



COVID-19: A MESSAGE FROM THOSE LIVING WITH NEUROLOGICAL DISORDERS

Authored by the European Federation of Neurological Disorders [EFNA]

Neurological disorders are mostly chronic, long-term conditions. Those affected may be at increased risk from Covid-19. However, as this strain of the coronavirus is new, the knowledge on how this will affect people with neurological disorders is still limited. Although, based on evidence to date, we can assume that those with such underlying disorders may be more at risk from the virus directly, but also due to being exposed to disruptions in healthcare provision. There are also concerns around the slowing pace and prioritisation of neuroscience research for our communities. In this statement, we explore these challenges as well as looking at the role of the neurological patient organisation during and after this crisis.

ENSURING EQUITABLE ACCESS TO TREATMENTS, SERVICES AND SUPPORTS

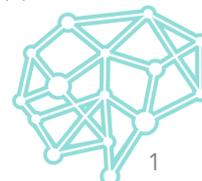
'Access' is one of the central themes of EFNA's advocacy activities and now, more than ever, we need to make sure that it is maintained.

An early diagnosis can have a positive impact on a person's long-term prognosis in many neurological disorders. However, if there is a delay in presenting to a healthcare professional, this can reduce the chances of treating and managing the disorder most successfully. Similarly, treatment delay or discontinuation are very real concerns in certain neurological disorders – particularly for those who may need access to cancelled outpatient clinics, rehabilitation and other therapies, opportunity to enrol in clinical trials and so on.

We call on healthcare providers to endeavour to continue to provide the care required by recovery phase of this pandemic. Although many of these conditions are not immediately life-threatening, quality of life can be severely impaired if appropriate treatment, services and supports are not available in a timely manner.

Digital tools, which were identified in [EFNA's position paper on access](#) as an enabler, should be optimised – and innovative approaches to R&D, regulation and reimbursement must be considered and encouraged during these challenging times; with successful interventions continuing to be supported in the recovery phase and beyond.

Although medicine shortages are not posing a major challenge for the community just now, this situation should be continually monitored, and action taken as soon as a threat to the supply chain is detected.



However, we need to think beyond medicines and healthcare services for those living with long-term, neurological disorders and other chronic conditions. Many of those affected rely on social services and supports to maintain their quality of life. These supports must be recognised as essential services for our communities, particularly in the recovery phase of the crisis when patients may need access to mental health services, support to return to work, etc.

This crisis has highlighted the fragmentation between our health, social and economic affairs but also emphasised the need for increasing cross-sectoral collaboration to address the health of our societies. Following this pandemic this cooperative approach must be encouraged.

In particular, the European Union should now take up a more ambitious role in coordinating health policies, within the framework of EU treaties.

Finally, equity of access also means that we must overcome stigma and discrimination in our societies when it comes to who can, and who cannot, avail of the scarce resources at the disposal of our healthcare systems. EFNA is eager to emphasise that we believe in a human rights-based approach and decisions should not be taken based on diagnosis or non-medical criteria alone (such as age), without taking an holistic view of an individuals' prognosis. Those with neurological disorders, particularly elderly patients, should not be systematically denied the treatment they need; many can live a long time and enjoy an excellent quality of life despite their age or diagnosis.

REINVIGORATING NEUROSCIENCE RESEARCH AND INNOVATION

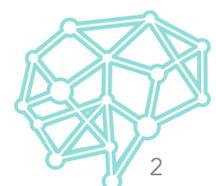
Beyond health and social care, our thoughts turn to research.

During the pandemic, neuroscientists across Europe left their labs as universities closed and the focus shifted to understanding and defeating Covid-19. Despite many researchers continuing to work productively from home – or turning their attentions to the fight against this virus – the pace of research in our field has inevitably slowed down.

However, neglecting neuroscience research will have repercussions in the years to come. Numbers are growing. More than 1 in 3 people will have a brain disorder in their lifetime – neurological disorders alone are the leading cause of disability and the second leading cause of death worldwide. This costs the EU economy over 800 billion euros per year. And, yet, we still have no cure for almost all of these disorders. Unless we continue to fund basic research into the underlying mechanisms of these diseases and clinical research to find more optimal treatments and – eventually – cures, these disorders will place an unsustainable burden on our societies.

Therefore, in the recovery phase, it will be critical that the European Commission maintains its commitment to supporting brain science, research and innovation. Brain disorders do not stop for Covid-19 – in fact there is emerging data to suggest that the virus may cause neurological complications. So, in the aftermath of the pandemic, there should be a substantial increase of available funding under Horizon Europe for health research and supporting disciplines – with neuroscience continuing to be a priority. Alongside such increased levels of research, better coordination and more efficient data management will be required.

Through science we will defeat this pandemic, but only through a reinvigorated neuroscience agenda, to make up for the time we have lost in these difficult months, will we defeat the emergency posed by neurological disorders – which could claim many more lives in the coming years.



For now, we must also ensure that we are collecting the data we need to assess the ongoing impact of this virus on those living with neurological disorders and any neurological complications that may arise in those who have been affected. Recommendations and guidelines will need to be produced and reassessed on an ongoing basis. This will be essential in the ongoing care of our patient community and those who will be diagnosed with Covid-19 in the weeks and months ahead.

SUPPORTING AND OPTIMISING THE ROLE OF NEUROLOGY PATIENT ORGANISATIONS

Research and innovation, and solutions to the challenges thrown up for our health and social care services must be person/patient-centred in their approach.

Neurology patient organisations, that are connected to their communities across Europe and have access to empowered patient advocates, can support healthcare services and governments in developing adequate solutions for patients', in particular in ensuring access to care at a time when crisis threatens to overwhelm ongoing service provision. Decision makers should ongoingly seek the views of these organisations in building their response during the crisis but also in preparation for, and throughout, the recovery phase.

Patient organisations can also be a good filter and trusted disseminator of reliable, accurate health information to their communities and the wider public. They should be supported to play this role.

However, we must not forget, that in many countries patient organisations provide essential services and supports within – and in addition to – the healthcare system. They may also be research charities or research funders. The European Institutions and national/regional governments should ensure that these groups are supported now, more than ever. With their long-term survival and sustainability under threat as revenue streams and fundraising opportunities dry up during the crisis – we call on current and prospective funders to realise the value of patient organisations and work, in a more flexible and forward-thinking approach, to protect them and the services they provide. They are a lifeline to many people living with neurological disorders.

EFNA, as one such patient organisation, will continue to work with our members and partners – representing all stakeholders in this field – to communicate and advocate for the needs for those affected by neurological disorders during and after this pandemic. This will be reflected in our updated plans for this year and beyond which will be communicated shortly.

We also encourage you to [get in touch with us](#) to share your challenges, examples of best practice or other resources that we can share with the community – as well as any opportunities for us to get involved and support the efforts on behalf of the patients we represent.

CONTACT:

Donna Walsh, EFNA Executive Director
executivedirector@efna.net

