

**TYMES TRUST Response to the DoHSC Consultation:
the Interim Delivery Plan on ME/CFS
4 October 2023**

TYMES Trust appreciates the time and dedication of everyone contributing to and compiling the DHSC *My full reality: the interim delivery plan on ME/CFS*.

For too long this devastating illness has been shrouded in controversy; far too many Children, Young People and their Parent/Carers (and some professionals) have been harmed by ignorance and misunderstanding of the illness, resulting in inappropriate medical care, social care, education provision, child protection proceedings and professional gaslighting.

The recent changes within the NICE guidelines, and this UK Department of Health and Social Care Interim Delivery Plan on ME gives us some long-awaited hope; however, we have some reservations and comments.

Overall, the plan is positive, and the crucial task of re-education (if implemented appropriately) will certainly support system improvement and support professionals to deliver individualised, quality, care and understanding to those living with ME.

The needs of children and young people are different to those of adults. Ideally, discussions and planning for children and young people should be progressed as an independent section within the Interim Plan.

The changes within the plan need to be implemented with a sense of urgency to avoid further harm and subsequent declining health for our children and young people as ME has a huge negative impact at such a vulnerable stage of life.

- 1. We recommend that a central advice line hub for professionals could be set up in tangent with the multiple departmental/service reform.**
- 2. We would like to see more hyperlinked references to the new NICE guidelines (and other supporting documents and appropriate contacts) throughout the entire plan.** Professionals who support and care for those living with ME are often time and resource-poor, and these reference links will facilitate professionals delivering care and support in a timely, informed and confident manner.
- 3. A firm diagnosis of ME is needed as early as possible to ensure protection from disbelief and needless pressure from education and Social Services.** It should facilitate ongoing medical support throughout the course of the illness. The department should make a clear recommendation as to whether GPs or paediatricians should have responsibility for the diagnosis and ongoing medical care and support.
However, an early diagnosis will only support children and young people if medical professionals have knowledge of ME and its presentation. Those who incorrectly believe ME to be a short-term or psychological illness do not, and will not, correctly support children and young people.



4. **It is crucial to understand that education is interrupted for significant numbers of children and young people with ME and that any education provision may be impossible.** However, access to the appropriate education may lessen this risk.

The Interim Plan states: *the starting principle should be for the child or young person to spend as much time as they can in the setting accessing face-to-face learning - schools will work with pupils and parents to support them to maximise their attendance in line with DfE's Working together to improve school attendance (<https://www.gov.uk/government/publications/working-together-to-improve-school-attendance>) guidance, taking into account the impact of each individual's medical condition including their capacity to expend energy.*

The above text and its focus on school attendance have often been the starting point for the issues surrounding the education of children and young people with ME. The focus is on attendance at school and not on what the young person can sustain without causing a relapse of their symptoms. Typically, at the start of the illness, some children cannot be educated at all; to do so causes relapses that further damage their long-term health. Medical and education professionals need to be aware of this.

Nowhere is it recognised that the energy required to get to school and be within the school environment is often too much for a child with ME. This must be considered. The use of Pupil Referral Units (PRUs) for children with ME is often an inappropriate environment.

5. **Currently, there is no school absence code for long-term illness.**

Point 44 of *The Working Together to Improve School Attendance* guidance states: *A part-time timetable must only be in place for the shortest time necessary and not be treated as a long-term solution. Any pastoral support programme or other agreement should have a time limit by which point the pupil is expected to attend full-time, either at school or alternative provision.*

It must be recognised that inappropriate education demands are most often the cause of serious relapses in children and young people with ME and those children require a long-term plan that may include home education (via the school/LA) and a part-time schedule for the longer term. Alternative Provision must be offered to children and young people with ME.

6. **Families who have children with ME have historically been challenged by Education Welfare Officers (EWOs)** - both those who are employed by local authorities and those who work as agents of the local authorities - as an EWO's focus is solely on getting children back into school. Absence Code 1: *Illness (not medical or dental appointment)* is routinely not used for children with ME and families are told their absence will be listed as unauthorised.

7. Any re-education programme must include these teams and alongside the recent call for absence codes relating to mental health (https://contact.org.uk/about-contact/news-and-views/mps-recommend-mental-health-absence-code-and-expansion-of-free-school-meals-to-tackle-persistent-absence/?utm_medium=email&utm_source=engagingnetworks&utm_campaign=wn3oct23&utm_content=whats+new+3+october+2023+-+Core) an absence code for longterm illness should be introduced removing the need for schools to routinely request evidence or to fine parents.



It is imperative that appropriate education is only considered when a child or young person is well enough. It should be clearly stated that *children should be allowed to get sufficiently well before being expected to begin any education and only when able, then begin to gradually attend school*. The use of ever-increasing school attendance targets is a form of graded exercise that must not be used.

To summarise, the focus should be *health first*.

Further information is available here:

Long Term Sickness Absence due to ME / CFS in UK Schools : An Epidemiological Study With Medical and Educational Implications

<https://www.semanticscholar.org/paper/Long-Term-Sickness-Absence-due-to-ME-CFS-in-UK-%3A-An-Microbiologist-Executive/7222202c161598499b343226c03b680a829c9fe1#related-papers>

8. **Young people aged 16-25 are a transitional age group** facing multiple challenges within health, social care and education as they fall between service and professional parameters.
These young people are often behind their peers in learning and gaining measurable attainment, exams etc. We believe flexible education at Sixth Form, College and University should be extended to young people living with long-term chronic illness. Extended, flexible, funded education provision must be provided; supporting both healing and health as well as the chance of attaining qualifications and the chance of independence in one's adult life moving forward. Young people with ME should also be entitled to continued support from a parent/carer to advocate for them when the need arises.
9. **Flexible/Remote Learning:** Local Authorities (LAs) often face challenges when providing appropriate flexible learning within their current educational provision. We would encourage LAs to investigate and subscribe to remote/virtual schools. One example is www.nisai.com where lessons are recorded, so if a young person is unwell, they can view or review a lesson when they are able.
10. **Severe ME is complex.** We feel the Interim Delivery Plan falls short when supporting individuals and families living with Severe ME. Due to its complex and devastating nature, we would recommend Severe ME is a separate section within the Delivery Plan.

More clarity and commitment is urgently needed within the delivery plan to support the Children and Young People severely affected with ME and the families. Their family/carers require urgent and individualised support, not challenge. We would like to see more accountability by professionals and organisations who cause unnecessary harm and distress to families.

11. **Multiple cases in family.** Tymes Trust is aware that having a parent and child with ME appears to be a safeguarding concern for most professionals. Professionals must be made aware that having more than one diagnosed case in the same family should not automatically trigger any safeguarding procedure.



12. **Research Funding:** We feel the plan does little to address the disparity in funding compared to other illnesses, and fully support ME Research UK's response to the Interim Delivery Plan.
13. **Tymes Trust has repeatedly been told** that families are threatened with Child Protection procedures if their children do not follow a treatment regime; this has to stop and must be part of any education plans for professionals. Families are also pressured to admit their children as an inpatient for "treatment". No details on this "treatment" are made available to parents or young people so it is impossible for them to give their informed consent or for shared decision making to take place.

We ask for clarity on:

1. How, and by whom, this improved multi-governmental department support will be monitored, and where will professional accountability for the delivery of best practices sit?

TYMES Trust feel strongly that this Interim Plan should do more to inform, educate and enable professionals to give the right, **individualised** support for these extremely unwell people.

TYMES Trust concurs with the comments and responses of our fellow Forward ME members including The ME Association, 25% Group, BRAME , ME Research UK.

