Conclusion

Energy limiting conditions (ELCs), a category that includes ME/CFS, Long Covid, fibromyalgia, multiple sclerosis, POTS, Ehlers Danlos Syndrome, inflammatory bowel disease, thyroid problems and lupus, are often poorly understood by the UK government’s social protection and poverty reduction programmes, healthcare professionals and the medical establishment, and the general public, leading to a range of adverse experiences for people with ELCs that contravene their human rights as outlined in the UNCRPD. This ignorance about ELCs means that the particular needs of people with ELCs, such as remote access to work and recreational activities, and access to domiciliary healthcare services, are also poorly understood and rarely met. People with ELCs were greatly disadvantaged by the UK government’s inadequate response to the COVID-19 pandemic, and many suffered in particular from a lack of access of healthcare.

ELCs should be recognised as a real and frequently debilitating form of impairment, and people with ELCs must be afforded the same rights and protections as other disabled people. There needs to be more and better research into ELCs and other conditions that predominantly affect women. This research should respect the lived experiences of people with ELCs and regard people with ELCs as genuine sources of knowledge about their own bodies. ‘Medically Unexplained Symptoms’ must be abandoned as a diagnostic category. Better mechanisms must be developed for reporting harms resulting from behavioural and psychological treatments.

Remote participation should be recognised as an accessibility need and made available for accessing employment and recreational activities. Access to domiciliary healthcare services, including screening and prevention services, should be made available to people who are housebound.

Rather than perpetuating stereotypes about disability ‘fakers’ and ‘scroungers’, the UK government should lead by example, changing their approach to disability-related benefits assessments to better reflect the lived experiences of people with ELCs, and raising awareness of ELCs and the needs of people with ELCs among the general public. Better preparations should be made by the government for the future for protecting people with ELCs in the ongoing COVID-19 pandemic and for future humanitarian emergencies. Our lives, basic needs, wellbeing and human rights should never be disregarded.