

**P-05-926 To Provide a Chronic Fatigue Department in Wales, Correspondence
- Welsh Association for ME & CFS Support (WAMES) to Chair, 27.04.20**

Jan Russell, Chair,
Welsh Association for
ME & CFS Support (WAMES)
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Dear Janet,

Thank you for seeking the views of WAMES on Petition P-05-926. We have a number of concerns and comments about the petition, the information supplied by the Health Minister and the current NHS service status.

1. Chronic Fatigue

Chronic fatigue is a symptom which is experienced by people with a wide range of illnesses. The petitioner is correct that if GPs, after doing basic blood tests, cannot find an obvious cause for the fatigue, they might assume the patient is depressed, even if they are not, leaving the patient to feel ignored & frustrated. Some patients with co-morbid depression will equally feel frustrated that their physical issues are being ignored. Some GPs have seen 'Chronic Fatigue Syndrome' as a convenient label to give patients complaining of excessive fatigue. This has sometimes led to people with MS, Parkinson's, MND etc. experiencing a delay in getting a diagnosis and beginning treatment.

I am unclear whether the petitioner believes they suffer from idiopathic chronic fatigue, Chronic Fatigue Syndrome (CFS) or Myalgic Encephalomyelitis (ME). Usually people with ME don't like to talk about chronic fatigue because it is only one symptom, may not be the most debilitating and can be misleading. ME is a debilitating chronic multi system disease that affects the neurological, autonomic, immune, endocrine, cardiac and energy metabolism systems. The key characteristic of ME is Post Exertional Malaise (PEM) though this may not be the best terminology for it. Basically it is an abnormal physiological response to normal activity. Patients experience a significant and prolonged worsening of ME symptoms, and a reduction in the ability to function. (<https://www.youtube.com/watch?v=TGlo1v7KVJQ>). Because of the presence of PEM, treatment for chronic fatigue in ME is significantly different than treatments for chronic fatigue in other medical conditions. It is therefore difficult to treat fatigue in ME in clinics set up to treat fatigue in e.g. pain conditions.

2. Diagnosis

GPs are often wary of giving a diagnosis for a condition they do not understand and cannot treat. We find they prefer to refer to a consultant, but unfortunately most consultants do not have the knowledge or interest to make a diagnosis of CFS or ME either. In addition the controversial *NICE guideline* for CFS/ME does not give a clear

picture of ME, making it difficult for doctors to accurately distinguish ME from other fatiguing conditions. The *NICE Guideline* is currently being revised, hopefully to recognise PEM as a defining feature and to recommend treatments & management strategies which acknowledge exercise or activity intolerance. The current guideline's treatment recommendations were based on research which has since been discredited (PACE trial). Unfortunately due to the Covid-19 crisis the completion date will inevitably be postponed well into 2021. There are a number of more evidence based diagnostic guides available, but none has the standing in the UK medical community that NICE has, though the *BMJ Good Practice guide* for CFS/ME does acknowledge the defining characteristic of PEM and the potential dangers of exercise programmes.

3. Current healthcare services for ME & CFS

Complementary therapies & alternative remedies - In the absence of understanding and advice from doctors we find that a number of patients are driven to seeking out alternative remedies for symptoms. Some of these can be very expensive, and while having some effect for some people with ME, are unlikely to treat the underlying dysfunction, so the patient continues to feel unwell, and financially poorer. The petitioner mentions the Myers Infusion, a cocktail of vitamins and minerals, as a potential treatment, which is not available on the NHS. A 2009 trial of Myers-type IV cocktail v placebo in Fibromyalgia patients found that no statistically significant differences were seen between *Intravenous micronutrient therapy* (IVMT) and placebo. I am not aware of any research trials in ME or chronic fatigue, but I suspect that it is unlikely it will become an option for the NHS in the foreseeable future.

ME/CFS Clinic - The ME/CFS clinic in North East Wales, mentioned by the Health Minister, offers management strategies based on the ACT protocol (Acceptance and Commitment Therapy). You need a diagnosis before referral, and I understand that not all people referred do in fact have an accurate diagnosis. The clinic is helpful for some mobile patients who can travel without causing a deterioration in symptoms. It has no medical input which means that medical problems can be overlooked. There is no follow up service and we know of one patient who went on to commit suicide. There is also no known outreach service, so it cannot help the many housebound patients in the area. The clinic is run by a part time clinical psychologist, who is heading for retirement, so it is uncertain how long it will be able to offer help to the small numbers it currently caters for.

Pain clinics - There are a few pain/ fatigue clinics that accept a small number of ME patients: Bronllys hospital (Powys), Llanfairfechan (Conwy), Cardiff and possibly the Swansea Bay pain service. Unfortunately they do not cater for people with exercise intolerance and PEM, so patients have to participate with care. The graded exercise/activity approach offered by some is the approach found to be unhelpful for people with ME. We have received a number of reports from people with ME who deteriorated markedly following attendance at the Llanfairfechain clinic. It has been impossible to find anyone within Betsi Cadwalladr UHB to take this seriously and the clinic continues to operate. We understand that pain clinics in Cardiff and Swansea Bay would like to extend their services to people with ME but do not have the capacity to do so, and have not received financial support for people with ME from their Health Boards. In addition the Bronllys hospital site is not accessible and

cannot accept people with limited function or in wheelchairs. The inpatient service is unsuitable for anybody who is not able to self-care or cook for themselves. The service's outreach fatigue and pain classes in different parts of Powys require a patient to be well enough to travel, so even *if* patients wished to attend, most couldn't.

Neuro clinics - Some years ago I asked Powys Neuro Clinics to accept patients with ME as it appeared to offer a suitable approach to helping patients by maximising function without causing harm, but I was told there was already provision for ME & CFS at the Bronllys pain & fatigue clinic!

EPP – some mobile people with ME have benefitted from attending Chronic Conditions Self-management courses, but as with the Pain clinics, fluctuating symptoms and travel induced relapses have meant not all can complete the course. Suitability is also dependent on the volunteer leader of each course understanding that exercise isn't good for everyone, so that pressure isn't applied on participants. There is an online self-management course in north Wales but we have received no reports of people with ME accessing it, maybe because people are wary, particularly in North Wales, of the NHS approach to ME. In 2018 Christine Roach, the programme manager for EPP, asked me to meet her to discuss setting up an ME specific self-management course, which I thought would be worthwhile, but that meeting has not materialised.

Technology – the pilot work done by Powys & AB HBs into digital support highlighted that those ME patients with acceptable broadband, technological know-how and ability to cope with screen time could benefit from online and video consultations, *if* there were experienced and/or sympathetic health professionals to interact with.

Patient information – I did some preparatory work on patient leaflets for the Implementation/ Advisory Group last year, but eventually was told that unless they followed the current *NICE guidelines* the leaflets would not be passed by the WG. This would not have been helpful for patients, so I stopped working on them.

Future Service Development for ME & CFS

The petitioner would like to see a Chronic Fatigue Department set up 'with a view to individuals being assessed properly.' Getting an accurate diagnosis is critical, but the *NICE guideline* and other sources suggest that diagnosis is possible in primary care, with only complex cases being referred on. Setting up a condition-specific service requires that GPs will refer people to it and HBs are convinced of the need. Also there would need to be many such services around Wales as travel can be highly detrimental for moderately and severely affected patients. There would also need to be equivalent paediatric services as the condition affects a significant number of children and young people as well.

For years WAMES has been asking for a commitment Wales-wide to:

- **Set up a rolling programme of training and awareness raising for GPs, paediatricians and other health professionals.** There have been many attempts by WAMES and others to encourage the existing training schemes to include ME, with little success.

- **Ensure that the trainers have experience of ME**, and are not just interested professionals sharing partial information or even misinformation. Also, it would be important to ensure that patient stories are included so a better understanding of the debilitating impact of the disease is communicated. [At the beginning of March *Health Education and Improvement Wales (HEIW)* hosted a GP training session in Cardiff led by Dr Nina Muirhead, a dermatology surgeon in Buckinghamshire. Nina also has a part time role at Cardiff Medical School and has had ME for a few years. This was very well received by participants. There was no plan for further sessions to be offered elsewhere in Wales.]
- **Develop an e-learning programme for GPs.** Although the RCGP developed one some years ago ME specialists find it misrepresents ME as a psycho-social fatigue condition and is not based on the growing body of research which points to the presence of multi-system dysfunction. At the request of the HEIW Dr Muirhead is currently developing an e-learning module, although it is uncertain when this might be ready, or even *if* it will be acceptable to the Welsh Government, as it won't follow the *NICE guideline*.
- **Ensure people with a diagnosis of ME are recorded via SNOMED** so HBs can plan appropriate local services and make a case for a specialist service. It is estimated, based on studies by the ME/CFS Biobank at the *London School of Hygiene & Tropical Medicine*, that there could be between 13,000 and 14,000 people of all ages in Wales with ME/CFS, 25% of whom are house or bed bound. It is clearly important to know where they are, what age and how severely affected they are (bed or housebound, or capable of part time work, with support).
- **Simple patient information, accessible online.** One of the plans for the patient info that I was writing for the *Advisory Group* was to put it online so patients could access it, even if their local GPs were not willing or able to advise them. It would appear that the only website where this could be done was as a link from the NHS Direct page on CFS/ME, and it was unclear who would be responsible for 'owning' and updating the leaflets. Individual HB websites are organised differently to each other and sometimes the only place they could host such patient leaflets would be on the pages of a specific service (if there were services for ME & CFS). Alternatively a charity could do it with NHS Wales endorsement, but WAMES doesn't unfortunately have the capacity to do this and we are not the only ME charity whose financial future is uncertain.
- **Identify GPs, paediatricians and consultants with a 'special interest' in ME and CFS**, provide them with training and support so they can establish a development strategy and services in their areas. Health Boards have named Clinical Leads in accordance with the 2014 *Task & Finish Group Report* but these are mostly therapists working in pain, or Board members with a largely administrative oversight of a range of conditions. Until there are 'clinical champions' in the Health Boards, speaking up for ME patients it is hard to see how services can develop in an appropriate way for each area of Wales.

Welsh Government initiatives for ME

WAMES has been involved with all the Welsh Government initiatives for ME & CFS over the years: the *Masterclasses* with poor uptake in 2002; the first *Task & Finish Group Report* in 2010; the second *Task & Finish Group Report* in 2014, the *T&FG*

Report Implementation Group 2014-2019. The *T&F Groups* covered ME, CFS, & Fibromyalgia (FM), which is a pain condition. While individual health professionals got involved in the initiatives, many had experience only of FM. Not all Health Boards have been consistently represented on the groups and most have not been prepared to commit any money or resources to help the ME/CFS/FM leads implement the recommendations of the 2014 Report.

The *Implementation Group* (renamed *Advisory Group*) has consisted of Welsh Government staff, therapists, patient reps and a few doctors. The doctors' experience has been largely in Fibromyalgia. The decision to merge the *Implementation/ Advisory Group* with other pain groups into a *Long Term Pain and Musculoskeletal Conditions Advisory Group* was mooted by Kevin Francis of the *Health Policy Directorate*, who has responsibility for all these conditions and was concerned about the lack of headway the ME, CFS & FM group had made with Health Boards.

The Health Minister is mistaken that 'this approach has received an overwhelmingly positive response from members of all the groups affected'. WAMES, Action for ME and the North East Wales ME/CFS clinic all expressed grave reservations that ME would get lost in a group of pain conditions, particularly if the name focuses on them. Kevin assures me that the name is a 'working title', but it is hard to see how the serious shortcomings in care for ME will be addressed alongside conditions that already have significant medical and clinical support.

Over the last 20 years the CE of the NHS and successive health ministers have requested feedback from Health Boards on the progress in implementing services. Not all Health Boards have responded and those that have, in my opinion, have shown little understanding of the reports' recommendations and little commitment to making service improvements. Unlike the Delivery Groups, the ME/CFS & FM Advisory Group has not been able to give directives, just recommendations, and has provided HBs with no money to fund any changes.

WAMES' role in future Welsh Government initiatives

Before Covid-19, WAMES was aware that we would have to make difficult decisions about what was a good use of our very limited finances and we have debated whether travelling to the new *Advisory Group* meetings would be worthwhile. What will happen to our financial situation and the launch of the new *LTP&MC Advisory Group* in the 'new Covid-19 world' remains to be seen. There may still be some value in having an input into developing strategies that encourage Health Boards to develop 'patient and professional education, effective diagnosis, self-management techniques' etc. but without the medical expertise supporting us it could be an uphill struggle to get noticed by health boards and persuade them to apply those strategies to ME.

In a world where shielding will have to continue for 'at risk' groups for an unknown length of time, it will not be possible for most of the WAMES team to leave home, let alone travel to meetings. Unfortunately video conferencing at the Welsh Government offices has not been very successful in the past. So there are a number of questions surrounding WAMES' continued involvement in Welsh Government initiatives for ME. What would make that worthwhile would be for ME to be taken seriously by the NHS

and Welsh Government as a condition in its own right and one which has more in common with some neurological conditions, than pain conditions.

I will be happy to supply more information about anything I have mentioned.

Yours sincerely,

Jan Russell