

**MYALGIC ENCEPHALOPATHY/CHRONIC FATIGUE SYNDROME
(ME/CFS) and FIBROMYALGIA (FM) TASK and FINISH GROUP**

Report and Recommendations

August 2014

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1. Introduction

Both ME/CFS and Fibromyalgia are complex conditions and although there are examples of good practice in Wales, challenges exist in accessing appropriate care and services.

At the end of 2013 an ME/CFS and Fibromyalgia Task and Finish Group was reconvened to focus on the practical means of improving NHS services and patient experience.

The group accepted the previous Task and Finish Group's recommendations that the use of Care Pathways remained valid. The challenge the group identified was in the delivery of services and ensuring consistent national access.

The recommendations below focus on strengthening implementation arrangements and improving patient voice in the system.

In making its recommendations, the Task and Finish Group has sought to identify the infrastructure required to support system change.

The Task and Finish Group believe that it is both possible and necessary to implement more effective pathways for ME/CFS and Fibromyalgia and to improve knowledge in the healthcare workforce. The recommendations should provide the tools to:

- increase timely diagnosis, allowing effective care to commence promptly
- provide effective self management advice much earlier
- minimise the chances of people's conditions becoming severe and/or requiring increased health service resources
- streamline referrals, ensuring more efficient and economic use of resources
- improve the experience and outcomes for patients,

2. Recommendations

Recommendation 1: Each Health Board to identify an Executive Board member with responsibility for overseeing implementation of the recommendations below

- The Board member should act as an advocate for service development, support the clinical lead(s) (see recommendation 2) and provide accountability for progress.

Recommendation 2: Each Health Board to identify, by April 2015, an appropriate clinical lead or leads for ME/CFS and Fibromyalgia to take forward the recommendations and to identify a “home” for services for ME/CFS and Fibromyalgia.

- Role(s) must be recognised in job plans and leads should have access to some administrative support.
- Depending on the available expertise within the Health Board, it may be appropriate to appoint separate leads for ME/CFS and Fibromyalgia, or to appoint a single lead to provide leadership for both patient groups.
- The clinical lead(s) should report regularly to the Board member.
- There is scope for some flexibility in deciding which speciality (or specialities) should take the lead, but the home should not be located in mental health services.
- As both ME/CFS and Fibromyalgia demand a multidisciplinary approach, the aim is to provide coordination and coherence in referral that has been lacking so far, not to suggest that the home speciality would see all patients.

Recommendation 3: Each Health Board to identify relevant specialists and those with expertise or interest in developing services to establish a stakeholder group or groups (including patient representation) to support the clinical lead or leads in ensuring the effective delivery of recommendations 4-8

- The stakeholder group(s) must bring together a multidisciplinary group, with a range of relevant specialists and patient representatives to advise on and contribute to delivering an effective care pathway for ME/CFS and Fibromyalgia.
- The stakeholder group(s) should be chaired by the clinical lead(s) who report to the Board member with responsibility for ME/CFS and Fibromyalgia.

Recommendation 4: Each Health Board to develop effective local pathways for children and adults with ME/CFS and Fibromyalgia, by drawing on the following:

ME/CFS:

- Map of Medicine - Chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) – suspected
- Map of Medicine - Chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) – management
- Scottish Good Practice Guidance on ME-CFS - <http://www.show.scot.nhs.uk/GoodPracticeStatementonME-CFSforGeneralPractitioners.aspx>

- Neurological Conditions Delivery Plan - <http://wales.gov.uk/topics/health/publications/health/strategies/neurological/?lang=en>
- Emerging guidance for supporting people with ME/CFS

Fibromyalgia

- Map of Medicine – Fibromyalgia
- EULAR guidance for Fibromyalgia - <http://ard.bmj.com/content/67/4/536.short>
- Service Development and Commissioning Directive for Chronic Non-Malignant Pain - <http://wales.gov.uk/topics/health/publications/health/strategies/pain/?lang=en> - and Arthritis and Musculoskeletal Conditions - <http://wales.gov.uk/topics/health/publications/health/strategies/arthritis/?lang=en>
- Fibromyalgia e-learning resource
- Emerging guidance for supporting people with Fibromyalgia

Recommendation 5: Each Health Board should undertake work to raise awareness of ME/CFS and Fibromyalgia in primary care, to support timely diagnosis and effective management of both children and adults

- Health Boards should provide support to GPs to support people living with ME/CFS and Fibromyalgia to become experts in their own care and self-management, as well as providing clear pathways for referral for specialist support as appropriate.
- The best methods to provide support for primary care practitioners will need to be further explored. The Implementation Group (recommendations 8 and 9) may advise on an 'All Wales' approach, but delivery would be managed locally as appropriate.

Recommendation 6: Each Health Board to identify the means by which they will provide support to people with ME/CFS and Fibromyalgia who need to attend hospital, or receive palliative care, as well as ensuring the delivery of care as close to home as possible, including the provision of telemedicine/home visits to severely affected patients unable to attend appointments via other means

- There is a need to meet the intensive and specialist care needs of the small numbers of people who need inpatient care or palliative care, and the larger group who may need to access domiciliary care.
- There is scope for the expansion of the delivery of telemedicine services via

Skype (for example), in line with Welsh Government commitments to incorporating innovations for patient consultation and treatment reviews, and care could be delivered by working with chronic management (though access to specialists may be required for those whose care could not be provided by community teams).

Recommendation 7: Each Health Board to produce a practical, realistic and timed action plan to improve patient experience of services by people with ME/CFS and Fibromyalgia during 2015-2018, and report annually on progress

- An initial draft action plan should be prepared by June 2015, indicating actions which the Health Board intends to take to implement the above recommendations. A final action plan should be developed by September 2015.
- An annual progress report should be prepared in March 2016, March 2017 and March 2018.
- Action plans and annual reports should be submitted to the Welsh Government and published on Health Board websites, as well as submitted to the Implementation Group for peer review and shared learning.

Recommendation 8: Each Health Board to release a representative (or representatives) to form an All Wales Implementation Group (which will also include third sector patient representatives)

- Representatives would be the Health Board clinical leads, with the group naturally being formed of a variety of different healthcare professionals. Additional representatives should be invited to join (or otherwise contribute) to the Group as appropriate to ensure an appropriate multi-disciplinary approach. In particular, members of the Task and Finish Group have identified the importance of involving a paediatrician.
- Patient representatives will play an important role on the Group.
- Welsh Government will be represented on the Group.
- The Group will appoint a Chairperson from the NHS, in agreement with Welsh Government.

Recommendation 9: The Implementation Group to provide an All-Wales overview of service-improvement for ME/CFS and Fibromyalgia in implementing recommendations 1- 8

The Implementation Group should:

- Share good practice and provide peer support and challenge to all Health Board's in their implementation of the above recommendations
- Provide advice on an All-Wales approach to the provision of training and support for GPs
- Keep under review the availability of guidance for the diagnosis and management of ME/CFS and Fibromyalgia; disseminate emerging good practice across Health Boards; identify available opportunities to collaborate with Universities and Public Health Wales on research projects relating to ME/CFS and Fibromyalgia and use the experience of service improvement in Wales to contribute to broader UK or international development of best practice guidance.
- Convene or coordinate, as appropriate, work to focus on the specific (and different) needs of people with ME/CFS and Fibromyalgia, undertaking individual work streams if required, in order to drive progress with the different pathways.
- Convene a multi-agency national group (including education and social services) to advise health boards and local authorities on delivering appropriate pathways for children and young people with ME/CFS and Fibromyalgia, and ensuring effective transition to adult services
- Consider availability of data and measures to monitor and report progress, in order to drive continuous improvement in Health Boards and to provide transparency to people with ME/CFS and Fibromyalgia and to the Welsh Government.
- Advise the Minister, following publication of Health Board annual reports on progress made and any further development needed

Recommendation 10: The Minister should write to Chairs of Local Health Boards outlining the recommendations, timescales for their implementation and reporting requirements

- There is a long history of slow progress in driving improvement for these patient groups. Progress was limited following the issue of the Map of Medicine pathways and it will be helpful to have a very visible Ministerial direction for these recommendations to be implemented.

Recommendation 11: The Task and Finish Group recommend the Minister agrees to the publication of the recommendations.

- The Task and Finish Group believe that it would be a positive move to make a public announcement in relation to the recommendations, signalling hope for patients and the need for Health Boards to respond proactively.

3. Background

- The true prevalence of ME/CFS in the UK is unknown, and estimates vary according to definition used, but has been estimated at between 0.2% and 0.4%. Advice provided by Public Health Wales to the Welsh Government in 2009 suggested using the mid range prevalence rate of 0.3% which would suggest around 9,500 people affected in Wales. Approximately 25% are severely affected. Estimates for prevalence of Fibromyalgia are higher, at 2% or above, although under-diagnosis makes estimates hard to verify.
- The previous ME/CFS Task and Finish Group, established in 2009, recommended the use of 2 care pathways¹ in Wales (one for use in “suspected” ME/CFS and one for use in the “management” of the condition). A separate pathway was developed for Fibromyalgia². The pathways were based on Map of Medicine Care Pathways and adapted for use in Wales.
- In May 2011 the then Chief Executive of the NHS wrote to Chief Executives of all Health Boards requesting them to develop services in line with the pathways with immediate effect. On seeking updates on progress in 2012 it was apparent that limited improvement had been achieved and patient concerns were being channelled through AMs and MPs. This suggested a lack of prioritisation and supporting measures were needed to enable implementation of the pathways. Patient complaints about (the lack of) services were high and frustration was expressed by healthcare professionals seeking to provide care for patients with these conditions.
- In 2013 the then Health Minister, Lesley Griffiths AM decided to reconvene the Task & Finish Group, a decision endorsed by the current Minister for Health & Social Services, Mark Drakeford AM. The Task and Finish Group met in December 2013, February 2014 and May 2014. Members of the group are listed in Appendix 1.
- In a speech which the Minister for Health and Social Services gave to the Welsh NHS Federation on 16 January 2014, he challenged the NHS to shape the future of care on the basis of ‘prudent healthcare’. Drawing on the work of the Bevan Commission, he summed up core principles he wants applied to health services in Wales:
 - Do no harm

¹ Map of Medicine: Chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) – suspected and Map of Medicine: Chronic fatigue syndrome and myalgic encephalopathy (CFS/ME) – management

² Map of Medicine: Fibromyalgia

- Undertake the minimum appropriate intervention
- Work in co-production with the patient, to consider “what can we do together to address the difficulties that you are experiencing”
- Deliver healthcare that fits the needs and circumstances of patients, and actively avoids wasteful care that is not to the patient’s benefit
- Deliver healthcare on the basis of equity, with clinical need and nothing else determining treatment by the NHS

The group has sought to make recommendations which will enable the development of care for these patient groups in line with these principles.

4. Examples of good practice

- Members of the Group identified a number of examples where Health Boards have built on established expertise to develop services for people with ME/CFS and Fibromyalgia. Although the services described below are not available universally across Wales, they show how existing resources can be used to develop management support for people with these conditions. It is important to stress that a variety of approaches are needed and that patients and carers should be part of the developing process.

ME/CFS in Powys

In Powys, people with ME/CFS can access services through the Pain and Fatigue Management Service run by the Local Health Board. This service runs clinics in which people with the condition receive a full biopsychosocial assessment following which a care plan is devised by the individual working in collaboration with the clinician. One option is to attend one of the community based pain and fatigue management programmes which are run at six locations throughout the county during the year but for more complex cases attending the three week residential programme is also an option. In addition, Powys Teaching Health Board is piloting “Invest in your Health Programmes” for people with any long term health condition and their carers, which people with ME/CFS are able to attend. Individual support is also available and given the rural nature of the county and the difficulty many people with chronic fatigue have in travelling, can be provided over the phone. To improve access still further the Pain and Fatigue Management Service is also looking to use video conferencing with people in their own homes.

Fibromyalgia in Abertawe Bro Morgannwg

Patients with a diagnosis of Fibromyalgia are referred into Rheumatology

Occupational Therapy from the Rheumatology Consultant, Chronic Pain Team or Physiotherapy. Patients are seen individually and a collaborated agenda is set for self management. If appropriate, patients are offered the opportunity to attend the FM group, which runs approximately every six months, one in Swansea West and one in Swansea East. The group runs once a week for 3 weeks, with 3 hour sessions to support self management. Graded exercise, in conjunction with a physiotherapist, is included and the group also considers the anatomy and physiology of FM and pain, identifying individual goals and how to build an action plan towards achieving those goals, sleep hygiene, relaxation, pacing and planning, communication, complementary therapy and building a support network. The service is constantly evaluated to ensure best practice and is in the process of expansion across the Health Board. If a patient chooses not to attend the group or if there is a wait until the next group starts, there is the option of attending individual sessions with the occupational therapist to work on their collaborated Self Management Plan. There is an open door policy for patients to speak to the Occupational Therapist regarding their Self Management Plan.

5. Main areas for development

The examples in section 4 are not replicated across all parts of Wales and provision is currently inadequate to meet the needs of people with ME/CFS and Fibromyalgia. The Task and Finish Group acknowledges that Health Boards have faced a number of challenges in implementing a pathway and providing services for people with ME/CFS and Fibromyalgia:

- limitations to the evidence base for appropriate interventions;
 - for ME/CFS, a lack of consensus about the diagnostic criteria and treatment and management options recommended by NICE and/or the interpretation of them by healthcare professionals
 - for Fibromyalgia, a lack of NICE guidance (although internationally recognised EULAR guidance is available)
- a shortage of professionals with specialist knowledge, interest or the confidence to diagnose
- few clinical champions within NHS Wales
- resource and financial constraints

The Group identified a number of key areas for development, which inform the recommendations.

The areas for development are:

5.1 Primary care and timely diagnosis

- Many GPs work extremely hard to support people with ME/CFS and Fibromyalgia but patient surveys and charity helpline records (for both conditions) show that this is not universally the case; many patients still do not feel that GPs take them seriously and some continue to report experiencing hostility. Patients express concerns that GPs seem to have limited knowledge of their condition.
- GPs meanwhile face significant challenges in diagnosis and management because of multiple and complex symptoms and a historic lack of consensus on diagnosis and treatment. This is compounded by the lack of a clear referral pathway and the limited specialist interest in diagnosis or providing treatment once a diagnosis is reached. Delayed and/or multiple referrals are common due to difficulty in identifying the condition and/or the most appropriate specialist, and diagnosis can sometimes take several years. Such significant delays in providing effective self-management support may result in considerably greater long term support needs.
- Achieving timely diagnosis for ME/CFS remains a significant challenge. Patient groups report that some GPs have a low understanding of the post-exertional nature of the condition, the sheer degree of physical debilitation which it can cause, sub-groups of patients and the range of severity that is seen. There are also difficulties with obtaining home visits where needed and with GPs understanding that, due to cognitive difficulties, patients may

need a written summary of discussions. Members of the Group who treat people with ME/CFS report that when they provide training for GPs, sessions tend to be attended by those who already have an interest, without the knowledge spreading further. The situation appears to be stable, rather than improving.

- The position for patients with Fibromyalgia can be very difficult. In addition to issues highlighted for ME/CFS, problems highlighted by patient groups include overlapping diagnoses, a diverse range of symptoms, an apparent lack of understanding by some GPs and the perception that pain is 'all in the mind'. Some patients find that they are sent away with painkillers, rather than GPs taking a more holistic view of the history and referring for pain management. '4 years of suffering' before reaching diagnosis was cited. Patient groups indicate that there is some evidence that more recently qualified GPs are, in general, a little better equipped to support patients than those who have been practising for a long time.
- A lot of excellent care can and should be managed in primary care, with as few professionals involved as possible, although - where appropriate - effective referral to suitable specialists should be easily accessible. Management should start before confirmed diagnosis and GPs should be proactive in working with patients to begin management and self-management.
- The concept of the 'key worker' may be helpful in considering the management of people with ME/CFS and Fibromyalgia; this role will frequently be fulfilled by the GP, but - depending on care pathways adopted in the Health Board - could be fulfilled by a number of other health professionals.
- To achieve this, Health Boards need to support primary care teams to work with patients to find the best management approaches. This requires support and access to specialist advice when needed, which is currently limited.

5.2. A coordinated Health Board approach, led by a clinical lead or leads

- ME/CFS and Fibromyalgia are relatively rare if compared to conditions such as diabetes with which there is greater familiarity. Providing care for people with these conditions should involve a wide range of different specialists (not all of whom are enthusiastic about supporting these patients), who play different roles in symptom management or – crucially – in providing support for self-management. Coordination of care is currently lacking and the Group felt that there could be considerable benefit in appointing a clinical lead or leads in each Health Board (either a lead to cover ME/CFS and Fibromyalgia, or 2 separate leads, depending on available knowledge/expertise). Because of the relatively small numbers of people affected, it was suggested that 2

neighbouring Health Boards could choose to work together to provide clinical leadership and coordination of patient care, if this proved to be the most effective means of using existing resource and knowledge/expertise and ensuring effective leadership and patient benefits across both the Health Boards.

- The consensus was, in the context of the required multi-disciplinary approach, there is room for flexibility as to the specialism of the clinical lead or leads, with the exception that the lead (for either condition) should NOT sit in mental health, which has sometimes been the case. It was noted that although mental health services have transferrable skills and understand case management, placing the lead in mental health services is inappropriate, causes stigmatisation and has tended to lack the multi-disciplinary team approach which is required. Psychologists on the Group stressed that their role is in supporting patients to manage the impact of the illness, and is not about treating it as a psychological disorder.
- This is not in any way to undervalue the important role which mental health services may play in supporting some people with these conditions. Depression or anxiety may be co-morbid and the pain, social withdrawal, lack of activity and difficulty accessing services - which often accompany these conditions - can cause depression and anxiety which may need treatment. Adequate attention must be given to the mental health needs of these patient groups.

5.3. Understanding and implementing the Map of Medicine pathways locally

- Although the Map of Medicine pathways should have been implemented previously, to date they have not been implemented effectively, and have therefore not made much impact on the health service or difference for patients.
- Implementing the pathways is not impossible and does not mean the establishment of entirely new services; it requires Health Boards to look at a range of existing services to see how they can be used to deliver support for people with ME/CFS and Fibromyalgia, and ensuring effective coordination and joined-up condition management across the range of specialities which have value to add.
- To achieve this, Health Boards need to explore what the pathways involve, and how they can be delivered at local level, using the existing skills and resources of the Health Board. The experience of work currently underway in Hywel Dda (relating to services for ME/CFS) suggests that the most effective results may be achieved by using the Map of Medicine pathways as a starting point but supplementing them with a range of other evidence-based guidance, such as the *Scottish Good Practice Statement of ME-CFS*. This is helpful for contextualising treatments referred to in the Map of Medicine and understanding the range of treatment approaches that may or may not be appropriate for different people, depending on how ME/CFS or Fibromyalgia

affects them and the severity of their condition. As the evidence-base for both conditions continues to develop, the best available guidance may change over time; clinical leads will need to remain abreast of developments. Pathways will consist of a range of approaches; a single approach is not appropriate for either ME/CFS or Fibromyalgia.

- A good local understanding of what needs to happen in primary and secondary care to deliver the pathway should raise standards. This work would provide a real opportunity to collaborate with service users to identify what services should look like. It would involve integrated team working to deliver different functions and 'localising' the pathway to help GPs at a local level.

5.4. Children's services and the transition from adult to children's services

As far as ME/CFS is concerned:

- According to the Association of Young People with ME, ME/CFS affects an estimated 1 in every 100 secondary school children in the UK. The youngest child diagnosed was just 2 years old.
- Care for children with ME/CFS is usually coordinated by a paediatrician but requires effective working with education and social services to ensure appropriate support to optimise recovery. Pressure to remain in school when children are insufficiently well can increase the severity and/or the duration of illness.
- Patient groups report that some children with ME/CFS are still being labelled as having 'Fabricated Illness', leading to child protection proceedings being taken against parents. Children are also referred to social services for non-attendance of school.
- Significant difficulties are also faced by young people with ME/CFS at the point of transitioning to adult services where the management of a supportive paediatrician who has negotiated the child's needs is lost at the same time as meeting difficulties in accessing adult services. This is particularly difficult for severely affected young people and supports the need for a clinical lead for services to facilitate an effective handover. Problems with transition have been reported across Health Boards and are not unique to ME/CFS.

For children/young people with Fibromyalgia:

- Patient groups report that it can take a long time to get a diagnosis (young people are often told that they have 'growing pains' despite evidence of familial aggregation and indications of genetic predisposition).
- Patient groups indicate that in their experience some paediatricians do not

have knowledge of Fibromyalgia and the complexity of symptoms involved.

5.5. Hospital and domiciliary services

- Patient representatives on the Group identified difficulties faced by people with ME/CFS who need to access hospital provision. Numbers are relatively low but patient experience for this group was described as exceedingly poor. Difficulties are also caused by the lack of a domiciliary service (which includes patients being unable to access any services or experiencing significant relapse as a result of attending appointments/treatment). It was suggested that numbers needing domiciliary services could be 25% of the ME/CFS patient group.
- Similar concerns were raised by patient representatives for Fibromyalgia. They also highlighted difficulties with obtaining alternative appointments after a patient has unavoidably been unable to attend a planned appointment due to the level of pain or inability to walk, which can vary significantly from day to day, within a single day and as a result of weather conditions.
- Those providing services indicated that they have no facilities available to provide domiciliary services, transport or telemedicine available from home.
- Difficulties with accessing care for those unable to attend appointment do not only apply to ME/CFS and Fibromyalgia patients but the needs of this sub-group of patients should be addressed in the development of local care pathways. This could involve the inclusion of community re-enablement teams and clinical nurse specialists in plans for delivering services as close to home as possible.

Appendix 1: Members of the Task and Finish Group

Contributors to the work of the Task and Finish Group were as follows:

Abertawe Bro Morgannwg	Clare Clark	Advanced Practitioner
Aneurin Bevan	Sally Lewis	GP and Primary Care Clinical Director
	Sarah Flowers / Rachel Griffiths	Clinical Psychologists
	Sue Jeffs	Consultant in Anaesthesia and Pain Management
Betsi Cadwaladr	Simon Neal	Consultant Clinical Psychologist
Cardiff and Vale	Jane Boyd	Clinical Director for Psychology and Counselling Services
Cwm Taf	Jonathan Richards	Professor of Primary Care, University of South Wales / Locality Clinical Director (Cynon), Cwm Taf Health Board / General Practitioner / Cwm Taf Champion for Chronic Fatigue syndrome
	Juan Delport	Head of Psychological Services
Hywel Dda	Claire Hurlin	Chronic Conditions Clinical Lead
Powys	Owen Hughes	Consultant Counselling Psychologist / Head of Pain and Fatigue Management Service
Velindre	Jo Hampson	Consultant Clinical Psychologist, Chronic Pain Programme (employed by Cardiff and Vale)
Fibromyalgia Wales	Carol Ross	Founder
	Yvonne Singleton	South Wales Support
Welsh Association of ME and CFS Support (WAMES)	Jan Russell	Chair
	Sylvia Penny	Youth and Care Officer

	Robert Messenger	Volunteer
Cardiff University	Ann Taylor	Reader in Pain Education and Research Department of Anaesthetics, Intensive Care and Pain Medicine
Welsh Government	Katherine Thomas (now Ann Noyes)	Senior Policy Manager / WG policy lead for ME/CFS and Fibromyalgia (Chairperson)
	Viv Collins	Policy Manager (Secretariat)
	Jason Stickler	Policy Officer (Secretariat)
	Heather Payne	Senior Medical Officer, Maternal and Child Health