the disease, misguided advice on activity levels – especially early on, long elapsed time from onset of illness to a confirmed diagnosis, an exhausting and protracted process of assessment before diagnosis, and unwillingness from GPs and others to provide symptom relief when it comes to sleep problems and pain. The process of diagnosing ME must be made more efficient, and take place sooner after onset. Patients with fatigue and PEM must be given advice on activity management even before the diagnosis is made.

Healthcare professionals who follow patients regularly over time receive the best assessments. Many got to know the patient before the onset of the illness, and meet patients regularly to gain a deeper understanding of how the disease manifests itself. Help from a psychologist or psychiatric nurse is perceived as useful when the goal is to provide support in the demanding situation of losing functional level and health. However, respondents generally experience cognitive therapy that aims to cure ME as negative, especially when it comes with graded exercise.

There is a need for more knowledge about symptom relief for ME patients. Relieving pain and helping with sleep problems is important to many and GPs and physiotherapists are praised for providing palliative care. Low-dose Naltrexone (LDN) is the drug treatment that is most often mentioned as having a positive effect on the course. Unfortunately, there are no clinical studies on the effect of LDN in ME patients, but the amount of positive feedback indicates that the effect should be investigated further in randomized trials.

## **9 The welfare administration makes ME patients even sicker**

The most disappointing – although not surprising – results from the surveys are related to ME patients' experiences with Nav (the Norwegian Labour and Welfare Administration). 881 responses indicate that Nav has had a negative impact on the disease. There are no respondents who say that measures under the auspices of Nav have contributed to an improvement or a return to work. Many say that they wanted to continue working as long as possible, but that

they have inflicted aggravation on themselves as a result (often after pressure from the employer, Nav, family and friends).

The positive contributions from Nav (145 respondents) are related to the granting of disability benefits: it has provided financial security and predictability, and the opportunity to adapt the level of activity to own health. The negative feedback seems to be related to both widespread attitudes among Nav employees, internal routines and guidelines (with decisions made by Nav central administration, in many cases contrary to the recommendations by the local Nav officer or the GP), and the rules for unemployment benefits and other social security schemes. The current benefits scheme is poorly adapted to the situation of ME patients. The median time from disease onset to the time of response in this survey was five years among respondents currently under examination. In contrast, Nav requires both a final diagnosis and a work capacity assessment within a four-year timeframe.

Many respondents also describe the period of receiving unemployment benefits as being characterized by stress, uncertainty, and demands from Nav to carry out activities and “treatments” that were perceived as a great burden. Nav demands activities that are incompatible with activity adaptation, and that does not take into account the fact that ME can be an unpredictable disease. Uncertainty related to the outcome of benefit applications and concerns about finances are also factors that contribute to deterioration. Many describe that they are afraid of losing benefits if they do not do as they are required by Nav, and that they therefore cannot take the necessary precautions in dealing with the disease. Young ME patients report the most problems with Nav. People with large fluctuations also have difficulties in gaining an understanding from Nav on how serious the disease is.

## **10 With better support, treatment and understanding, a good ME life is possible**

There are several distressing findings in this study: far more ME patients experience a deterioration rather than an improvement over time, and the healthcare service and the welfare administration greatly contribute to a worsening of the course of the illness for an already seriously ill group of patients.

The good news is that the factors that contribute positively or negatively to the processes can be changed, and do not require breakthroughs in medical research. This requires, however, that health and welfare authorities use the knowledge that we already have about the ME patients’ health situation and experiences, as documented in research and broad patients surveys such as this one. A great deal can be done to create a better course of the illness for ME patients, with a lower symptom burden and better health and quality of life.

We summarize these measures in five points.



1. *Activity management from day 1*
2. *Believe in the patient*
3. *Symptom treatment from the healthcare service*
4. *Changes in Nav's rules and practices*
5. *Facilitation and practical help in everyday life*

## References

- Bråthen, Isabel. 2016. Barn og unge med ME og deres familier, erfaringer med helsevesen, skole og kommunalt hjelpeapparat. Hva utgjør gode forløp? Oslo: Norges ME-forening.
- Cairns, R., and M. Hotopf. 2005. "A systematic review describing the prognosis of chronic fatigue syndrome." *Occupational Medicine* 55 (1):20-31. doi: 10.1093/occmed/kqi013.
- Chu, Lily, Ian J Valencia, Donn W Garvert, and Jose G Montoya. 2019. "Onset patterns and course of myalgic encephalomyelitis/chronic fatigue syndrome." *Frontiers in pediatrics* 7:12. doi: <https://doi.org/10.3389/fped.2019.00012>.
- Helsedirektoratet. 2015. Nasjonal veileder: Pasienter med CFS/ME: Utredning diagnostikk, behandling, pleie og omsorg. Oslo: Helsedirektoratet.
- Lacerda, Eliana M, Keith Geraghty, Caroline C Kingdon, Luigi Palla, and Luis Nacul. 2019. "A logistic regression analysis of risk factors in ME/CFS pathogenesis." *BMC neurology* 19 (1):275. doi: <https://doi.org/10.1186/s12883-019-1468-2>.
- Magnus, Per, Nina Gunnes, Kari Tveito, Inger Johanne Bakken, Sara Ghaderi, Camilla Stoltenberg, Mady Hornig, W. Ian Lipkin, Lill Trogstad, and Siri E. Håberg. 2015. "Chronic fatigue syndrome/myalgic encephalomyelitis (CFS/ME) is associated with pandemic influenza infection, but not with an adjuvanted pandemic influenza vaccine." *Vaccine* 33 (46):6173-6177. doi: <https://doi.org/10.1016/j.vaccine.2015.10.018>.
- O'Connor, Kelly, Madison Sunnquist, Laura Nicholson, Leonard A Jason, Julia L Newton, and Elin B Strand. 2019. "Energy envelope maintenance among patients with myalgic encephalomyelitis and chronic fatigue syndrome: Implications of limited energy reserves." *Journal of Chronic illness* 15 (1):51-60. doi: doi:10.1177/1742395317746470
- Schei, Trude, and Arild Angelsen. 2020. Sykdomsforløp for ME: Hva er typiske forløp, og hva forverrer er forbedrer forløpet? Oslo: Norges ME-forening.
- Schei, Trude, Arild Angelsen, and Elin Myklebust. 2019. De alvorligste ME-syke: Sykdomsbyrde og hjelpetilbud. Oslo: Norges ME-forening.