30 April 2018

Cabinet Secretary for Health & Social Services

National Assembly for Wales
Cardiff Bay
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Dear Vaughan Gething,

**#TimeForUnrestWales**

A year has passed since I last wrote to you and the Health Boards about the difficulties that patients with ME and CFS have when trying to access help from the NHS.  At that time we asked for a commitment to help health professionals #BeMEAware.  The response was partial and lukewarm!   During 2018 there has been growing pressure from patients and their families to join the global #TimeForUnrest campaign and so a number of campaigns are taking place this year under the #TimeForUnrestWales banner.

WAMES has become particularly disillusioned with the attempt to kick start an improvement to NHS services for people with ME and CFS, initiated by the Welsh Government, for the following reasons.

**Task & Finish Group**

It is 4 years since the Task & Finish Group for ME, CFS and FM published its recommendations. The Report recommended that Health Boards: Appoint an executive lead; Appoint a clinical lead by April 2015; Identify relevant specialists and those with expertise or interest in developing services to establish a stakeholder group (with patient involvement); Develop a clinical pathway; Provide training for doctors and raise awareness of the illness in both adults and children, amongst NHS staff ; 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; Produce an action plan; Send a representative to an all-Wales implementation group.

* Not all HBs have an active executive lead who has taken responsibility for representing ME at an executive level and ensures the clinical lead has the necessary support for implementing the recommendations
* Although some HBs have appointed clinical leads, none are known to have a medical knowledge of ME and some have very little experience of ME or other neurological conditions. Not all attend the all-Wales Group
* Only 3 HBs are known to have held stakeholder groups in the past, 2 with patient involvement. Clinicians with an interest in ME and CFS have not always been released to take part in the service improvement process
* While most HBs have a clinical pathway of sorts they give little guidance to health professionals in navigating suitable services within their HBs and are not used within their HBs. Few have made links with the Neuro Delivery plan implementation groups in their HB, but it was confirmed at the recent Neurological Conditions Group meeting that their remit does not cover ME, CFS and FM, in spite of ME being classified as neurological by the WHO (G93.3)
* I have heard of only 1 training session for a small group of GPs being held in the whole of Wales in the last 4 years
* My attempts to initiate a discussion in the All Wales Group on how to alleviate the extreme suffering of severely affected and bed-bound patients (some of whom have committed suicide in desperation) have always been ignored
* Even if a HB has produced an action plan, few, if any, have been followed up on
* Not all HBs have regularly sent a representative to the All-Wales group

**All Wales Implementation Group**

An All Wales Implementation Group has been meeting a few times every year with a remit to: share good practice; provide an all-Wales approach to the provision of training and support for GPs; review guidance; undertake individual work streams in order to drive progress with the different pathways; advise health boards and local authorities on delivering appropriate pathways for children and young people; consider availability of data and measures to monitor and report progress; report to the Health Minister.

* While the Group has shared about what they have and have not been able to do for people with ME and CFS in their HBs, there is a lack of consensus about what constitutes ‘good practice’ and there has been little discussion of the best way to manage this patient group in an all-Wales approach
* There has been no discussion or provision of an all-Wales approach to training and support for GPs
* Because some in the group promote the clinical guidance based on a psycho-social aetiology of the illness and some prefer the clinical criteria based on biomedical research, and some don’t have the medical knowledge and experience to have a point of view, there has been no discussion of clinical guidelines
* HBs have been reluctant to share their basic pathways and none except Hywel Dda have done significant work on a local pathway
* The needs of children and young people and the problem with transition have only been mentioned in passing
* I am unaware of measures to monitor and report progress, if there were to be any progress
* I hope that as Cabinet Secretary for Health you have received reports of the lack of progress within the AWI group?

I was unable to attend the December meeting of the Group but sent a request for training and awareness to be made a priority of the Group, but I have received no minutes of that meeting, so do not know if the matter was discussed.

**Main areas for development**

Section 5 of the T&FG Report outlines the main areas for development as: Primary care and diagnosis; A coordinated Health Board approach; Implementation of Map of Medicine; Pathways locally; Children’s services and transition; Hospital and domiciliary services.

It is the view of WAMES that the current lack of progress in all development areas will continue and the All-Wales Implementation Group will be destined to be an ineffective talking shop, until there are enough NHS staff, and especially GPs and paediatricians, who really understand the nature of neurological ME and see the severity of the condition and the serious impact it has on the daily lives of patients. What is needed are people who can see past chronic fatigue (a major symptom in many medical conditions, including many other neurological conditions) and give an accurate diagnosis and basic management guidance,  which recognises and takes into account the characteristic post-exertional response (which makes many standard interventions inappropriate). The level of misunderstanding and lack of knowledge of ME and CFS within the NHS is staggering!

**The current situation**

There are estimated to be up to 12,600 people with ME and CFS in Wales, one of  the largest groups of neurological patients. Few have a diagnosis of ME from the NHS. About 25% are likely to be severely affected - bed-bound or house-bound – and 10% are young people under the age of 16.  Many have given up visiting their GP, even if they are well enough to get to the surgery. With and without help and support, a number deteriorate and become weak and severely incapacitated.  Many others request referrals to a wide range of specialist doctors and therapists in a desperate attempt to find answers and some relief. Unfortunately very few of those practitioners are equipped to provide appropriate and effective diagnoses and support. A few are given a Chronic Fatigue Syndrome diagnosis but later discover they actually have other neurological conditions such as MS or Parkinson’s, or treatable conditions such as sleep apnoea or Lyme’s disease. When seeking help for co-existing complaints people with ME can be faced with inappropriate treatment suggestions due to the lack of understanding of the implications of ME.

The huge strain that inadequate funding and staff shortages has been placing on the NHS is well known. It would therefore seem to be a matter of urgency to make better use of the current resources and reduce the strain on the NHS (by reducing the number of unnecessary consultations and referrals) and also on patients (who feel ignored and disbelieved which can lead to mental health problems and additional distress through a longer journey until they find a management plan). The only ME clinic in Wales run by a consultant (Dr Paul Underwood) has been closed down, apparently in an attempt to keep Withybush Hospital staffed and open. The CFS/ME rehabilitation clinic in NE Wales, which has provided help to a small number of mobile patients, is run by a psychologist who is shortly to retire. There is a strong economic argument to invest time and money in improving diagnosis and management of ME and CFS. This would also meet the legal and moral requirement to provide informed and appropriate care.

As the Neuro Delivery Plan implementation group has decided not to include ME and CFS within their remit, in spite of them being classified as neurological conditions, it is unlikely that patients with ME and CFS will be able to benefit from any of the improvements and initiatives developed by them, such as awareness raising and Patient Reported Experience recording (PREMS). Once again people with ME are being ignored and left out in the cold, so it is even more important that special arrangements are made to ensure we are not ignored in perpetuity.

**WAMES’ request**

WAMES therefore asks you to provide, as a matter of urgency, support and finance for a national training and awareness programme which takes into account:

* There are no medical experts in Wales available to share their knowledge, and if we wait for them to ‘miraculously appear’ there will be no training and awareness undertaken. Experienced expert clinicians from outside Wales would need to be invited to take part. WAMES can recommend suitable experts.
* Because there is controversy over aetiology, diagnostic criteria and management advice it would be important to develop a strategy that accepts this current tension and informs staff about it.  Many NHS staff are happy to accept the current NICE guidelines (now being revised) whose treatment recommendations are based on a psycho-social understanding of CFS and partially based on research results that have been found to have been inaccurate). On the other hand patients and some NHS staff know about the biomedical research revelations and understand ME to be a condition classified as neurological with neuro-immune-endocrine involvement. Neither belief should be allowed to be a barrier to patients getting a diagnosis and accessing medical care and other support. e.g. A medical diagnosis is necessary to access social care, transport, educational adjustments, benefits etc.  Without social care severely affected patients can live in squalor and extreme distress. Carers are collapsing under the strain of caring for their loved ones alone.  The right of patients, including children,  to choose the care they wish should be included as a theme running through the programme.
* A training / awareness programme needs to be developed for use across Wales by experienced trainers so that an even standard is achieved in spite of the lack of local knowledge, the controversies surrounding the illness, and the limitations of outside experts with no knowledge of the NHS in Wales. This programme should also give staff the opportunity to hear the experiences of people with ME and CFS.
* A national training initiative could also include funding to enable clinicians to attend major conferences and workshops in England, where they can learn from international researchers and experienced clinicians.
* There is a need for Health Boards to hold ongoing awareness sessions to ensure a wide range of staff are reached over a period of time.

Please do not let another ME Awareness day (May 12th) go past without any steps taken to improve awareness of ME and CFS within NHS Wales.

Best wishes,

Jan

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Chair / Cadeirydd

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