

THE NORWEGIAN ME ASSOCIATION



NORGES MYALGISK ENCEFALOPATI FORENING

**THE NORWEGIAN ME ASSOCIATION
NATIONAL SURVEY
ABRIDGED ENGLISH VERSION**

by Gunn J. Bringsli, Anette Gilje and Bjørn K. Getz Wold

Oslo, 12th May 2014

Preface

The Norwegian Myalgic Encephalopathy Association is pleased to be able to present a long awaited systematic feedback from ME patients themselves, during the spring of 2012. It was high time to document the ME patients' perception of their own situation, hopefully in order to guide future ME therapy and assistance. The Norwegian ME Association is grateful to our previous Secretary General, Anette Gilje, and a member of our board, Gunn Bringsli, who jointly initiated the survey. They were later joined by a survey expert and coordinator of the fundraising for bio-medical ME research, Bjørn K. Getz Wold, to complete the report: "ME patients in Norway – still secluded?" by Gunn J. Bringsli, Anette Gilje and Bjørn K. Getz Wold, Oslo, 12 May 2013.

The Norwegian ME Association followed with great interest when our British sister organization, The ME Association, published a survey in 2010. We could also follow the survey of the health and care of patients with ME/CFS published by SINTEF, the largest independent research organisation in Scandinavia, in 2011. This was the same year the revised International Consensus Criteria was published (Carruthers 2011) and then recommended by the Norwegian Directorate of Health in early 2012. In 2011, we received inspirational news when Professor Mella and Dr. Fluge, from the oncology department at Haukeland University Hospital, Bergen, published their double blind study into the use of Rituximab on ME patients. They documented that 10 of 15 patients recovered permanently or temporarily from both physical and cognitive symptoms following treatment with this medicine (Fluge et al. 2011). Dr. Fluge found that several of these ME patients suffer from the effects of their illness as much as cancer patients towards the end of their life. The study was groundbreaking in two ways. The result gave hope for an effective biomedical treatment in the near future. At the same time it gave a strong indication that ME is a biomedical disease, and that a psychiatric diagnosis F48.0 Neurasthenia, or other psychological explanations, are inappropriate for these patients.

It will take some time before the full impact of this groundbreaking insight is felt. Two editorials in the Journal of the Norwegian Medical Association have expressed worries that the view of a patient organisation may even be considered at all when it comes to setting priorities and allocating resources in the health sector. (Bjerkestrand 2012 Haug 2012). The only ward for children and young people up to 18 years of age in the capital Oslo is located at the Maternity and Children Clinic at the National Hospital (one of the hospitals within the Oslo University Hospital group). This clinic has chosen to ignore the recommendations of the Norwegian Directorate of Health, by retaining their own diagnosis (Wyller 2011). However the National ME Centre for adults at Aker Hospital (part of the Oslo University Hospital group), applies the national recommendations and is building up research-based expertise in diagnosis, as well as recommending pacing as treatment.

Drs. Mella and Fluge will be in charge of a nationwide, multi-centre, double-blind study of around 150 ME patients from mid-2014. This has been made possible due to the efforts of the ME Association in soliciting media coverage and lobbying members of parliament and officials in the Ministry of Health and care services. Private funds have been raised by the ME and You foundation and MEForskning.no, under the direction of the ME Association.

Responding to requests to communicate more widely, we now publish this abridged version of the national survey in English. It has been prepared by one of the authors, Bjørn K. Getz Wold. We would like to thank Linda Tannenbaum, Executive Director of the Open Medicine Foundation and Ellen V. Piro, retired long-term Leader and Secretary General and Ann Arnecke, both of the Norwegian ME Association, for assisting with this abridged English version of the report. The unabridged version of this report with all technological information is available in Norwegian on the Norwegian ME Association website:

<http://me-foreningen.com/meforeningen> or directly from <http://me-foreningen.com/meforeningen/innhold/div/2013/05/ME-foreningens-Brukerundersøkelse-ME-syke-i-Norge-Fortsatt-bortgjemt-12-mai-2013.pdf>

Gry Finstad Molland, Secretary General, The Norwegian ME Association.

1 Introduction

ME, or ME/CFS is not a new disease. ME cases were already described in the 1950s and included in the WHO's International Classification of Diseases, ICD-10, Code G93.3, in 1969. The CFS diagnosis was introduced 25 years ago, but ME/CFS was a long hidden disease. The sickest ME patients were secluded in semi-dark, soundproof rooms. The public health care system had little to offer and ME patients were pushed into oblivion, or perhaps rather towards institutions or family care. The health care system promoted psychosocial treatment, followed by graded exercise therapy. It might have served some patients with only chronic fatigue, but these therapies made the situation worse for ME patients. Unfortunately, the situation was not much better when this survey was conducted last year.

1.1 Who are the ME patients?

For this survey there are 10 – 20,000 ME patients said to be living in Norway, by the Norwegian Directorate of Health in 2012¹. Many of these are likely to have been diagnosed based upon the 2003 ME criteria, covering a wider range of patients (refer to Carruthers et al 2003&2011). The current more precise criteria were first documented and globally recommended in 2010 (here in Norway from early 2012). Unfortunately, as documented by the SINTEF report (Lippestad 2011), there is no national consensus and quality control of the diagnosis made, and how ME is diagnosed. On average in 2008 and 2009, 1883 patients were given the internationally recognised ME diagnosis G93.3, Post viral fatigue syndrome; slightly less than 2000 patients were given either the F48.0 Neurasthenia or other fatigue or fatigue and burnout diagnoses. Additionally over 4000 patients were given related diagnoses and almost 19,000 were registered for observation for possible disorders of the nervous system.

1.2 What are the typical ME symptoms?

The typical picture of ME is characterised by the central nervous system and muscles being easily exhausted (rapid fatigability) and the patients experience flu-like illness, fatigue and general worsening of symptoms after exertion. There is an abnormal and slow recovery period – a week or several months, contra 24 hours or so in healthy individuals. The fatigue, which can be triggered by minimal activity, cannot be compared with the usual fatigue that healthy people experience after exertion, but is described as a neuro-immune power failure. The condition can vary in intensity from hour to hour, day to day, week to week or month to month. Fluctuations in symptom intensity and nature are related to either physical or mental/cognitive activity. A worsening of symptoms (relapse) may last up to several days after physical or mental exertion (reading, watching TV, listening to lectures, long conversations). Increasing physical or mental exertion beyond the body's tolerance-limit leads to a worsening of the disease. The symptoms can be extremely severe, and death may occur. Symptom intensity is unpredictable and fluctuating. Mildly affected patients can do part time jobs, while the most severely affected lack even the strength to turn over in bed, reliant on help to eat or get their daily nutrients (if need be via nasogastric tube, or intravenously), and for their daily hygiene.

1.3 How to reach all ME patients with a national survey?

Unfortunately there is not a register of all ME patients in Norway². Since it was not possible to select a representative sample of all ME patients in Norway, we extended an open invitation to all members of the Norwegian ME Association and all readers of our website. As with any service-user or consumer survey, it was expected to cover a broad range of respondents, experience and opinions, but was not able to show how widespread or representative the experiences and opinions were.

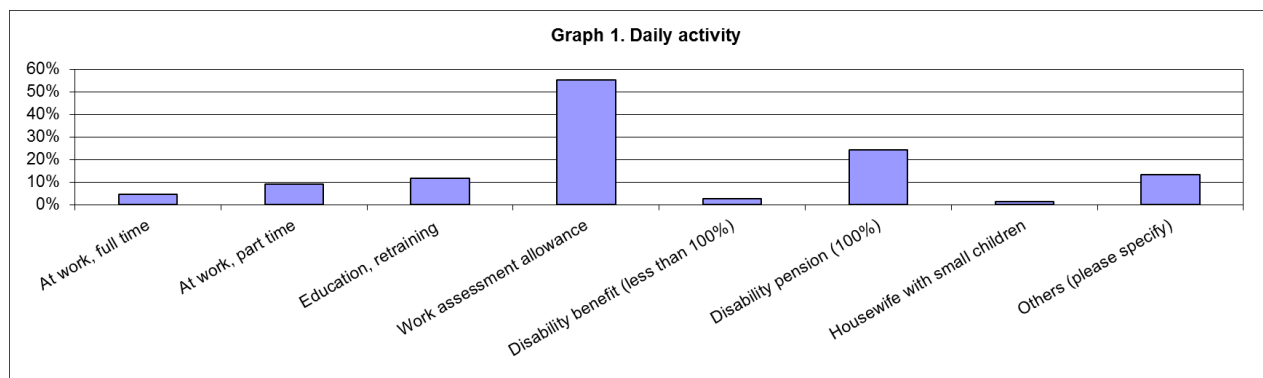
We expected to receive more feed-back from patients with strong and opposing opinions and more response from active users of social media. *Summarised, we should have expected to receive a broad range of common experiences and opinions, but are unable to decide what is the most common experience or opinion.*

¹ The National Directorate of Health refers to Reyes et al (2003) who estimates prevalence up to 0.23 % and Jason et al (1999) who give an estimate of 0.42 %. This yields an estimate of 11,500 to 21,000 ME patients in Norway with 5 million inhabitants.

² Beginning in 2008, all patients diagnosed by hospitals, polyclinics and health specialists were registered. Hence in the future it may be possible for research institutions to be able to select a sample of patients given the ME diagnosis in 2008 or later.

2 Activity and quality of life

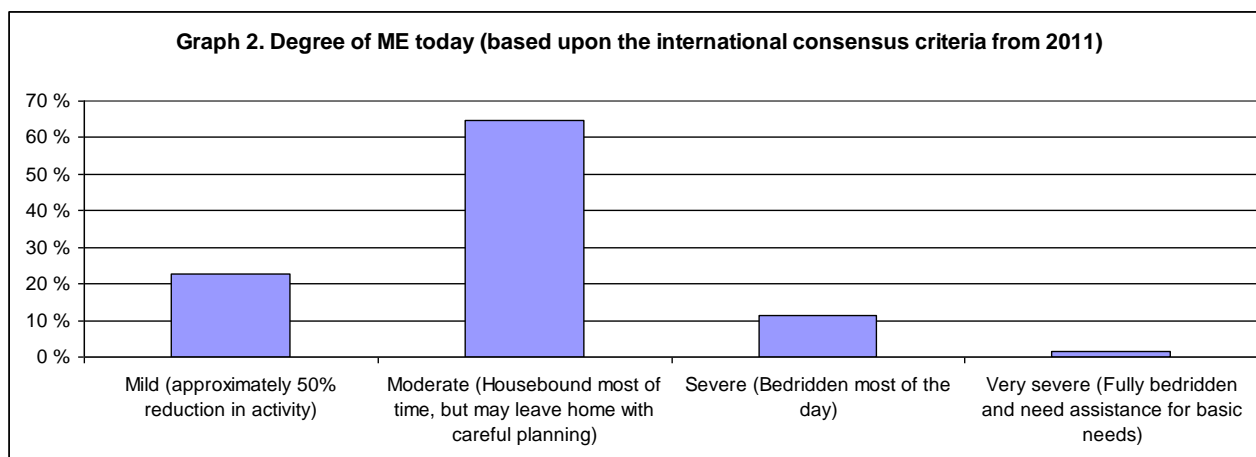
2.1 Main economic activity and income source



Most of the ME patients were on some kind of public social benefit. More than half received temporary rehabilitation benefits, while 1 in 4 was granted 100% disability pension and more than 1/10th were being educated, trained or retrained. A few were able to work full time, some part-time, some received reduced disability pension and some stayed at home caring for young children. Among respondents with ME for ten years or less, two thirds received temporary rehabilitation benefits. This type of benefit is supposed to be limited to 4 years and hence does not reflect a very predictable economic situation for these ME patients.

2.2 Severity of ME and daily challenges

How do ME patients manage daily life? This is dependent upon the severity of the illness. The new consensus criteria from 2010 categorise ME patients as “mild”, “moderate”, “severe” and “very severe”. However, we laymen would rather re-label these categories, “half capacity”, “housebound” (may only leave the house with careful planning), “bedridden” and “totally dependent upon assistance even for basic needs”. We may then better understand the severity of this illness.



Almost 2/3rds had moderate ME. That does not sound too serious, but these patients are housebound and may only leave the house with careful planning. One quarter were only mildly affected, while 1/7th were severely ill and bedridden. 15 patients were totally bedridden and dependent upon assistance for even basic needs.

3 Medical history, needs and requests

The vast majority had received their ME diagnosis, but only after considerable time. Only half were diagnosed within 3 years and one in five ME patients had to wait for 10 years or more. Meanwhile, two of the five received additional diagnoses, either en route to an ME diagnosis or in addition to their ME diagnosis. This picture illustrates two very different situations – 1. Difficulty getting an ME diagnosis and 2. The presence of other diseases and symptoms. Many have received diagnoses based on a psychiatric clinical picture, as reflected in what we hear from our members, who state that their illness is given a psychiatric dimension. The SINTEF report (Lippestad 2011) shows that there is great uncertainty and lack of agreement

about the diagnostic codes being used across the various medical disciplines and health authorities, which could have a bearing on the type of illness diagnosed.

Nearly three out of four assume that a viral or bacterial infection contributed to triggering the disease. More than one in three anticipated that prolonged stress had contributed, often in addition to either an infection or a vaccination. More than 1 in 7 believed that vaccines contributed to triggering the disease. Meningococcal, influenza and tetanus are frequently listed vaccines. Just over half of the ME patients believed that there were at least two trigger factors that have contributed to their ME disease.

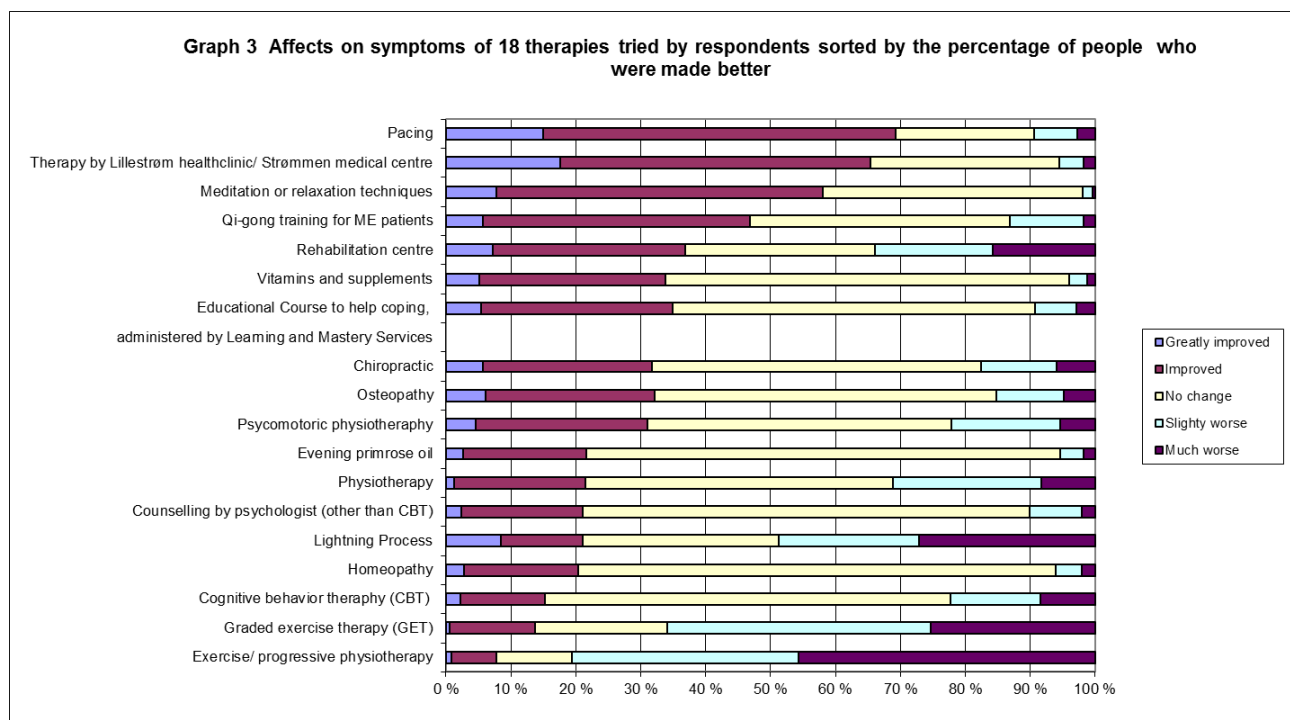
3.1 Grave symptoms

Prior to the release of the 2011 Rituximab-study, there was no confirmed general biomedical treatment. The health care system lacked a systematic approach to reduce secondary symptoms. This therapy is still only available on an experimental basis (Helse Bergen, 2013 and Open Medicine Institute, 2012), hence we asked the respondents to report how grave their symptoms were. For the whole group and each sub-group the gravest symptom was a *significant exercise-induced energy failure, as a result of physical or mental strain*. On a scale of 1 = least problematic, to 5 = most problematic, the majority of the respondents entered 4 or 5 with an average of 4.3. The symptom "sore throat and enlarged lymph nodes" is particularly extensive in the age group 21-30 years. This age group also scored highest on clear flu-like symptoms, problems with gastro/intestinal tract and sensitivity to certain foods, drugs, chemicals and odours. For the group under 20 years, pain was also a very serious symptom in everyday life (Breivik et al, 2006 & Rustøen et al, 2004). All groups also found *disturbed sleep pattern*, a serious problem.

3.2 Medical therapy

Despite the lack of a systematic set of biomedical therapies for reducing the secondary symptoms, there are still a number that have been tried. The survey tried to review the therapies tested by the ME patients.

On average the ME patients had tested 7 types of therapies. This is both a reflection of the lack of any offer of a cure for ME and that the public health service does not even offer any therapy to reduce secondary symptoms. ME patients have tested a number of both public and private options. Pacing is the most common therapy, where a patient learns to reduce their activity level to around 70 per cent of their normal capacity. With meditation and relaxation techniques as the third most common therapy, we learn that the main focus is to take control of one's own capacity. Vitamins and mineral supplements are commonly used by 4 out of 5.



The critical issue is whether these therapies have improved the situation, shown no effect, or rather made the situation worse. A therapy which helps some, without worsening their situation, is obviously worth other patients testing.

There are in fact a number of such gold standard therapies which have improved the situation for some patients, whilst having no impact on others. Other therapies should be considered seriously before trying, since many patients may end up in a worse situation, or suffer serious relapse.

There are two groups of therapies which improve the situation for many and only make it worse for a very few:

- Pacing and various types of meditation and relaxation techniques including Qi-gong-training for ME patients have improved or even greatly improved the situation for two of three who have tested these therapies. They only made the situation worse for 1 in 10, or even less.
- Therapy by Strømmen Medical Centre and its predecessor Lillestrøm Health Clinic, improved the situation for 2 out of 3 patients, and only made it worse for 1 out of 20.

At the other end of the scale we found two other therapies which improved the situation for a very few but made it worse or even considerably worse for many:

- Exercise training/ progressive physiotherapy and graded exercise therapy only improved the situation for around 1 out of 10 and made the situation worse for 2 out of 3, and seriously worse for half of these.
- Lightning Process, which improved the situation for 1 out of 5, made the situation worse for half the patients, and seriously worse for 1 out of 4.

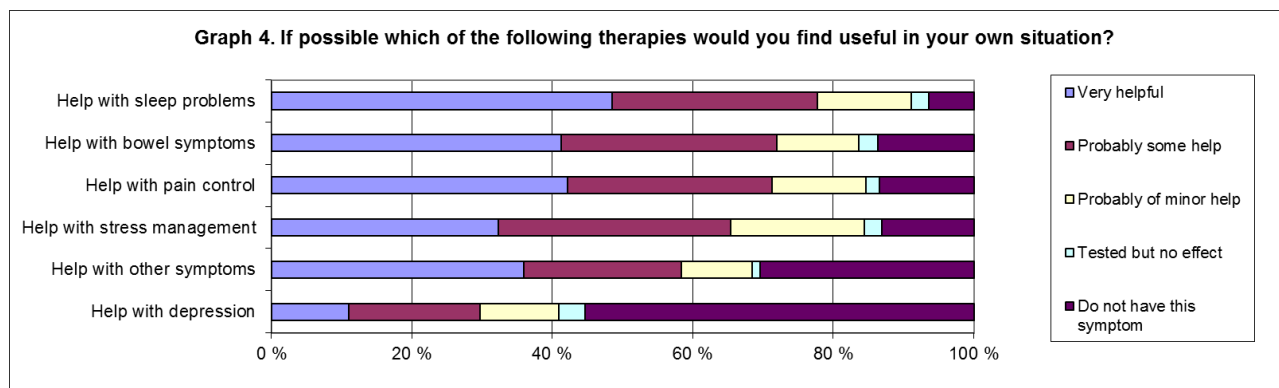
The other therapies have caused a more balanced effect, showing an improvement in some and a worsening in others. The mainstream offer of cognitive therapy and coping courses by psychiatrists and psychologists hardly changed the situation in either direction for the majority.

In order to study the experiences of ME patients with less frequently used treatment services, we must content ourselves with collecting data showing any improvement (improvement + large improvement) and no worsening (neither somewhat worse nor considerably worse). That tells us that the therapy given by Professor Kenny de Meirleir has improved the situation for 3 out of 4 and only made it worse for 1 out of 10. The opposite is the case for therapy offered by the Clinic for Children at the National Hospital/ Oslo University Hospital, which only shows an improvement for 1 in 10 and made the situation worse for 1 in 4.

4 Priority list for therapies

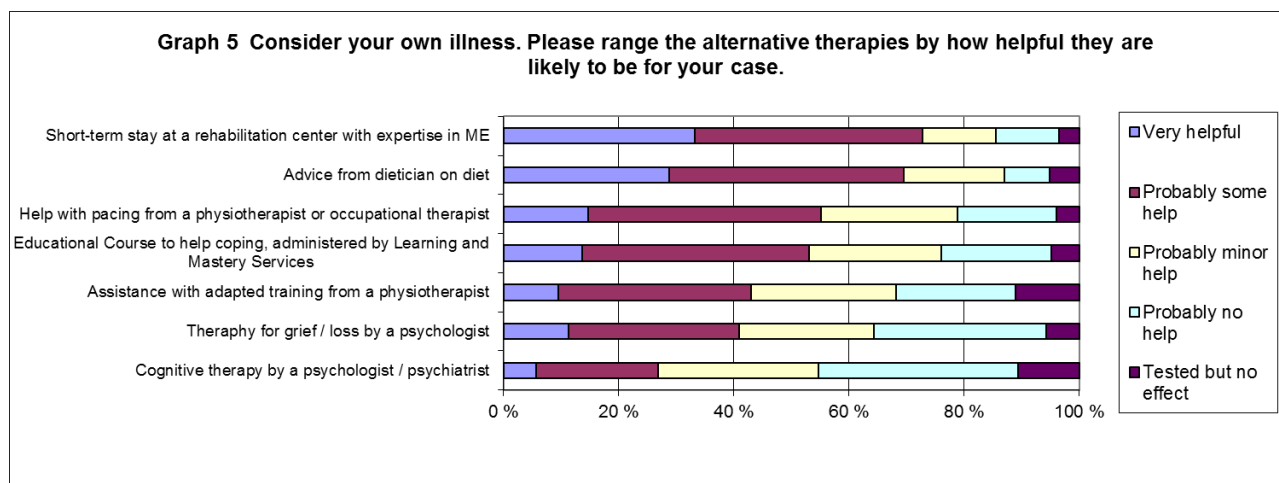
4.1 The current lack of therapy for ME patients

This survey covers ME patients who had tested several therapies and suffered chronic disease. Currently only half of them are under any medical supervision. 1 in 7 was not able to tell whether they had any medical supervision and 2 of 5 told that they were currently without any medical supervision. This is not a matter of the lack of supplementary therapy, over and above what is given by the public health service, but more about the lack of any assistance for reducing the secondary symptoms of ME disease. Since there is no curative treatment available (apart from experimental therapy, as in Rituximab), reducing secondary symptoms is the only available option to help patients. Even this option is missing for 4 out of 9 ME patients. It is hard to imagine any other group given equally poor medical supervision and therapy from the public medical service.

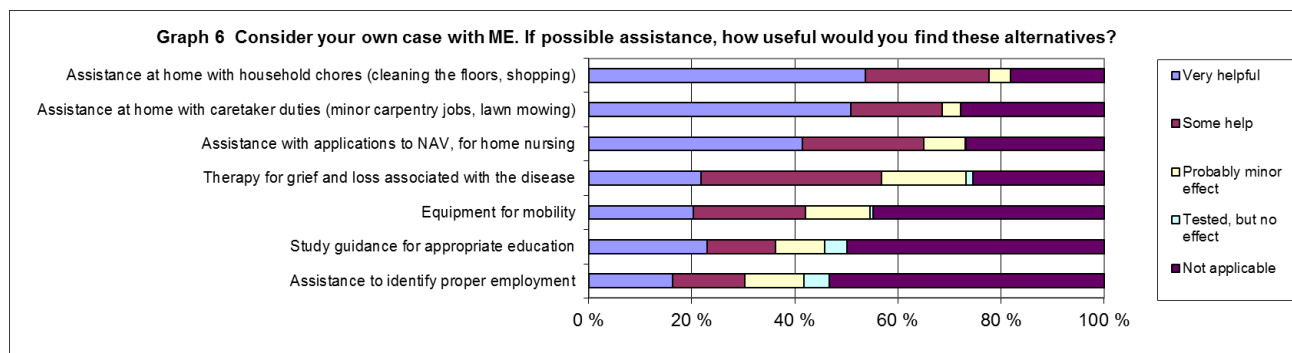


Hence, we asked the ME patients for their own main priorities for medical assistance.

It is clearly not the case that ME patients do not seek assistance. They ask for help to handle their secondary symptoms. 2 out of 3 ME patients would find it useful to get medical assistance in order to handle sleep disorders, bowel-symptoms or relieve pain. Almost the same number would benefit from assistance with tackling and relieving stress.



Quite a number said they would like help from various health care professionals. Combined therapies given at a rehabilitation centre with special expertise in ME, headed a wish-list from 3 out of 4 patients, who thought this would be very, or somewhat helpful. It may be that a number of ME patients are aware that others have been helped by this type of rehabilitation centre. Sølvskottberget, with versatile professional skills adapted to ME patients was one such centre, but has unfortunately closed after losing public financial support.



More than half of the respondents reported that practical help at home for every day chores and also for larger tasks, would be very helpful and roughly 3 out of 4 think it will at least provide some help. To get daily home care is in fact more or less a precondition for ME patients in order to practise the necessary pacing within their capacity. In addition, with such assistance they may even be able to socialise and enjoy small pleasures of everyday life. Many ME patients do get assistance from their local authority, but there is obviously a general need for such assistance.

Finally, we asked the ME patients how they rated their quality of life. Nearly 2 out of 3 reported that their quality of life was less good or even poor. You may however turn that around and be impressed by the fact that more than 1 in 3 ME patients reported their quality of life as good. It is amazing that this group of people is able to cope with a difficult situation and view the good side of life, whilst coping with an ME disease. This is a sound basis for further action to improve the situation for them and other ME patients.

5 Summary findings

1096 ME patients in Norway have responded to this survey. Half of them are members of the Norwegian ME Association, while the other half responded to the invitation in social media to join the survey. Unfortunately it was not possible to conduct a survey of a representative sample of ME patients, since there is no register of ME patients available. The survey, whilst not providing a representative sample, does give a comprehensive picture of common situations experienced by common groups of ME patients. This was achieved by virtue of its open invitation and the large number of respondents.

These are severely affected patients. The vast majority of these patients live on social benefits – either temporary rehabilitation benefits, or some kind of disability pension. 3 out of 4 ME patients are housebound (can only leave the house with careful planning). Quite a few are bedridden and many are dependent on assistance to manage daily life. It is not without reason that Dr. Fluge from the oncology department at Haukeland University Hospital expressed the view that many of the ME patients in their Rituximab study faced a quality of life in line with patients with advanced cancer.

6 out of 7 ME patients have been given an ME diagnosis, but this has typically taken three years. More than half have had to wait 6 years or more. Many have also been given a psychiatric diagnosis on the way to a diagnosis of ME. Nearly 3 out of 4 assume that viral or bacterial infection triggered the disease, but also prolonged stress, vaccines or trauma were considered as possible triggers. ME patients are experiencing energy failure as the worst problem, yet they also struggle with sleeping disorders, sweating/freezing, flu symptoms, bowel problems, hypersensitivity to certain food items, pain and dizziness. These symptoms are part of the ICC/Canadian criteria, but may also be caused by secondary diseases that often accompany the ME disease. For instance, a number of ME patients have postural orthostatic tachycardia syndrome (POTS) where a galloping heart often causes overheating and sweating in key body parts, at the same time as which their hands and feet are extremely cold. Symptoms such as pain may even have a long-term, negative impact due to possible changes in the nervous system. Half of the respondents had been sick for 6 years or less, while about 3 out of 10 had been sick for 10 years or more.

Given the lack of curative treatment, many ME patients have tested a variety of therapy options. This is understandably both physically and mentally exhausting, as well as a financial burden.

What is the experience of the ME patients themselves? What does help? The answers are pretty straight forward. Two groups of therapies improve the situation for many and only make it worse for a very few:

- Pacing and various types of meditation and relaxation techniques, including Qi-gong-training for ME patients, has improved or even greatly improved the situation for two of three of those who have tried. These techniques only made the situation worse for about 1 out of 10.
- Private medical therapy by Prof. Kenny de Meirleir and Strømmen medical centre and its predecessor Lillestrøm health clinic improved the situation for 2/3 or ¾ and only made it worse for a very few.

At the other end of the scale we also find two types of therapies, which improved the situation for very few and made it worse or even considerably worse for many:

- Exercise training/ progressive physiotherapy, graded exercise therapy and therapy at the Children's ward at Rikshospitalet, made the situation worse for a large number, i.e. from 3 to 8 out of 10 patients. This type of therapy only improved the situation for around 1 in 10.
- Lightning Process is only slightly better. It has triggered a worse situation for half and a severely worse situation for 1 out of 4, but at least improved the situation for 1 out of 5 ME patients.

The respondents experienced a very poor medical follow up. Only half had a medical follow-up at all and less than half found their general practitioner or other health service provider to be well informed and up to date with the ME diagnosis. ME patients in this study acknowledged their need for assistance.

Approximately two out of three believed that it would be very helpful, or at least of some help, towards getting assistance in handling sleep disorders, bowel symptoms, pain and stress. The majority of ME patients would appreciate a short term stay at a rehabilitation centre offering therapy for ME patients, a nutritionists advice, help with pacing from a physiotherapist or occupational therapist, or techniques in how to cope with ME. In addition, the majority expressed a need for regular assistance with daily chores, assistance with home maintenance, assistance with applications for various public benefits and assistance to learn how to cope with grief and accept their situation.

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