There have been many failures to support ME patients with biomedical research to provide the fore-mentioned, and restore funding to transform into  treatments, as should have been the case since the 1950’s and before the condition was treated as behavioural since the 1980’s. Below is a brief account of the steps charities and patients have taken to change this whilst hundreds of patients have died and many more have suffered a living death without treatment or care, denied benefits when they refused participate in harmful treatments called graded exercise and CBT, and so were refused further care.

There are harrowing cases of harm and neglect over decades.

At the end of October after many extensions and after withdrawing the publishing date several hours before publication, NICE finally published the Guidelines on ME/CFS removing Graded exercise therapy and CBT as treatments for ME/CFS which it placed there in 2007 with poor and very poor evidence. Patients and charities feel this is still not sufficient and can be used to continue to harm patients, and there are still no effective treatments in the guidelines.

Thank you for this opportunity.

Awareness-raising

22. The Committee is concerned at the persistence of negative attitudes, stereotypes and prejudice against persons with disabilities, particularly persons with intellectual and/or psychosocial disabilities and persons with neurological and cognitive conditions such as dementia and Alzheimer’s, and about their social protection entitlements

23. The Committee recommends that the State party, in close collaboration with organizations of persons with disabilities, strengthen its awareness-raising campaigns aimed at eliminating negative stereotypes and prejudice towards persons with disabilities, particularly persons with intellectual and/or psychosocial disabilities and persons with neurological and cognitive conditions such as dementia and Alzheimer’s. To that end, the State party should include mass media strategies and campaigns, with different target audience groups, based on the human rights model of disability.

Right to life (art. 10)

26. The Committee notes with concern that the substituted decision-making applied in matters of termination or withdrawal of life-sustaining treatment and care is inconsistent with the right to life of persons with disabilities as equal and contributing members of society.

27. The Committee recommends that the State party adopt a plan of action aimed at eliminating perceptions towards persons with disabilities as not having “a good and decent life” and recognizing persons with disabilities as equal to others and part of the diversity of humankind. It also recommends that the State party ensure access to life- sustaining treatment and/or care.

Freedom from exploitation, violence and abuse (art. 16)

38. The Committee is concerned about abuse, ill-treatment, sexual violence and exploitation of women, children, intersex persons and elderly persons with disabilities, and the insufficient measures to prevent all forms of exploitation, violence and abuse against persons with disabilities. It is also concerned at reports of cases of disability hate crime, in the absence of consistent data collection and differences in legal provisions for sentencing different types of hate crime, particularly in England and Wales.

39. The Committee recommends that the State party, in close collaboration with organizations of persons with disabilities, and in line with target 16.3 of the Sustainable Development Goals:

(a) Establish measures to ensure equal access to justice and to safeguard persons with disabilities, particularly women, children, intersex persons and elderly persons with disabilities from abuse, ill-treatment, sexual violence and exploitation;

(b) Define comprehensively the offence of disability hate crime, and ensure appropriate prosecutions and convictions;

(c) Ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities, in accordance with article 16 (3) of the Convention.

40. The Committee is concerned that persons with disabilities, including women, intersex persons, girls and boys, reportedly continue to be subjected to involuntary medical treatment, including forced sterilization and conversion surgeries.

Living independently and being included in the community (art. 19)

44. The Committee is concerned about:

(a) The fact that the State party’s legislation fails to recognize living independently and being included in the community as a human right that enshrines individual autonomy, control and choice as intrinsic aspects of that right;

(b) Policies and measures that affect the ability to live independently in the community, such as the reduction in social protection schemes related to housing, household income and budgets for independent living, as well as the closure of the Independent Living Fund;

(c) The fact that responsibility for supporting independent living has been transferred to the devolved administrations and local authorities without providing appropriate and earmarked budget allocation;

(d) The fact that many persons with disabilities are still institutionalized and deprived of the right to live independently and be included within the community, when: (i)

they lack the financial resources to afford personal assistance; (ii) local authorities are of the opinion that they can provide assistance within care homes; and (iii) the cost rationale constitutes the main parameter of an assessment;

(e) The lack of support services and accessible public facilities, including personal assistance, for persons with disabilities, regardless of sex, gender, age and other status, to live independently and be included in the community.

45. The Committee recommends that the State party, in line with the Committee’s general comment No. 5 (2017) on living independently and being included in the community and the Committee’s report on its inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out under article 6 of the Optional Protocol to the Convention:

48. The Committee is concerned that parents with disabilities do not receive appropriate services and support, resulting in children being removed from the family environment and placed in foster care, group homes or institutions. It is also concerned at the insufficient funding for parents of deaf children to learn sign language.

49. The Committee recommends that the State party:

(a) Ensure appropriate support for parents with disabilities to effectively fulfil their role as parents and ensure that disability is not used as a reason to place their children in care or remove them from the family home;

53. The Committee recommends that the State party, in close consultation with organizations of persons with disabilities, especially organizations representing children and young persons with disabilities, and in line with the Committee’s general comment No. 4 (2016) on the right to inclusive education and targets 4.5 and 4.8 of the Sustainable Development Goals:

59. The Committee recommends that the State party, in close collaboration with organizations of persons with disabilities across all territorial entities, in line with the Committee’s report on its inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out under article 6 of the Optional Protocol to the Convention, guided by article 28 of the Convention and implementing target 10.2 of the Sustainable Development Goals:

(a) Introduce, adopt and implement legislative frameworks to ensure that social protection policies and programmes across the State party secure income levels for all persons with disabilities and their families, by taking into account the additional costs relating to disability, and ensuring that persons with disabilities are able to exercise their parental responsibilities. The State party must ensure that members of the new Employment and Support Allowance work-related activity group have access to full compensation of disability-related costs;

(b) Carry out a cumulative impact assessment, based on disaggregated data, of the recent and forthcoming reforms of the social protection system for persons with disabilities, and in close collaboration with organizations of persons with disabilities define, implement and monitor measures to tackle retrogression in their standard of living and use the cumulative impact assessment as a basis for policy development across the State party;

(c) Repeal the Personal Independence Payment (Amendment) Regulations of 2017 and ensure that eligibility criteria and assessments to access Personal Independence Payments, Employment Support Allowance and Universal Credit are in line with the human rights model of disability;

(d) Ensure that the budget allocation is sufficient for local authorities to meet their responsibilities regarding assistance for persons with disabilities, and extend support packages to mitigate the negative impacts of social security reform in Northern Ireland;

(e) Conduct a review of the conditionality and sanction regimes concerning the Employment and Support Allowance, and tackle the negative consequences on the mental health and situation of persons with disabilities.

Participation in political and public life (art. 29)

NICE

2007 Submissions -

<https://www.investinme.org/Article-301%20Ian%20Gibson%20NICE%20Guideline%20Witness%20Statement.shtml>

<http://www.investinme.org/IIME%20Campaigning-NICE-Clinical-Guidelines.shtml>

<http://www.investinme.org/Documents/PDFdocuments/Invest%20in%20ME%20-%20CFSME%20Consultation%20Stakeholder%20Comments%20Form%20-%20Official%20IiME%20Response.pdf>

<http://www.investinme.org/Documents/PDFdocuments/IiME%20Official%20Response%20Final%20to%20CG53%20Full%20Guidance.pdf>

<https://meassociation.org.uk/2007/01/nice-guideline-mea-response/>

<https://meassociation.org.uk/2007/09/nice-guideline-on-mecfs-mea-statement/>

<https://meassociation.org.uk/2007/09/nice-guideline-on-mecfs-mea-statement/>

<https://www.tymestrust.org/txt/view200611nicesubmission.txt>

Judicial Review

<https://www.investinme.org/IIME%20Campaigning-NICE-Guidelines%20IiME%20Response.shtml#IiME_Response>

<https://www.investinme.org/IIME%20Campaigning-NICE-Whats-Next.shtml>

<https://www.investinme.org/Article-361%20Statements%20of%20Concern%20-%20CBT-GET%20JR%20Feb09.shtml>

The Gibson enquiry into ME

<http://www.investinme.org/Article-009%20Gibson%20inquiry%20IiME%20response.shtml>

<http://www.investinme.org/Article-009%20Gibson%20inquiry%20respice%20finem.htm>

2013 Review - static list

<https://www.investinme.org/Documents/NICE/ClinicalGuidelineStaticListAndSHCommentsNov13.pdf>

10 year surveillance review 2017.

<https://www.guidelines.co.uk/news/recommendation-on-graded-exercise-therapy-removed-from-nice-guideline-on-myalgic-encephalomyelitis/chronic-fatigue-syndrome/456482.article>

<https://www.nice.org.uk/guidance/ng206/evidence/evidence-reviews-october-2021-9265183021?tab=evidence>

Brian Hughes summaries how evidence for graded exercise and CBT was “low” and “very low” (which begs the question, how was this evidence ever permitted to be used for fifteen years, passing two reviews and a judicial review?)

In the 2007 NICE guideline:

* *CBT was promoted as a treatment for ME/CFS — on the basis of 4 RCTs*
* *GET was promoted as a treatment for ME/CFS — on the basis of 5 RCTs*
* *The limitations of these studies were largely ignored by the NICE guideline committee*

By contrast, in this year’s NICE guideine:

* *CBT is no longer promoted as a treatment for ME/CFS —*[***on the basis of 172 individual CBT outcomes, as examined across multiple studies***](https://www.nice.org.uk/guidance/gid-ng10091/documents/evidence-review-7)
* *GET is no longer promoted as a treatment for ME/CFS —*[***on the basis of 64 individual GET outcomes, as examined across multiple studies***](https://www.nice.org.uk/guidance/gid-ng10091/documents/evidence-review-7)
* *Study limitations were examined closely by the NICE guideline committee.*[***For all studies of CBT and GET to date, NICE graded all the evidence accumulated as either “VERY LOW” or “LOW” quality***](https://www.nice.org.uk/guidance/gid-ng10091/documents/evidence-review-7)

<https://thesciencebit.net/2021/08/10/journalists-covering-me-cfs-dont-ask-about-the-new-nice-guideline-ask-about-the-old-one/>

Royal College refuse to stop using graded exercise against proof of damage to patients (see evidence in NICE project documents)

Medical leaders sign joint statement in response to NICE guidance on ME/CFS

<https://www.rcplondon.ac.uk/news/medical-leaders-sign-joint-statement-response-nice-guidance-mecfs>

Invest in MER summary

<https://www.investinme.org/ng206-guidelines-publication-oct2021.shtml>

Dr Myhill #MAIMES campaign and complaint to the GMC about the PACE trial authors

<https://www.drmyhill.co.uk/wiki/My_Complaint_to_the_GMC_about_the_PACE_authors>