

# WAMES' ME/CFS Delivery Plan Proposal for Wales

26 October 2023

WAMES welcomes the DHSC's [Interim delivery plan on ME/CFS](#) for England. We also are pleased that the Welsh Government is

*'keen to review the views of their residents on the interim delivery plan so that they can consider the implications for local policy.'*

WAMES has therefore drawn together some thoughts on the themes and actions in the plan which we believe Wales should also be considering.

## Key actions for Wales:

- Wales-wide commitment to co-production
- encourage biomedical research
- develop a pro-active strategy to educate train and raise awareness amongst professionals
- raise awareness of how people with ME/CFS and unpaid carers can access relevant support
- avoid the 'red flags' of unhelpful language

## Co-production

The English Delivery Plan was developed by the UK government department DHSC through co-production, specifying:

*'we must trust and listen to those with personal experience of ME/CFS'.*

WAMES believes a commitment to co-production is important in normal circumstances, but more so with ME/CFS. As the investigations of the working groups and workshops report, people with ME/CFS have endured decades of conflicting theories about our condition and treatment approaches, and disinterest or hostility from the healthcare profession. In such a climate, even the most well-meaning professionals would find it difficult to develop effective strategies and pathways without the input of a range of lived experience.

## Key action for Wales – Wales-wide commitment to co-production

The Welsh Government's [Social Services and Well-Being \(Wales\) Act](#) 2014 places a duty on Local Authorities to:

*'put in place transparent arrangements where people are equal partners in designing and delivering services'.*

The [Co-Production Network for Wales](#)' slogan is 'All in this together' and advises NHS Wales of the need to:

*"work together as equal partners.  
Co-production definition: shared power and shared responsibility."*

Currently some Health Boards are planning engagement and/or co-production for the expansion of the Adferiad services for other post-viral illnesses. Some Health Boards appear reluctant to engage with service users and their advocates. WAMES would like to see a more thorough Wales-wide commitment to co-production in Health Boards and local authorities, but also at a national level, to develop a strategy or delivery plan. We believe this will reduce the amount of 'trial and error' in the development of services and improve outcomes for people with ME/CFS in a timely manner.

## Research

The delivery plan is based on the premise that:

*'we do not know enough about ME/CFS,  
which must change if we are to improve experiences and outcomes'.*

The Medical Research Council (MRC) has had a funding [highlight notice](#) for ME/CFS prioritising biomedical research over psycho-social research since 2003 and this now particularly welcomes proposals that address one or more of the research areas identified by the ME/CFS Priority Setting Partnership for ME/CFS research.

The Delivery plan's Research working group identified the need to encourage and support researchers and clinicians to research ME/CFS and establish effective patient and public involvement and engagement (PPIE).

### **Key action for Wales – encourage biomedical research**

For many years research has been done in Cardiff on fatigue and mental health, but has not had a focus on people with strictly defined ME/CFS and fatigue, so has added nothing to knowledge about the condition.

Although the research community is much smaller than in England, there are scientists in Wales who are keen to develop their initial research and contribute to the search for a diagnostic test. WAMES would like to see strategies developed to encourage them, and emerging researchers, to get involved in this and other aspects of biomedical research and to work in collaboration with other research groups throughout the UK, thus speeding up the search for breakthroughs in the understanding and treatment of ME/CFS.

## Attitudes and education of professionals

One group of problems revealed by one of the Working Groups relate to patients not being believed, understood, supported and given equal treatment to other chronic illness groups. Also identified were the limited opportunities for education and training in ME/CFS, at both an undergraduate and postgraduate level for all professional groups, and the problem of out-of-date information remaining in circulation.

### **Key action for Wales – develop a pro-active strategy to educate train and raise awareness amongst professionals**

These problems also exist in Wales and WAMES would like to see the recommended actions for England also taking place in Wales in a coordinated way, with attention to additional problems experienced in Wales:

- develop a strategy to increase our knowledge of public sector professionals' current attitudes towards ME/CFS, to help show where there are gaps in understanding that need

to be targeted (Action 7). As services for ME/CFS have started launching in Wales their success will depend on the willingness of doctors to accept and diagnose ME/CFS. Other professionals will receive referrals from the new Services and will also need a thorough understanding of the key characteristic of ME/CFS ie Post Exertional Malaise/ Post Exertional Symptom Exacerbation (PEM/PESE) in order to deliver services that will help and not harm. WAMES believes there's a need to begin monitoring and engaging with professionals in every Health Board area of Wales as soon as possible. (Action 7)

- develop a centralised shared learning resource to support the training given to NHS professionals which utilises existing on-line tools that are in line with NICE guidelines. Future e-learning modules should complement them, with a commitment to update. (Action 10)
- a Wales-wide commitment to using trainers in Health Boards with experience in ME/CFS, not just Long COVID. This includes both training in understanding ME/CFS and management approaches.
- a Wales-wide commitment to improving the understanding of fluctuating conditions and energy limiting disabilities throughout NHS Wales. Penalising patients for unexpectedly being unable to make appointments or complete a course of treatment because of the nature of their illness leads to unequal access to healthcare.
- ensure all NHS online information sources and print resources about ME/CFS throughout Wales reflect the revised NICE guideline NG206 and do not contradict each other, including NHS Wales 111. (Action 9)
- encourage all Welsh medical, nursing, education and healthcare sciences colleges to raise awareness and absorb training into their curricula, including using direct patient experience of ME/CFS. (Action 10)
- NHS Cymru to work with the DES to ensure there is a shared understanding of the nature of ME/CFS and the needs of children and adults in education, and provide centralised updated guidance for teachers, teaching assistants and home tutors on education for children with ME/CFS in school and remote guidance for those who cannot attend school. (Action 11)
- improve understanding of ME/CFS in social care by supporting the BASW in their commitment to raise awareness and knowledge with the social work profession. And develop shared educational resources and protocols between NHS Cymru and CIW so that no one with ME/CFS is refused care due to lack of understanding of PEM/PESE and the fluctuating nature of the condition. (Action 12)
- assess the effectiveness of new services using, amongst other markers, those contained in the Delivery Plan section Quality of Life, (4) and Language use in relation to ME/CFS (Supporting Info).

## Living with ME/CFS

The working group felt there was a need for existing services:

*'to support people with everyday life in better ways,  
while we wait for research to help identify new treatments.'*

The 6 key areas most important to people living with ME/CFS and unpaid carers were:

- *overarching quality of life* – reduced by loss, stigma, disbelief, isolation, practical issues
- education, training for work and social care support (for children and young people with ME/CFS)
- *health services* – difficulty getting a diagnosis & lack of care for ME/CFS is compounded for those moderate, severe, or very severe patients who often struggle to access healthcare for other health needs.
- *adult social care support* – difficult to access and care is often uninformed about PEM/PESE and fluctuating nature of ME/CFS
- *employment support* - inclusive and flexible job opportunities (paid or unpaid) are limited for people with ME/CFS and recruitment processes often are not accessible

## **Key action for Wales – raise awareness of how people with ME/CFS and unpaid carers can access relevant support**

- explore ways that Welsh Government and public services can show recognition that ME/CFS is a disability and encourage reasonable adjustments to enable people with ME/CFS and their families to take part in services and activities to improve quality of life.
- all service planning needs to cater for children and young people and ensure families don't 'face inappropriate investigations and safeguarding referrals to children's social care.' It is important to acknowledge that children and young people can advocate for themselves in some circumstances. For those who are severely or very severely affected they may need a parent or independent person to advocate for them.
- there is a need to scope the extent and nature of the understanding of ME/CFS and services for children and young people across Wales, so gaps can be addressed and lessons learned to develop a strategy for health, education, social care, safeguarding, disability and employment training.
- there is a need to standardise services. Health Boards in Wales are developing services at different paces with little access to experienced ME/CFS professionals, some with no services for children, using different guidelines and with varying degrees of input from patient groups. It is going to be difficult to achieve a uniform level of service across Wales with the additional Adferiad funding.
- look for ways to increase awareness among people with ME/CFS and their unpaid carers of support available from adult social care and how to access it by collaborating with stakeholders to disseminate information and guidance (adult social care services). (Action 16)
- look for ways to increase awareness among people with ME/CFS about how to feed back or make a complaint about care, treatment or service they have received. Many are unaware of their rights under the NHS Constitution and how to navigate the NHS complaints process (health service) (Action 16)
- Unpaid carers find it difficult to get a timely and accurate assessment of their needs as noted in the Welsh Government's [Social Services and Well-Being \(Wales\) Act 2014](#). identify how best to raise public awareness of ME/CFS (Action 16)
- Welsh Government to work with Public Health Wales to ensure that all people eligible for public health screening receive it in a place which is appropriate for them when the individual is not able to attend a central venue.

## Language

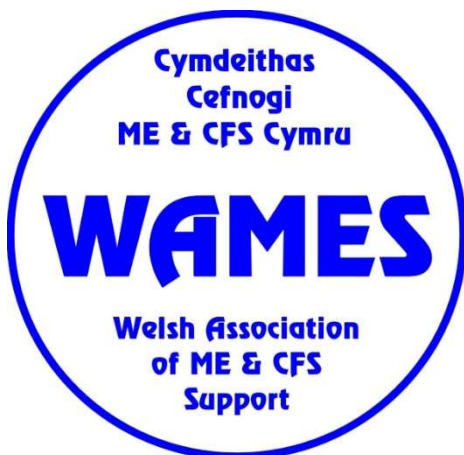
The DHSCC intend to complete a 'Language matters in ME/CFS' guide (Action 15) by the end of July 2024 and this could be very useful, though a long time to wait.

### Key action for Wales – avoid the 'red flags' of unhelpful language

WAMES would like the post-viral services in Wales to learn about the effects of language and the 'red flags' they send up as **soon as** Health Boards begin to name their new service and design their web pages. That includes language that belittles, is linked to views that have been debunked or may have been acceptable for a Long COVID service but cannot always be used for an ME/CFS service without creating the wrong impression and deterring future users. (Action 15)

### In conclusion

WAMES asks the Welsh Government to build on past preparatory work and, like the DHSC in England, embark on a journey to improve the lives of a forgotten community of people with ME/CFS and post-viral illness, with the collaboration of the community itself.



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