

## **Myalgic Encephalomyelitis Debate, Tynwald, 19th May 2021**

### **Speech delivered by Mr David Ashford, Minister for Health and Social care**

---

I want to start by making a bold statement that for far too long ME sufferers have either not been able to access the services they need to help support them to live their daily lives or been dismissed with the condition and its effects on their lives being marginalised.

I would also at this point like to pay tribute to the ME Support Group. Despite all of the frustrations and on occasions brick walls they have come up against, they have continued to fight for ME sufferers to achieve both the recognition and services they require and I think it is 33 years this year that they have been fighting for this.

For many years, ME sufferers have even struggled to have it acknowledged that their illness exists at all with on occasions their suffering being outright dismissed. It sounds like a crazy statement to have to make but I'm going to make it anyway and that is that M.E. does exist. Not only does it exist but it severely limits the ability for sufferers to live any form of normal life.

I have several friends personally both on island and in the UK who suffer from this debilitating illness so I can say I have seen at first hand the impact on people's lives, unable to move or undertake even basic tasks with complete and utter exhaustion setting in and the frustration and depression that comes with that and the impact on the individual's mental health. So it shouldn't be under-estimated.

It was the ME Support Group when I became Minister and I met with them on the 12th of August 2019 after seeing their petition in the July of that year that made me aware of the issues and the daily struggles that they have been facing day in and day out and finding out in fact that no service was being developed, despite the budgetary allocation made prior to me becoming Minister.

At that point, it was insisted by me that some form of service be delivered. Since then the Department has sought to try and bring forward a service. To be honest, it hasn't over that period been able to move forward wither quickly enough or comprehensively enough and I would say in all honesty, it stalled completely at several stages for various reasons.

In October 2019, we moved to set up and run a pilot scheme for the remaining months of 2019 and to have a consultant-led service in place by April 2020. Unfortunately, as with a lot of our service development, this was affected by the Department's need to focus on the initial Covid response and that fact that, although a consultant to lead the service had been appointed, they decided to leave the post once the pandemic hit and several attempts to re-cruit since then have failed to achieve the desired outcome.

One thing the pandemic has done has shown how much support services are needed with evidence of Long Covid emerging and the service needs to support those sufferers as well.

So we have basically and frustratingly lost 14 months of potential progress. However, in a bizarre way, that delay has actually turned out to be beneficial as the original focus was to be in a consultant-led service, very much in the old style of doing things of having a consultant pointing service-users into all the services.

## **Myalgic Encephalomyelitis Debate, Tynwald, 19th May 2021**

### **Speech delivered by Mr David Ashford, Minister for Health and Social care**

---

The more I and the Department have looked at this again, using that breathing space of those 14 months, we are not convinced this is the most effective way of delivery services or, as Mr Speaker touches on in his question, either the most financially efficient way of delivery support.

There is now a growing body of evidence that identifies dysfunction in the immune system and neurological and energy metabolism systems in people with M.E. To prevent symptoms being exacerbated, the severity of a patient's condition can be greatly impacted by actions in the early stages but too often safeguards and pitfalls are not shared until damage has already been done.

Unfortunately I was not able to attend the members' briefing by the ME Support Group due to prior commitments I couldn't move at short notice. But, after reading the 'Not Waving but Drowning' 25 M.E. case studies from the recent presentation to Tynwald members of which members have all got a copy, the opening quote is really powerful and described how M.E. affects lives.

That opening quote, for those outside this Court who haven't read it, is: **"The single biggest factor determining recovery and remission from M.E. at this point is appropriate rest in the early and severe stages of the illness. The importance of avoiding ever-exertion in M.E. cannot be overestimated."**

Without going through all the case studies, some of the key points that emerge are:

- ME is real and it's a physical illness, complex and fluctuating but devastating, worse than most people are able to imagine and people with ME. have a very low quality of life
- Delay harms health, important to get prompt and accurate diagnosis
- Need for GP education and pathway referrals and finding appropriate support is a nightmare and in many cases impossible.
- Returning to work too early is typical and can harm prognosis. Return should be phased and guided by an M.E. specialist
- Patients have fallen between the cracks of the health and social care systems, something Dr Grieg herself alluded to in the evidence.
- M.E can be extremely severe and debilitating – in other words just talking or standing can be very difficult and trouble can be traumatic, causing days, weeks or months of symptom aggravation and setback.

Looking at our existing services, since 2015 there have been six hours a week of clinical time including the community adult therapy team to provide both physiotherapy and occupational therapy for patients with M.E. in the community, either in a patient's home or in one of our gyms located in Nobles. Six hours, Mr President, six hours is nothing. It is not going to go anywhere.

A business case was submitted as part of the /18-/19 revenue bids which I have referred to, to expand the service and the funding which was £90,000 allocated entirely to fund a consultant psychologist, which is the consultant post to which I have previously referred. His role was to

act as the service leader to co-ordinate care for all patient within the services. Unfortunately, we were unsuccessful in recruiting a substantive consultant and a locum consultant was employed, who worked part-time on island. Clinics were developed including promotion of MDT-working, with physiotherapy and occupational therapy. But, as I said, due to Covid the locum consultant couldn't maintain his working pattern and left in March 2020, leaving the physiotherapy and occupational therapy from the community therapy team delivering 100% of the pilot service.

The continued borders issues and the new for a resilience service have led to an opportunity to review the model, including the development of a Long Covid pathway.

In summary, as a health care system we are committed to working closely with ME Support (Isle of Man) to develop a service that that young people and adults can be promptly and accurately diagnosed and supported by the appropriate illness intervention advice.

### **So how do we go about this?**

Well, activity has been based on the CG53 implementation guidance for M.E. and the Journal of Primary and Community Carer article on Long Covid. Both actually recommend a tiered model where the lower tiers can be provided by guided self-help. Tier Two would be delivered by community practitioners and healthcare liaison psychologists, both on island. And Tier 3 delivered by a tertiary centre.

We have agreed to develop an integrated community care approach that incorporates M.E., CFS and Long Covid, who will be supported by both face-to-face and virtual support and advice from specialists, including support from experts in the field in the UK, using the Liverpool network and that would be based on the recent NICE guidance.

That guidance is supporting improved awareness and understanding, early diagnosis, access to care, care planning and condition management.

To also improve the training referral pathway and guidance available to GPs, and that work will be commencing and ongoing. And also to implement procedures across all GP surgeries on island to ensure consistent, standardised and effective early diagnosis but also to establish a clear framework to determine the times allocated to each patient by the M.E. Service Support team on a sliding scale based on severity.

One of the key themes that emerges as you look at what other jurisdictions have done successfully is that engagement and understanding in primary care is absolutely key, which is exactly what Dr Grieg has told us this morning. Dr Grieg has just explained some of the engagement that had previously taken place but, if any sufferers are to receive the treatment and support they require, then it is essential we have that fundamenta; understanding of the condition at a primary care level and that is why I have asked the Department to look again at having a champion within primary care to try and move things forward.

Manx Care also aims to co-author the new services model and consideration of best practice

## **Myalgic Encephalomyelitis Debate, Tynwald, 19th May 2021**

### **Speech delivered by Mr David Ashford, Minister for Health and Social care**

---

examples with the Isle of Man ME Society. We do need to be cognisant that a therapy work force will also be a challenge, however Manx Care are working through the guidance and benchmarks required and looking at innovative ways to ensure the right multi-disciplinary teams and that's the key thing, Mr President, multi-disciplinary teams are in place and will deliver the best service to our population, so this includes GP networks and also first-contact practitioners.

So, despite the fact that things have had to pause over 14 months, I actually think that this breathing space has allowed us to delve much deeper into what sort of service is needed and to challenge and change away from the old-style consultant-led service and to engage in much more modern, therapy-based thinking around the delivery of services.

Manx Care will work closely with the ME Support Group to develop this service as after all it is those that are suffering that know this illness better than any of us ever could and they also know what works and what doesn't.

Before finishing, Mr President, I have mentioned Long Covid and it is important to make clear that, while with being a small jurisdiction, the overall service for M.E. sufferers and Long Covid may be an over-arching combined service as it would not be practical either clinically or financially, to create duplicate, separate support services. It is important, too, that it is acknowledged that they are in many respects two different things with treatment approaches potentially needing to differ. It won't necessarily be a one-size-fits-all model.

So, while there may be overlaps with the overall service provision, it will need to be taken into account that they may need different types of support and therapies and should not just be classed as being the same thing. That would not be respectful to either M.E. sufferers or Long Covid sufferers, so we shouldn't be making the mistake simply because they both come under the same umbrella service or thinking that they are the same thing or the support required in exactly the same.

Mr President, it has been a long and arduous road to get here, none more so than for M.E. sufferers themselves, some of whom have spent decades with what little energy they have fighting simply to get the recognition that their condition even exists. It is not going to be plain sailing going forward as it is never easy changing mindsets and also introducing new services. And I'm absolutely certain there will be bumps on the road along the way.

So this is very much the start of a journey in developing a new therapy-based service that is able to focus on the needs of M.E. sufferers that Manx Care, and myself, and everyone in this honourable Court is committed to by working closely with the M.E. Support Group. I only believe that by close working we can deliver help and support for both those who have suffered in silence and also those who have struggled to get their voice heard.

I would also like to commend the Honourable Member for Arbory, Castletown and Malew, Mr Cregeen, for bringing forward this debate today because, as Dr Grieg said, wider public awareness is needed as well and the more wideness of that understanding we can get the better and with that, Mr President, I resume my seat.