

ME/CFS in Northern Ireland

Position Statement as at 31 August 2016

Introduction

ME/CFS is a condition that has greatly puzzled healthcare professionals and, for many years, it has been debated as to whether it was actually an illness at all.¹⁻⁴ In recent years, however, understanding of this condition has improved and there is now agreement with a number of bodies that the condition does exist.⁴

Indeed, the WHO International Classification of Diseases (ICD) classifies ME/CFS as a chronic (long term) neurological condition⁵ with physical symptoms that can be as disabling as multiple sclerosis, rheumatoid arthritis and congestive heart failure.⁶

What cannot be agreed, however, is what type of treatment is appropriate or even what the condition should be called. In the UK it is known as:

- Myalgic encephalomyelitis/encephalopathy (ME)^{4,7}
- Chronic fatigue syndrome (CFS)^{4,7}
- Post-viral fatigue syndrome (PVFS)⁴
- Chronic fatigue immune dysfunction syndrome (CFIDS).⁴

What is known, however, is that 250,000 people^{4,7,8} of all ages in the UK are affected by this condition. Specifically, there are more than 7,000 cases in Northern Ireland,⁹ with 10% of patients suffering from moderate to severe symptoms. However, there is no dedicated specialist ME/CFS service in Northern Ireland.

Since 2013, the Patient and Client Council (PCC) has been supporting people with ME/CFS to ensure their voices are heard by decision makers. The aim of this paper is, therefore, to provide an overview of the current provision of services in Northern Ireland.

What is ME/CFS?

ME/CFS is a long-term, debilitating illness that is difficult to diagnose, has no accepted cure and no universally effective treatment.⁴ It usually develops when people are in their early 20s to mid-40s,⁷ although children between the ages of 13 and 15, or even younger, can also be affected.⁸ It is also more common in women than in men.⁷

If the symptoms are mild, some people can continue with work or study, but may need to sacrifice social activities at the weekends in order to rest. If symptoms are severe, people can become seriously disabled and housebound.⁸ In some extreme cases, individuals have to be tube-fed to stay alive.¹⁰



Symptoms of ME/CFS

Symptoms include fatigue, poor short-term memory and concentration, painful muscles and joints, problems with sleeping, stomach pain and other problems similar to irritable bowel syndrome, sensitivity or intolerance to light, alcohol and certain foods, and psychological difficulties, such as depression, irritability and panic attacks.^{6,8,11}

Dizziness, problems with controlling body temperature and problems with balance are also symptoms.^{6,8,11} These vary from person to person and, while remission can occur, relapse is common.¹²

People in Northern Ireland have also reported suffering seizures, an inability to remain upright¹³ and psychological distress resulting from these physical difficulties.

What causes it?

The cause of ME/CFS is not known, although there are several theories. Some experts think that a viral infection,^{5,8} such as glandular fever, can trigger the condition. Certain bacteria⁵ have also been suggested as a cause, such as those that cause pneumonia.

While feeling tired after a viral illness is normal, people with ME/CFS say it is not 'tiredness' that they experience, but an overwhelming fatigue.⁵ In fact, post exertional malaise (PEM) a 24 to 48-hour delayed exacerbation of all symptoms is one of the defining features of ME/CFS.^{4,11}

The viral infection trigger does not explain, however, why the symptoms persist or get worse. In some cases, there has been no infection before the onset of symptoms. The theory does not explain, either, why some people develop the condition gradually.⁵

Other suggested causes of ME/CFS include:

- Problems with the immune system;^{5,8}
- A hormone imbalance;^{5,8}
- Psychiatric problems, such as stress and emotional trauma;⁵
- An inherited tendency towards ME/CFS.⁵

It may be a combination of all of the above, but what is generally agreed is that more research is needed to understand what causes the condition.^{7,8}



Diagnosis

Diagnosis is difficult as the symptoms are not exclusive to ME/CFS, and one or more additional disorders can be present, such as fibromyalgia, irritable bowel syndrome, Hashimoto's thyroiditis, Raynaud's disease or phenomenon and Sicca syndrome.¹³

As there are no definitive tests for ME/CFS, this also makes diagnosis difficult. There are, however, a number of guidelines. While there is no standard clinical method used in the UK, many GPs follow the National Institute for Health and Care Excellence (NICE) guidelines (2007).

NICE guidelines acknowledge that individual treatment programmes should be offered, but the guidelines favour psychological approaches to therapy, as well as graded exercise therapy (GET) and cognitive behavioural therapy (CBT).

Other commonly used guidelines are:

1. **Oxford Criteria (1991)** – developed for and by psychiatrists. These guidelines are less rigorous and may include patients whose only symptom is fatigue.
2. **London Criteria (1994)** – still used by the Medical Research Council to assist decisions about funding for ME-related projects (all psychiatric). Main criticism is that the criteria have never been published so cannot be used objectively.
3. **Centers for Disease Control and Prevention (CDC) Criteria. Also known as the Fukuda definition (1994)** – guidelines developed in the USA, which focus on the single symptom of fatigue. Critics say it is too broad and unspecific.¹⁴
4. **South Australian Criteria (2002)** – these favour a biological explanation for causes and are similar to the Canadian Consensus Criteria (CCC).
5. **Canadian Consensus Criteria (2003)** – these guidelines favour a biological explanation for causes.
6. **Royal College of Paediatrics and Child Health (RCPCH) Guidelines (2004)** – these are oriented towards ME/CFS being a psychological illness, but have since been superseded by the NICE guidelines.
7. **International Consensus Criteria (2012)** – these criteria have been developed by an international panel of clinicians, researchers and academics who have, collectively, diagnosed/treated more than 50,000 patients with ME. This builds upon the CCC, although the six-month waiting period before diagnosis is no longer required. The criteria also prefers the single term myalgic encephalomyelitis (ME) because it indicates an underlying pathophysiology and does away with the confusing and misused term 'fatigue'.¹³

Patients in Northern Ireland largely favour the adoption of the International Consensus Criteria and the Canadian Consensus model.



Diagnosis is usually via blood tests, urine tests and scans to rule out other conditions with similar symptoms, so diagnosis can take a considerable amount of time.¹⁵ Using different criteria, however, means that it is even harder to establish a proper baseline for treatment and cure.¹³

There is, however, extensive research currently ongoing in the UK, US and Australia into the use of biomarkers as a means to support diagnosis, which was outlined in presentations to delegates at the Invest in ME International ME Conference in London on 3rd June 2016.

Misdiagnosis is common.¹⁶⁻¹⁸ Indeed studies have revealed that there is a high level of misdiagnosis of ME/CFS. For instance, a study conducted in London in 2007-2008 concluded that half of all patients referred to a specialist ME/CFS clinic had alternative medical and psychiatric diagnoses.

This work highlighted that diagnosing ME/CFS can be complicated and suggested that making a diagnosis in primary care may not be the best guidance. This study suggested that more specialist ME/CFS services (with a mix of specialist doctors) are needed to provide a diagnostic service that meets the requirements of people.¹⁶

Furthermore, a 2010 study carried out by ME Research UK on data provided by a specialist diagnostic clinic in Newcastle-upon-Tyne also noted that misdiagnoses rates of more than 40% had been reported.¹⁷

Specifically, postural orthostatic tachycardia syndrome (PoTS), where the heart rate increases by more than 30 beats per minute when standing, causing dizziness, fatigue and other symptoms, was a frequent finding among ME/CFS patients in a 2008 study. This study concluded that testing for PoTS should be part of the diagnosis, but this has not been recommended in the NICE guidelines.¹⁸

Can it be treated?

There is currently no known cure, and there is controversy over the recommended treatments, which depends on the clinical definition of ME/CFS. Broadly, there are two schools of thought: one that regards ME/CFS as a psychological disorder, and the other - supported by all UK and international charities - that it is a biological illness.

In 2011, a group of UK mental health professionals published the results of a £5 million trial of more than 600 ME/CFS patients in *The Lancet Psychiatry*.¹⁹ The Pacing, graded activity and cognitive behaviour therapy: a randomised evaluation (PACE) trial that was part-funded by the Medical Research Council and the Department of Health.



Using a combination of GET and CBT, the trial was based on the theory that ME/CFS was perpetuated by the patient's belief that they suffered from a biological disease and that exertion would only make them worse.

The PACE theory postulated that this decision to cease physical activity for long periods would cause muscle atrophy and other negative systemic physiological impacts, leading to more fatigue and other symptoms in a self-perpetuating cycle.

Understandably, this study caused outrage among ME/CFS patients and their associated charities. Since publication, however, the PACE trial has been somewhat discredited by scientists because of concerns regarding changes in methodology. There is currently gathering momentum for the trial to release data and make it available for scrutiny. Despite this, NICE guidelines currently recommend CBT, GET and activity management programmes.⁶

On 25 June 2014, at a meeting chaired by the Countess of Mar at the House of Lords, and attended by Forward-ME - a UK group of ME charities and voluntary organisations - Professor Mark Baker, Centre for Clinical Practice Director at NICE, admitted the following:

- The guideline failed to address the real issues in ME/CFS;
- It did not promote innovation;
- It had a disappointing impact on specialist care and commissioning issues.²⁰⁻²¹

What is acknowledged, however, is that a full recovery to the lifestyle enjoyed prior to ME/CFS is rare.^{4,22}

There is however ongoing work which is looking specifically at the treatment of ME/CFS. One study identified that ME/CFS possesses an objectively identifiable chemical signature in both men and women which targeted metabolomics can provide actionable treatment.²³ Another study looked at the immune system of patients who have recently developed ME/CFS and found that it looked somewhat different from those who have been ill for much longer. This ongoing study aims to identify biomarkers in blood that can be used for diagnosis, to predict illness progression and to track responses to interventions.²⁴ It is hoped these studies will help lead to diagnostic tools and possible treatment therapies.

ME/CFS services in England, Scotland, Wales and Republic of Ireland

In 2013, there were 49 specialist ME/CFS centres in England. Of those, 55% of the centres treated patients with severe ME/CFS, with their interventions following NICE guidelines, although 33% did not provide a service for bed-bound patients. The



remaining 12% offered occasional or minimal support where funding allowed. There was one NHS unit providing specialist inpatient ME/CFS provision in England.

A study conducted by The BMJ in 2014 focusing on the provision of services (not clinical outcomes) for adults found there were substantial variations in access to specialist care for patients with severe ME/CFS. Where treatment was provided, this appeared to comply with NICE recommendations for this patient group.²⁵

In addition to these specialist ME/CFS centres, there are 12 Clinical Network Coordinating Centres (CNCCs) across England that advocate the development of services and improved clinical care in their area. Each CNCC has an individual, named clinical champion or network coordinator. Advice to patients, GPs and carers about services is available from the network coordinator at each centre.²⁶ Patients can contact any of the CNCCs for information, but referrals must be made by a healthcare professional. These services report positive outcomes in terms of helping patients to self-manage the illness, but patient opinion is mixed.

In 2009, a voluntary organisation called the British Association of CFS/ME (BACME) was formed following the merger of the CFS/ME Therapists Network and the Clinical Network Coordinating Centres National Collaborative.

BACME's stated objectives are to champion evidence-based approaches to the treatment of CFS/ME, such as those recommended in the NICE guidelines; to support the delivery of services and to enable the delivery of services to maintain standards of care in the treatment of CFS/ME, as set out in the NICE guidelines; to encourage and facilitate the systematic and rigorous audit, benchmarking and evaluation of CFS/ME assessment, treatment and services.²⁷

Its executive committee comprises one representative from each CNCC, eight elected individual members, two to four patient/carer members, and one observer/member from each of a maximum of four national UK CFS/ME organisations that support the objectives of the BACME.

National charities do not, however, support BACME's objectives because the organisation strictly adheres to NICE guidelines. In fact, the charity Invest in ME rejected an invitation from BACME to apply to become an executive member of the organisation for that very reason.

In a statement, the charity said: 'It would be unethical of Invest in ME to sign up to such a constitution, and Invest in ME's aim remains to find ways other than those set out in the NICE guidelines to treat patients diagnosed with ME according to the Canadian Clinical Consensus guidelines, or improvements on those.'²⁸

The ME Association reported in 2010 that the West Midland ME Groups Consortium was calling for BACME to be examined by the All Party Parliamentary Group on ME.



The consortium was concerned that BACME, which had apparently taken over as the training forum for NHS staff involved in the care of people with ME/CFS, 'needed to be more publicly accountable, would benefit from wider patient participation and was too much under the influence of the psychiatric lobby'.²⁹

In other parts of the UK, support charity WAMES (Welsh Association of ME & CFS Support) has told the PCC that there is no published care pathway that fully meets the needs of people with neurological ME; that CBT and GET are neither appropriate nor cost-effective treatment options; there are no existing services that cater specifically for adults, children or young people with neurological ME, and there were no diagnostic services.

Information from support groups in Scotland paints a similar picture, and other studies suggest that, in many places, it is still not possible to see a local ME specialist.³⁰

In the Republic of Ireland the Health Service Executive refers to the use of NICE guidelines with a particular emphasis on CBT and GET.

UK progress

While progress across the UK has, in the main, been very slow, there are now indications that ME/CFS is being regarded in a far more scientific way. There is a wider acceptance of it being a chronic neurological condition requiring greater investment in biomedical research.

Through the work of the UK based charity Invest in ME, a European ME Research Group was established in 2015, which brings together leading European researchers to collaborate on and establish multi-site international biomedical research projects. Invest in ME also helped to establish the European ME Alliance (EMEA), involving 13 different European countries. EMEA recently joined the European Federation of Neurological Associations to further promote ME in Europe.

Invest in ME Research is also forging ahead with plans to create a Centre of Excellence for ME within the Norwich Research Park in Norfolk, which is also home to the Genome Analysis Centre.³¹ The project will utilise existing resources and facilities, and provide a hub of scientific and clinical excellence for ME within Europe.

On 3rd June 2016, representatives from the PCC attended the 11th Invest in Me International ME Conference in London, where eminent speakers from the UK, US, Finland, Germany, Australia and Spain gave presentations on their research. Delegates also learned that NICE is considering revising its ME/CFS guidelines in 2017 and has invited clinicians and healthcare professionals to contribute to the process.



ME/CFS services currently available in Northern Ireland

There are more than 7,000 cases of ME/CFS in Northern Ireland - 10% of whom have moderate to severe symptoms.⁹ However there is currently no specialist ME/CFS diagnosis or treatment centre in Northern Ireland.

Patients with moderate to severe symptoms may be referred to HSC trusts for a short Condition Management Programme (CMP). This is currently being implemented through a pilot scheme in the Northern HSC Trust. This pilot is the first step in the development of a regional network of expertise in ME/CFS, which will also offer support to GPs and other primary care organisations.³²

Prior to 2014, GPs could refer patients to a Chronic Fatigue Syndrome Clinic that had been held in Belfast City Hospital since around 1986. This was not a formally commissioned clinic, however, and was run on a special-interest-only basis. After the lead consultant retired in 2014, the clinic closed, and this meant people had no expert consultant to whom they could be referred.

Instead, the Belfast HSC Trust provides an occupational therapist in line with NICE guidelines once a diagnosis has been made by a GP.³³ As GPs do not receive any formal training in ME/CFS misdiagnosis can be common.

People in Northern Ireland can also choose to pay for private treatment to see a consultant who flies over from London once a month. Other than that, the only other support patients receive is via the four patient-run charities based in Northern Ireland:

- ME Support Northern Ireland;
- FMS/ME Awareness NI;
- Fibromyalgia Support Northern Ireland;
- Hope 4 ME and Fibro Northern Ireland (formerly known as the Newry & Mourne ME Fibromyalgia Support Group).

The Patient and Client Council and ME/CFS

The PCC first became aware of this situation in 2013 following a fibromyalgia/ME focus group as part of the *People's Priorities* report process. Following that, the Chair of what is now Hope 4 ME and Fibro Northern Ireland gave an impassioned presentation at one of the PCC Board meetings.

Since then, people have been sharing with us their lived experiences, including cases of misdiagnosis that meant other conditions, such as cancer, went undiagnosed. Others described how their experience of exercise-based programmes aggravated their symptoms and they felt this had set them back in their recovery.



People highlighted the need for a specialist centre in Northern Ireland to improve diagnosis and identify better treatment options.

The most important need identified by the patients was for the restoration of a secondary care medical consultant to enable patients to get a reliable diagnosis, as well as to support GPs with the treatment and care of patients.

Following this engagement, the PCC came on board to provide an interface between patients, medical professionals, support groups and decision makers in the Health and Social Care Board (HSCB). ME Support Northern Ireland and Fibromyalgia Support Northern Ireland also joined in with later discussions.

Since then, Hope 4 ME, which was formed in 2011, has hosted five international conferences and two medical professionals' educational conferences on ME/CFS in Northern Ireland.

In February 2014, Professor Mark VanNess, of the Workwell Foundation in California, gave a presentation in Stormont about how GET can be physiologically harmful due to the broken aerobic pathways of ME/CFS patients.

At the same meeting, Hope 4 ME and Fibro Northern Ireland organised a silent protest and requested that Northern Ireland adopt the Canadian Consensus Criteria guidelines, pointing out that, as Northern Ireland has a devolved government, it has the legal right to make decisions independent of the Westminster government.

A subsequent online petition was signed by more than 1,200 people and presented to the Local Assembly by Dominic Bradley MLA. The motion also called for a regional specialist ME/CFS consultant to lead a multidisciplinary team to diagnose and treat patients with ME/CFS and the associated syndrome, fibromyalgia. This is to be put forward for parliamentary debate, although no date has yet been set.

The PCC also sought the views of the four charities and organised meetings with the HSCB. In February 2015, the PCC organised the #invisibleME Symposium at the Riddel Hall in Belfast, which was attended by the Health Minister, healthcare professionals, support groups, HSCB members and MLAs, as well as patients and carers.

The HSCB Commissioning Lead for ME and fibromyalgia services in Northern Ireland spoke at this event and noted that the HSCB was considering an expansion of the CMP that was being trialled by the Northern HSC Trust. CMP follows NICE guidelines and is of the psychological disorder school of thought, which offers lifestyle advice and coping techniques in a 12 session programme.



The Commissioning Lead also spoke about investing £250,000 for the services and said that a model would be developed for these services. When we held a meeting with the HSCB three months later, in May 2015, the model had not yet been formulated. In the most recent draft Commissioning Plan for 2016/17 this is still the proposed model.

At a meeting held on 29th May 2015 with the Chief Executive of the PCC, the Commissioning Lead, patients and carers, it was agreed that the HSCB would develop a proposal to re-establish a secondary care medical consultant post. This agreement had not been followed through. At the June 2016 HSCB meeting, the PCC Head of Operations raised this issue.

This position was viewed by patients as hugely disappointing as they feel their most important need is for a proper diagnosis as early as possible in the illness.

On 4th July 2016, Mr Dean Sullivan, HSCB Director of Commissioning, issued a letter to all HSC Trust medical directors seeking expressions of interest in a post for a regional consultant for ME/CFS (three Programmed Activities [PAs] per week).

In July 2016, PCC officers have engaged with senior clinicians and scientists across health and social care to gather advice and opinion on how to best support ME/CFS patients and their families. The general consensus of opinion is that ME/CFS is definitely a physical illness with potential psychological implications.

ME/CFS affects patients in many ways. They are not a homogenous group. Thus, professionals agree that many patients do indeed have an incorrect diagnosis. The most important need is for them to initially get a diagnosis. Historically, this service was provided by secondary care general physicians. As medical consultants are now generally specialised, it is virtually impossible for patients to access such a service.

The PCC is continuing with its efforts to get more recognition for people with ME/CFS. Recently, we have discovered that two counties in England – Norfolk and Suffolk – have been permitted to adopt a care model that is more akin to the Canadian Consensus Criteria guidelines.

In August 2016, patients supported by the PCC met the Chief Scientific Advisor to the Department of Health to discuss the possibility of a clinical trial of a drug which is currently being used in a private trial. The possibility of conducting a trial pilot is currently being developed.

In addition PCC staff have been developing outline proposals for a GAIN Audit of the implementation of NICE guidelines in Northern Ireland and patient experience of same.



Conclusion

There are more than 7,000 cases of ME/CFS in Northern Ireland 10% of who have moderate to severe symptoms.⁹ However, there is no specialist diagnosis or treatment centre in Northern Ireland.

Through our work and engagement with people with ME/CFS and clinicians, we are aware that misdiagnosis can be common and some people have told us that exercise-based programmes have aggravated their condition. Other people say that CBT can help them cope with the consequences of their illness.

On this basis, the PCC is asking healthcare decision makers in Northern Ireland to make the following issues a matter of priority:

- Patients are given a proper diagnosis using a standard clinical method that will establish a proper baseline for treatment/cure;
- That there is a centre in Northern Ireland for the diagnosis and treatment of people with ME/CFS. The first step in this process is the reinstatement of a secondary care medical consultant to enable proper, timely diagnosis, and to support GPs with the treatment and care of patients;
- That the Condition Management Programme should no longer be deemed as an appropriate treatment for patients in Northern Ireland with moderate to severe ME/CFS.



Glossary of clinical terms

Cognitive behavioural therapy (CBT): a talking therapy that can help people manage their problems by changing the way they think and behave.

Chronic fatigue immune dysfunction syndrome (CFIDS): a complex and debilitating chronic disease characterised by extreme fatigue that cannot be explained by any underlying medical condition. The fatigue may worsen with physical or mental activity, but doesn't improve with rest.

Chronic fatigue syndrome (CFS): as for CFIDS.

Condition Management Programme (CMP): a 12-week, voluntary programme delivered by healthcare professionals that aims to help people better understand and manage their health symptoms and return to a healthy lifestyle.

Congestive heart failure: heart failure that occurs when the heart is not pumping enough blood to meet the body's needs. As a result, fluid may build up in the legs, lungs and in other tissues throughout the body.

Fibromyalgia: a disease characterised by chronic pain, stiffness and tenderness of muscles, tendons and joints, without detectable inflammation.

Glandular fever: an infectious viral disease characterised by swelling of the lymph glands (notably in the neck, armpits and groin) and prolonged physical and/or mental weariness.

Graded exercise therapy (GET): a physical activity that starts very slowly and gradually increases over time.

Hashimoto's thyroiditis: an autoimmune disease in which the immune system turns against the body's own tissues which, in the case of Hashimoto's, is the thyroid. Symptoms of an underactive thyroid include poor ability to tolerate cold, a feeling of tiredness, constipation, depression and weight gain.

Irritable bowel syndrome (IBS): a chronic disorder involving abdominal pain, bloating and changes in bowel habits, such as diarrhoea. It is caused by an overactive bowel.

Multiple sclerosis (MS): a disease in which damage to the myelin coating around the nerve fibres in the central nervous system and to the nerve fibres themselves interferes with the transmission of nerve signals between the brain, spinal cord and the rest of the body. Symptoms include numbness, tingling and stiffness in the limbs, difficulty walking, spasms, fatigue, weakness, bowel and bladder problems.



Myalgic encephalomyelitis/encephalopathy (ME): as for CFIDS.

Neurological: the science of the nerves and the nervous system, especially of the diseases affecting them.

Pacing: taking a balanced, steady approach to activity – mental and physical – to counteract the common tendency to overdo things and suffer the ill effects afterwards.

Pathophysiology: the study of changes in the way the body works that result from disease.

Pneumonia: lung inflammation caused by bacterial or viral infection, in which the air sacs fill with fluid or pus causing a cough with phlegm or pus, fever, chills and difficulty breathing.

Post-exertional malaise (PEM): a 24 to 48-hour delayed exacerbation of all symptoms of ME/CFS.

Postural orthostatic tachycardia syndrome (PoTS): a condition in which the heart rate increases by more than 30 beats per minute when standing, causing dizziness, fatigue and other symptoms.

Post-viral fatigue syndrome (PVFS): as for CFIDS.

Raynaud's disease or phenomenon: a disease characterised by spasm of the arteries in the extremities, especially the fingers, usually brought on by constant cold or vibration. Symptoms include pallor, pain, numbness and, in severe cases, gangrene.

Rheumatoid arthritis: a chronic progressive disease causing inflammation in the joints and resulting in painful deformity and immobility, especially in the fingers, wrists, feet and ankles.

Sicca syndrome: a disorder of the immune system identified by its two most common symptoms - dry eyes and a dry mouth.



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