

Covid-19: Shaping the Future of Neurology Advocacy

May 21, 2020

SYNOPSIS OF CHALLENGES AND OPPORTUNITIES

- The main issue for the neurology community during this pandemic is not access to medicines, but to services and supports.
- There have been many reports of difficulty (or impossibility) in accessing outpatient clinics e.g. rehabilitation services, pain management clinics, mental health supports, etc.
- There have also been issues with more complex healthcare needs e.g. cancellation of neurosurgeries, decrease in thrombectomy coverage, problems with access to ventilation and gastric feeding in advanced/progressive diseases, etc.
- This is hugely problematic for those with long term, chronic conditions. Here, medication is only part of optimal ongoing disease management, which is needed to monitor disease progression, complications, new/exacerbated symptoms, side effects of treatment, etc.
- There are a number of factors at play here – services were cancelled to stop the spread of disease, the health workforce was redeployed to deal with the influx of Covid cases and there was a widespread fear amongst patients themselves to present (example: stroke patient waited until he had his third stroke in a week before presenting for treatment in a French hospital because he believed hospitals were only for Covid patients).
- There were also issues in terms of information. There is an ‘info-demic’ with a proliferation of inaccurate information – ranging from poorly and hastily conducted research to dangerous misinformation on social media. However, there is a lack of credible, targeted information for the neurology patient population (and others). Patient organisations and medical societies are quickly trying to fill this gap but we need more systematic collection of data, over the longer term. EAN has set up its EANcore Covid-19. See: www.ean.org
- Patient organisations are also seeing an increased demand for their services but a decrease in resources, as opportunities for fundraising initiatives are restricted, staff are let go temporarily (furloughed), etc.
- Patient organisations have also had to adapt to a new way of working very quickly. Do we need more skills building in organising virtual meetings, online advocacy and fundraising, etc.



- We need to better recognise and reward the value of patient organisations. This should happen at EU level with core funding and support but also – nationally – where many patient organisations are running healthcare services (e.g. hospices, respite centres, rehabilitation services, helplines, specialist nurse clinics, etc.) and/or are major research funders, etc.
- We're also seeing a major impact on research with clinical trials slowed or halted, as well as basic research coming to a standstill as universities and laboratories close across Europe. The fear is that this will not be restarted if Covid monopolizes research agendas, but we must reinvigorate neuroscience if we are to find cures and treatments for these diseases.
- Many neurological disorders were first discovered in the 1800 and 1900s but, as yet, we have no cures (e.g. PD, AD, MS, etc.) – and treatments are not optimal for many. In fact, these disease are increasing (at least 1 in 3 will have a neurological disorder in their lifetime [EAN say closer to 1 in 2], and neurological disorders are the leading cause of disability in the world, and second leading cause of mortality). As the population ages and environmental/lifestyle risk factors increase, we are facing into an epidemic of chronic disease – with the neurological disorders to the forefront. We need to push for the same sense of urgency in this space but this is not happening, and other disease areas are leaving us behind in terms of prioritisation and resource allocation.
- Beyond treatment, we need to think of the social impact. Many patients with neurological disorders have been in isolation. As countries open up, these people are still being asked to stay home. How can we ensure the safe return to work and education for these vulnerable groups? And how can we ensure that the neurology patient community are included in any such actions in the recovery phase? We need to explore the 'inequality of consequences'.
- We also need to recognise the increasing burden on caregivers who are expected to fulfil their duties 24/7 with no outside help, respite services and so on.
- What impact will this have on the mental health of all those affected?

These are the challenges but there are some solutions...

- The increased budget for health at EU level is a first step, but this needs to be spent wisely and neurology must not be neglected. We need to push our advocacy and awareness around non-communicable diseases, and make sure that neurology is to the forefront because it is responsible for the largest disease burden amongst NCDs.
- There must also be more coordinated action at EU level: An EU Union for Health!



- Beyond health, we need to ensure that neuroscience is prominent in the next EU framework programme, and we need to see health featuring across all policies. The digital transformation is one obvious area for this convergence. The pandemic has accelerated our dependence on digital solutions. However, it has also shown the gaps in this approach. We are not all equally digitally literate, we do not all live in areas where connectivity is high, for certain patient populations this will never be the solution, in some member states it is expressly forbidden and in others the infrastructure is available in some regions but not others – increasing health inequalities. There is also a lack of evidence on the difference in the outcomes (positive and negative) of telemedicine for patients.
- What the pandemic has shown us is that lockdown was required because our systems were not prepared for a surge in patient numbers. This is because so many patients with chronic conditions are seen in hospital settings by specialists. However, many would prefer to be seen in their communities by multi-disciplinary care teams, supported by digital applications/therapeutics/telemedicine (with access to specialists as/when required). This shift in the patient pathways for chronic disease patients would provide added capacity to our healthcare systems to deal with emergencies as they arise, whilst also addressing patient needs and preferences – in line with a move towards personalised healthcare.
- And, finally, we need to ensure that patients are part of the recovery phase planning and implementation, as well as in plans to future proof our healthcare systems. Meaningful and effective patient involvement is essential.

WHAT WILL EFNA DO?

- Organise a webinar with the World Health Organisations and the Non-Communicable Disease Alliance [NCDA] to discuss how we can ensure that neurology is featured prominently in efforts to address the impact of Covid-19 on people living with non-communicable diseases [PLWNCDS]. EFNA members and partners will be asked to submit their questions and comments in advance to ensure all concerns are addressed.
- Join WHO's Global Forum on Neurology and Covid-19 to present a neurology patient perspective
- Write to the European Health Commissioner to ensure that neurology is clearly part of the Covid-19 recovery plan across the EU, and benefits from the increased EU health budget. This letter to be endorsed and disseminated by EFNA members and partners, and will include a request for a meeting/participation in a virtual roundtable.
- Provide our members with templates and tools which they can use to advocate a common message in their specific disease areas/regions.



- Work with the European Academy of Neurology on a questionnaire to collect the current and future challenges/opportunities for neurology patients during and after the pandemic – with the view of publishing a paper and devising recommendations for neurologists and on the provision of neurological care.
- Organise a series of ‘How to ... in a virtual world’ online training workshops for neurology patients/organisations. These could focus on skills such as optimising virtual meetings, advocating online, fundraising virtually, etc.
- Create a series of videos/animations on cross-cutting topics with partner organisations on topics such as Covid-19 and mental health (e.g. resilience, loneliness, etc.), the burden on carers, impact on employment and education, etc. These videos would be directed to neurology patients and capture the broader impact of Covid-19 on their health and social care, but look towards future-proofing and improving these services and supports.
- Reach out to EFPIA (the trade association for the pharmaceutical industry in Europe) to organise a virtual meeting with industry and neurology patient organisations/representatives to discuss topics such as the halting of clinical trials, the future of clinical neuroscience, support of patient organisations and so on.
- Work with the European Brain Council to advocate for the prioritisation of brain research in the next EU framework programme.
- Represent the voice of the neurology patient community in relevant forums and high profile events on Covid e.g. Politico Webinar on Covid-19 and Chronic Diseases, etc. – as well as integrating the Covid learnings into our future advocacy plans (e.g. MEP Interest Group on Brain, Mind and Pain)
- Continually update our Covid Hub at www.efna.net
- Working with broader groups such as the European Patients’ Forum, EU Health Coalition, Patient Access Partnership, European Alliance for Patient Access, and so on, on common topics and themes affected the broader spectrum of patients and other healthcare stakeholders.

