

COVID-19: THE IMPACT ON PEOPLE WITH NEUROLOGICAL CONDITIONS AND FAMILY CARERS

REPORT OF A NATIONWIDE
SURVEY CARRIED OUT BY THE
NEUROLOGICAL ALLIANCE OF
IRELAND

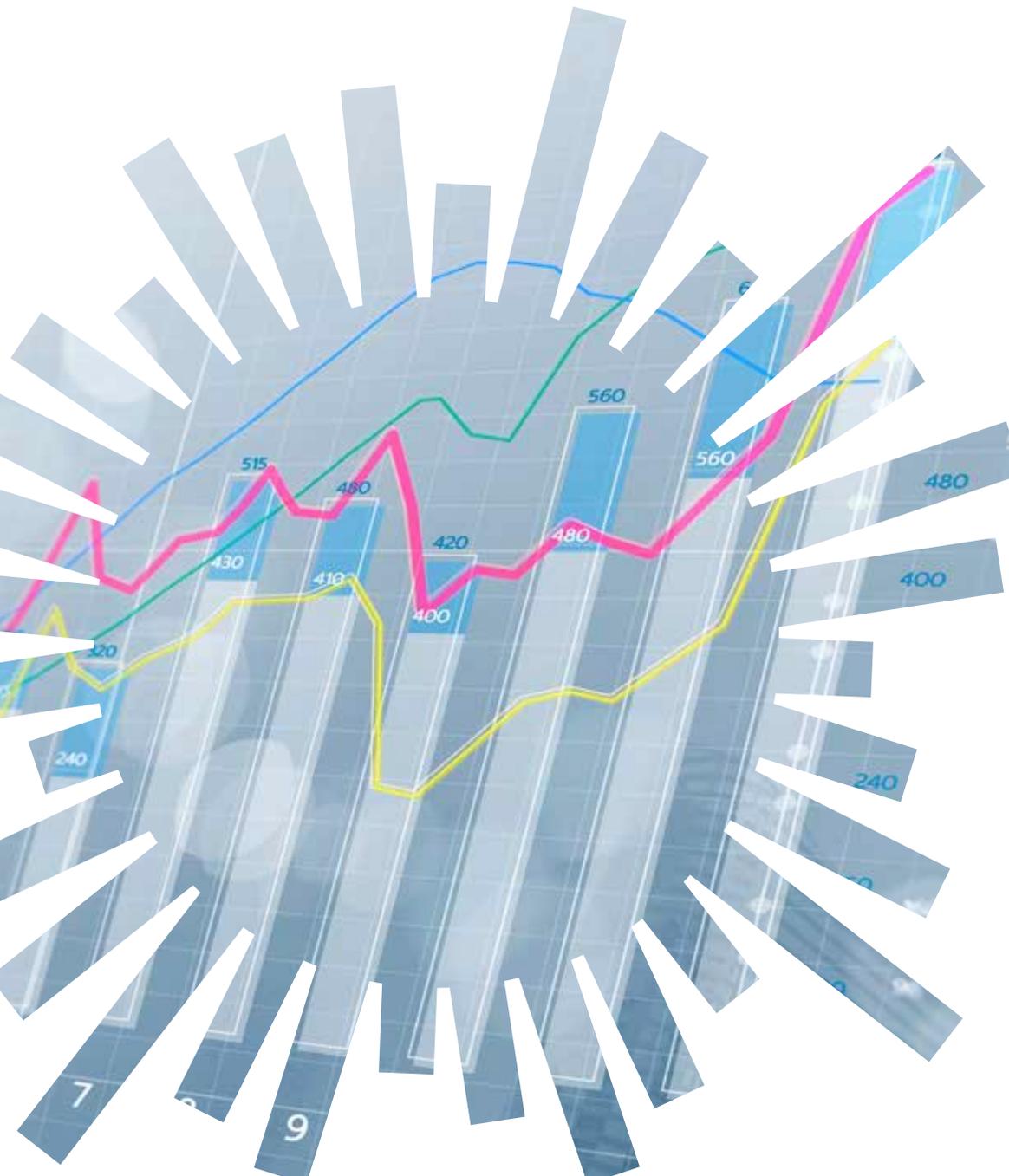
MAY 2020



An Roinn Forbartha
Tuaithe agus Pobail
Department of Rural and
Community Development



government supporting communities



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Summary Findings

LIVING WITH LOCKDOWN

IMPACT OF COVID-19 ON PEOPLE WITH NEUROLOGICAL CONDITIONS & FAMILY CARERS

FINDINGS FROM THE LATEST RESEARCH CARRIED OUT BY THE NEUROLOGICAL ALLIANCE OF IRELAND ON OVER 600 PATIENTS AND CARERS NATIONWIDE SHOW THAT:

26%

of patients had significant challenges in accessing neurological care, including outpatient appointments, diagnostic tests and ongoing treatments which are delivered in a hospital setting

40%

of patients listed voluntary organisations as the single most important source of information on COVID-19 specific to people with their particular condition

38%

of carers reported a significantly increased burden of care due to being unable to receive help from family members/services

ONE FIFTH

of patients did not have sufficient information on what to do if their neurological condition deteriorates at this time

ONE THIRD

of patients reported a significant impact on family life/relationships and on emotional wellbeing. One fifth were significantly impacted financially as a direct result of COVID-19

OVER HALF

of family carers reported a significant impact of the lockdown on family life/relationships and emotional wellbeing

ONE FIFTH

of family carers were significantly impacted financially

Forward and Recommendations



Neurological conditions are mostly chronic long term disorders. The potential impact of the 2020 COVID-19 pandemic on those with neurological disease is still being investigated. However what we do understand is the impact on this group of chronic disease patients and their families due to disruptions in healthcare provision. People with neurological conditions access a wide range of health and social care supports, often struggling in a normal context to navigate a complex set of supports with huge gaps in service provision, lengthy waiting times for diagnosis and treatment and long waiting times between appointments. The outbreak of COVID-19 and the resulting lockdown led to significant changes in access to healthcare in Ireland with the curtailment of many hospital services, redeployment of staff across the health system to COVID care and prevention. In the community a wide range of crucial services including respite, home care, day services and other supports crucial to those with neurological conditions and their families have also been significantly affected.

This nationwide survey was developed by the Neurological Alliance of Ireland in order to better understand the impact of COVID-19 on individuals living with neurological conditions and those who care for them. We wanted to examine the consequences of the lockdown on access to services and treatments across both hospital and community, access to information and advice on what to do and the impact of COVID-19 in other areas including family life and emotional wellbeing. Most importantly we sought to hear directly from

people with neurological conditions and carers in their own words and these testimonies are shared throughout the report. We would like to thank all those who responded to the survey in such numbers during this most challenging of times.

We are very concerned by the issues highlighted in this report, showing the impact on access to healthcare services and information needs identified by respondents. There is huge pressure on neurological care services, including those provided by voluntary organisations, to cope with the current pandemic and the burden on services that is inevitable when lockdown measures are eased. We are urging politicians and policy makers to take the following steps:

- Voluntary organisations provide the community infrastructure for neurological care in Ireland, the service simply cannot be sustained if these charities are forced to curtail services or close altogether. There is an urgent need to secure the sustainability of neurological charities affected by the loss of fundraising income due to COVID-19
- There is a critical need to invest in neurology and neurorehabilitation services: while COVID-19 has exacerbated the challenges experienced by people with neurological conditions, many were already struggling to get the care they needed.



¹ Covid-19: A message from those living with neurological disorders (March 2020) European Federation of Neurological Associations <https://www.efna.net/covid-19-a-message-from-those-living-with-neurological-disorders/>

Summary Recommendations

NAI continues to liaise with the National Clinical Programmes in Neurology and Neurorehabilitation as well as other areas of the health services in relation to the needs of people with neurological conditions both during and subsequent to the COVID19 outbreak.

SPECIALIST COMMUNITY SERVICES

The majority of neurorehabilitation and other specialist supports for people with neurological conditions are provided by voluntary sector organisations many of which rely on public fundraising. The impact on these services is likely to be significant and action is urgently needed to ensure these services are sustained in the immediate and longer term.

NEUROLOGY SERVICES

Neurology services were already experiencing their highest ever waiting lists and lengthy waiting times pre-COVID. Additional resources will be required to allow services to resume in a post-COVID environment. The Neurology Clinical Programme is currently developing a detailed consensus statement on future changes and requirements for neurology and neuropsychology services going forward, calling for the return of staff deployed during the COVID outbreak, investment in telemedicine and additional resources to address the backlog and increased demand for neurology services post COVID.

NEURODIAGNOSTICS AND THERAPEUTIC INTERVENTIONS

There is a significant backlog for access to diagnostics which will require additional resources post COVID. These include neurophysiological based investigations (EEG, EMG), neuroimaging, epilepsy monitoring and neuropsychological assessments as well as therapeutic interventions.

NEUROREHABILITATION SERVICES

Neurorehabilitation services have been curtailed in both hospital and community settings while the rehabilitation needs of those discharged early from rehabilitation facilities due to the COVID outbreak as well as those with ongoing neurorehabilitation requirements will need to be met. Additional neurological consequences of COVID19 are anticipated. This will place pressure on existing rehabilitation services which were already inadequate to meet demand. Investment is critically needed to implement the National Neurorehabilitation Strategy which has seen no investment to support the current three-year implementation framework.

HOME CARE, RESPITE AND OTHER SUPPORTS

Our survey highlighted the significant additional burden faced by family carers faced with the withdrawal or curtailment of respite, home care and other supports. It is vital that these services are resumed but only with the resources and oversight needed to ensure that they can be provided safely and in conjunction with the wishes and requirements of family members and individuals themselves.

Summary Recommendations

Continued

RESIDENTIAL AND SUPPORTED LIVING FACILITIES TELEMEDICINE

The COVID19 outbreak highlighted the lack of adequate step down and transitional facilities and the reliance on nursing homes to support discharge from hospital settings. The Neurological Alliance and other stakeholders have long called for an end the practice of accommodating younger people with complex care needs in nursing homes and the provision of transitional and longer stay facilities and appropriate home care packages to facilitate choices about care.

COMMUNICATION AND CONSULTATION WITH SERVICE USERS

One of the key findings of this survey is the uncertainty and anxiety experienced by people with neurological condition and family carers in relation to their future health and the availability of services. It is vital that any changes to service provision are developed in consultation and communication with all service users. In addition, there is a need for targeted communication to those with specific neurological conditions. Many of those responding to our survey were unsure of the risk for themselves or for family members of returning to work, using transport etc and their entitlement to raise those concerns with employers for example.

Neurology services have been at the forefront of developing telemedicine and other e-health initiatives, now more important than ever in a post-COVID environment. Significant investment will be required to make this a realistic choice for both patients and practitioners. NAI is also concerned that telemedicine should be used appropriately and should not replace face to face care when this is needed. Finally, people without access to technology should not be disadvantaged when it comes to their healthcare in a post-COVID environment.

Neurological Alliance of Ireland

The Neurological Alliance of Ireland is the national umbrella body for over thirty not for profit organisations working with people with neurological conditions and their families. It works to promote the development of services and supports for people with neurological conditions in Ireland through advocacy, policy development, awareness and research.

Profile of Respondents

This survey was developed by the Neurological Alliance through consultation with member organisations and clinicians working in neurological services.

The survey was hosted by NAI on survey monkey during April 2020. Recruitment took place through patient organisation websites and through social media, inviting responses to the survey.

There were 680 responses in total to the survey. Most of the respondents were people living with a neurological condition with a small proportion of family carers. The majority of respondents were living with family members. The most common neurological conditions among patient respondents to the survey were multiple sclerosis (63%), Epilepsy (13%) and Migraine (9%). The most common conditions among the family carer sample were multiple sclerosis (25%), Huntington's disease (18%) and Parkinson's disease (18%).

Table 1.1 Age of Respondents

	PATIENT RESPONDENTS	FAMILY CARER RESPONDENTS
LESS THAN TWENTY	1%	11%
TWENTY TO FORTY	37%	19%
FORTY TO SIXTY	53%	37%
MORE THAN SIXTY YEARS	9%	33%

Table 1.2 Gender Breakdown of Respondents

	PATIENT RESPONDENTS	FAMILY CARER RESPONDENTS
MALE	17%	
FEMALE	83%	

Table 1.3: Living Circumstances of Respondents

	PATIENT RESPONDENTS	FAMILY CARER RESPONDENTS
LIVING ALONE INDEPENDENTLY	10%	2%
LIVING ALONE WITH HOME CARE SUPPORT	2%	2%
LIVING WITH FLATMATES ETC	4%	86%
LIVING WITH FAMILY MEMBERS	80%	2%
IN A RESIDENTIAL SETTING	4%	6%
IN A NURSING HOME	0%	

Table 1.4: Regional Breakdown

	PATIENT RESPONDENTS	FAMILY CARER RESPONDENTS
LEINSTER	53%	60%
MUNSTER	30%	24%
CONNAUGHT	12%	14%
ULSTER	5%	2%



Table 1.5: Neurological Conditions Among Groups of Respondents

Neurological Condition	Patient Respondents	Neurological Condition	Family Carer Respondents
Acquired Brain Injury	2%	Alzheimers Disease/Dementia	3%
Dystonia	1%	Acquired Brain Injury	6%
Epilepsy	13%	Brain Tumour	1%
Chronic Pain	3%	Epilepsy	11%
Hydrocephalus	1%	Huntingtons Disease	18%
Migraine	9%	Hydrocephalus	2%
Multiple Sclerosis	63%	Motor Neurone Disease	2%
Muscular Dystrophy	2%	Migraine	5%
Parkinson's Disease	3%	Multiple Sclerosis	25%
Stroke	1%	Muscular Dystrophy	1%
Rare Neurological Condition Not Included in List	2%	Parkinson's Disease	18%
		Progressive Supranuclear Palsy	3%
		Stroke	3%
		Rare Neurological Conditions	2%

Access to Information Among People with Neurological Conditions and Family Carers

Findings and analysis

PATIENT RESPONDENTS

Table 1.2 Gender Breakdown of Respondents

	HSE WEBSITE	HSE HELPLINE	GP	NEUROLOGY SERVICE	VOL ORG WEBSITE	VOL ORG HEPLINE
GENERAL COVID	78%	2%	3%	5%	11%	1%
CONDITION SPECIFIC	24%	0%	6%	26%	40%	4%

Table 2.2: Self-report on main source of information (family carer respondents)

	HSE WEBSITE	HSE HELPLINE	GP	NEUROLOGY SERVICE	VOL ORG WEBSITE	VOL ORG HEPLINE
GENERAL COVID	72%	6%	7%	4%	9%	2%
CONDITION SPECIFIC	35%	4%	7%	12%	38%	4%

Respondents were questioned on their main source of information in relation to (a) COVID-19 in general, i.e. symptoms, self isolation, etc and (b) condition specific information relating to COVID-19, e.g. potential risk for people with specific neurological conditions, risks associated with immune-suppressant medications etc. While most listed the HSE (Health Services Executive) website as their main source of general information on COVID-19, a high proportion of respondents relied on voluntary organisations as their main source of condition-specific information.

INFORMATION ON VARIOUS ASPECTS OF COVID-19 AND ACCESSING SERVICES DURING LOCKDOWN

While the majority of patient respondents were satisfied that they had sufficient information on various aspects of COVID-19 and accessing services, it is of concern that over a third of respondents felt they did not have sufficient information as it relates to their specific neurological condition, rising to half among family carers. A fifth of patient respondents were unsure how to contact their neurology service at this time, with a fifth unsure what to do if their condition deteriorates. The percentages were slightly higher for family carers. These findings suggest that more needs to be done to reach out to provide advice and reassurance targeted at individual patients and their families. One fifth of family carers had insufficient information on what to do if their home care support was impacted, this points to a clear need for communication on this specific issue.

Table 3.1 Self Report as to sufficient information on various aspects of COVID-19 and accessing services (Patient Responses)

	YES	NO	NOT SURE/ DON'T KNOW	NOT APPLICABLE TO MY SITUATION
GENERAL ADVICE ON COVID, SYMPTOMS, WHAT TO DO	87%	4%	9%	0%
CONDITION-SPECIFIC INFORMATION ON RISKS ETC	46%	35%	18%	1%
HOW TO CONTACT MY NEUROLOGIST AT THIS TIME	61%	22%	14%	3%
PRACTICAL SUPPORT IN COMMUNITY	61%	13%	7%	19%
HOW TO ACCESS HELP IF NEUROLOGICAL CONDITION DETERIORATES AT THIS TIME	64%	21%	14%	1%
HOW TO ACCESS HELP IF HOME CARE IS IMPACTED AT THIS TIME	24%	12%	10%	54%

Table 3.2 Self Report as to sufficient information on various aspects of COVID-19 and accessing services (Family Carer Responses)

	YES	NO	NOT SURE/DON'T KNOW	NOT APPLICABLE TO MY SITUATION
GENERAL ADVICE ON COVID, SYMPTOMS, WHAT TO DO	82%	10%	8%	0%
CONDITION-SPECIFIC INFORMATION ON RISKS ETC	33%	50%	16%	1%
HOW TO CONTACT MY NEUROLOGIST AT THIS TIME	50%	28%	17%	5%
PRACTICAL SUPPORT IN COMMUNITY	62%	14%	9%	15%
HOW TO ACCESS HELP IF NEUROLOGICAL CONDITION DETERIORATES AT THIS TIME	55%	23%	19%	3%
HOW TO ACCESS HELP IF HOME CARE IS IMPACTED AT THIS TIME	22%	21%	15%	42%



Neurological Patient Organisations: Responding to the Challenge of Covid-19



As the situation with COVID19 in Ireland continues to develop, Epilepsy Ireland will endeavour to provide the most up to date advice for people with epilepsy and their families in the most

clear and concise way possible in order to ease any concerns that you might have. We have outlined responses to the most common questions we have received to date below:

1) Where can I find general information on COVID19?

The best and only source of information regarding Coronavirus in Ireland is available from the HSE and the Department of Health. Please do your utmost to ensure that you are following information that has been issued from reputable sources.

2) Does having epilepsy make me more prone to the virus?

There is no known evidence that having epilepsy makes you more susceptible to catching the virus. However, please note that for many people with epilepsy, having a fever can lead to increased seizure activity. This is because the body is under stress in trying to fight off the illness and therefore lowers your seizure threshold. Apply the official preventative advice issued by the HSE in your day to prevent you from catching the virus.

3) Will there be frequently asked questions (FAQs) – Migraine and Covid-19

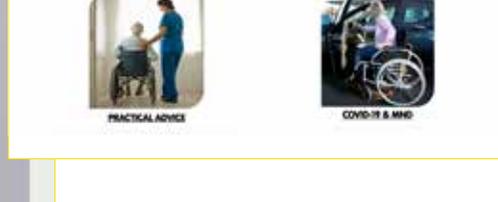
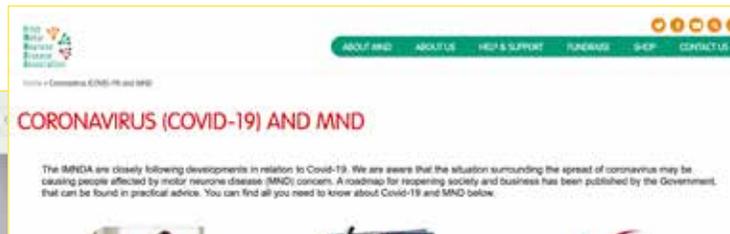


Neurological charities responded rapidly to the need for condition-specific information among their members, developing comprehensive web-based resources, sourcing international material and posting up to date information and advice as needed.

“Our patient organization has provided excellent advice and ongoing phone and online support”

“My MS care worker calls me every day”

“Patient organization doing a fantastic job staying in contact”



Spinal Injuries Ireland

Who we are Services Resources Stories Events News Publications

According to the World Health Organisation a spinal cord injury (SCI) is one of the most devastating and life changing injuries that a person can sustain. However following medical and rehabilitation intervention and with the relevant support, a SCI is not only survivable but an individual can continue to lead the life that they had envisaged prior to injury. Spinal Injuries Ireland (SII) is the only support and service agency in Ireland for people who have sustained a spinal cord injury and their families. We provide a person centred service to assist people to engage fully in society. Recent figures show that an average of 3 people per week sustain a spinal cord injury in Ireland. Spinal Injuries Ireland is dedicated to ensuring that those people affected by this life-changing injury never suffer alone.



Neurological Patient Organisations: Responding to the Challenge of Covid-19



MDI logo and navigation menu: HOME, ABOUT MDI, WHAT WE DO, HOW TO HELP, NEWS, CONTACT, DONATE.

Welcome to the MDI website. Content and updating of information is ongoing on our website, therefore if you cannot find what you are looking for please contact us.

KEEP SAFE & STAY HEALTHY
Suggestions for things to do for young members while confined to their homes

Logos for Coronavirus COVID-19 Public Health Action, HSE, and Eilís na Míreann Government of Ireland.

MS Ireland has been closely following developments in relation to COVID-19. This is a rapidly evolving situation which we will continue to monitor carefully. We have consulted with neurologists, our friends at MS Trust UK and other patient organisations to ensure we are providing you with up-to-date, relevant and expert information. Below is the initial information based on our current knowledge. This will be under continuous review as our knowledge of the virus improves.

If you have specific concerns in relation to your own health or that of a loved one, we would advise that you contact your GP, MS Nurse or Neurologist. We will keep this page updated on a regular basis.

Please browse the relevant sections below. If you have any questions email info@ms-society.ie or call our information line 1850 233 233 open from 10am-5pm Monday to Friday.



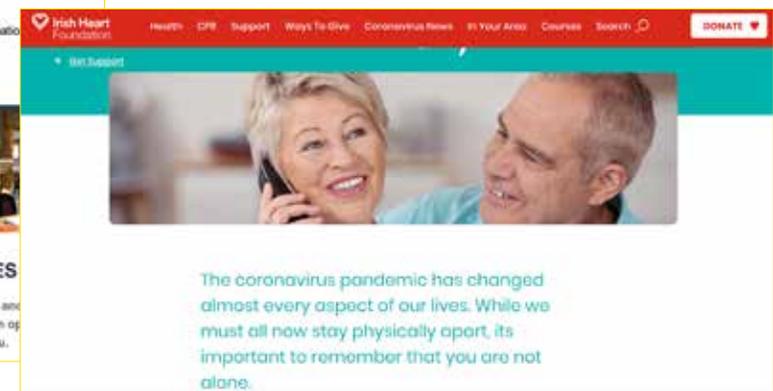
COVID-19 AND MS
Information on COVID-19 and advice for People Living with MS.



INCOME SUPPORTS
As a result of the Covid-19 pandemic, the Government has introduced the 'COVID-19'...



OUR SERVICES
Our Regional services and information line remain open. We are here to help you.

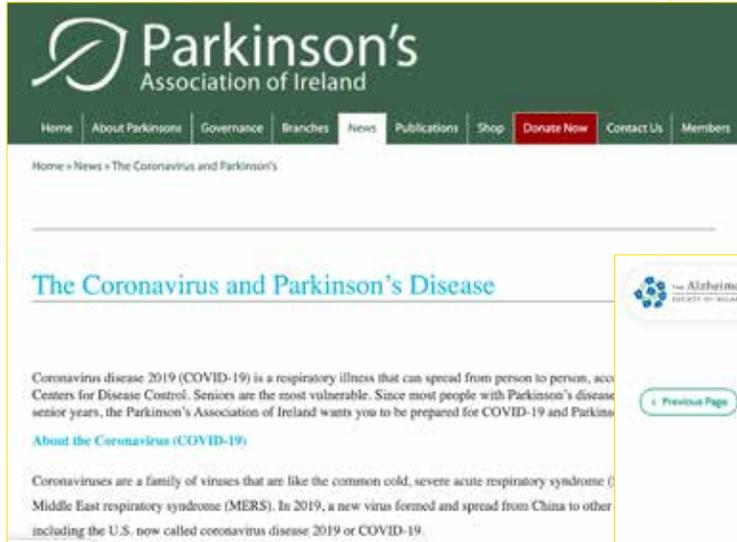


Irish Heart Foundation logo and navigation menu: Health, CPE, Support, Ways To Give, Coronavirus News, In Your Area, Courses, Search, DONATE.

800 Support



The coronavirus pandemic has changed almost every aspect of our lives. While we must all now stay physically apart, it's important to remember that you are not alone.



Parkinson's Association of Ireland logo and navigation menu: Home, About Parkinson's, Governance, Branches, News, Publications, Shop, Donate Now, Contact Us, Members.

Home » News » The Coronavirus and Parkinson's

The Coronavirus and Parkinson's Disease

Coronavirus disease 2019 (COVID-19) is a respiratory illness that can spread from person to person, according to the Centers for Disease Control. Seniors are the most vulnerable. Since most people with Parkinson's disease are senior years, the Parkinson's Association of Ireland wants you to be prepared for COVID-19 and Parkinson's.

About the Coronavirus (COVID-19)

Coronaviruses are a family of viruses that are like the common cold, severe acute respiratory syndrome (SARS), and Middle East respiratory syndrome (MERS). In 2019, a new virus formed and spread from China to other countries, including the U.S., now called coronavirus disease 2019 or COVID-19.



Alzheimer Society of Ireland logo and navigation menu: Home, About Dementia, Living with Dementia, Get Support, Get Involved, Creating Change, National Helpline 1800-341-541.

Previous Page

Coronavirus (Covid-19) Update

Content

1. Services still operating
2. Useful resources for people with dementia and their families during COVID-19
3. Tips for people with dementia and supporting people with dementia in the community

Live Chat Online Now



SBHI COVID-19 Support Group Now live!

Minding your Mental Health - COVID-19

SBHI COVID-19 Support Group
We are delighted to inform you that we have launched a COVID-19 Support Group for SBHI service users on Facebook!
<https://www.facebook.com/groups/SbhiSupportGroup>

Impact of Covid-19 on Financial Wellbeing, Family Life/ Relationships and Emotional Wellbeing

One third of patient respondents reported a significant impact of COVID-19 on family life/relationships and on emotional wellbeing, rising to over half of family carers. When the percentages for both “significant” and “some impact are taken into account, the overwhelming majority of respondents have experienced an impact of COVID-19 on key areas of quality of life.

Table 4.1: Self report on impact of COVID19 on financial wellbeing, family life/relationships and emotional wellbeing (Patient Responses)

	SIGNIFICANT IMPACT	SOME IMPACT	NOT SURE/DON'T KNOW	NO IMPACT
FINANCIAL WELLBEING	19%	38%	6%	37%
FAMILY LIFE/RELATIONSHIPS	31%	48%	4%	17%
EMOTIONAL WELLBEING	32%	58%	2%	8%

Table 4.2: Self report on impact of COVID-19 on financial wellbeing, family life/relationships and emotional wellbeing (Patient Responses)

	SIGNIFICANT IMPACT	SOME IMPACT	NOT SURE/DON'T KNOW	NO IMPACT
FINANCIAL WELLBEING	21%	48%	3%	28%
FAMILY LIFE/RELATIONSHIPS	55%	35%	1%	9%
EMOTIONAL WELLBEING	59%	38%	1%	2%

Accessing Neurological Care Services During Lockdown

Table 5.1: Self-report on access to a range of services and supports during lockdown (Patient Responses)

	EXPERIENCING TO A LARGE EXTENT	EXPERIENCING TO SOME EXTENT	NOT EXPERIENCING	NOT APPLICABLE TO MY SITUATION	NOT SURE/ DON'T KNOW
REDUCTION IN PHN VISITS DUE TO COVID	3%	3%	9%	82%	3%
DELAYS IN ACCESSING COMMUNITY AHPS DUE TO COVID	10%	11%	8%	68%	3%
WITHDRAWAL OF HOME CARE BY PROVIDERS DUE TO COVID	3%	3%	5%	89%	0%
YOU/YOUR FAMILY DECIDING TO WITHDRAW HOME CARE	6%	10%	13%	68%	3%

Table 5.2: Self-report on access to a range of services and supports during lockdown (Family Carer Responses)

	EXPERIENCING TO A LARGE EXTENT	EXPERIENCING TO SOME EXTENT	NOT EXPERIENCING	NOT APPLICABLE TO MY SITUATION	NOT SURE/ DON'T KNOW
REDUCTION IN PHN VISITS DUE TO COVID	9%	12%	7%	66%	6%
DELAYS IN ACCESSING COMMUNITY AHPS DUE TO COVID	24%	17%	6%	46%	7%
WITHDRAWAL OF HOME CARE BY PROVIDERS DUE TO COVID	8%	9%	10%	69%	4%
YOU/YOUR FAMILY DECIDING TO WITHDRAW HOME CARE	11%	23%	14%	51%	1%

Family carers were more likely to experience delays and difficulties in accessing the services listed in the survey, with most patient respondents identifying that the issues raised in this section were not applicable to them. Nearly one fifth of family carer respondents were experiencing delays in accessing allied health professional services such as physiotherapy/ speech and language therapy in the community, rising to over 40% when responses are included for those experiencing this issue “to some extent”. Over a third reported significant or some impact of deciding to withdraw home care due to the threat of COVID-19. A smaller percentage were impacted by providers withdrawing care, highlighting that families are themselves making these decisions in view of their concerns about COVID-19.

Over half of families were taking on more of the tasks associated with caregiving themselves.

ACCESS TO SERVICES: RESPONDENT'S COMMENTS

An analysis of patient comments showed that 25% had significant issues in accessing services/treatment for their condition. Most were concerned about the implications for their health and unsure when services would return to normal

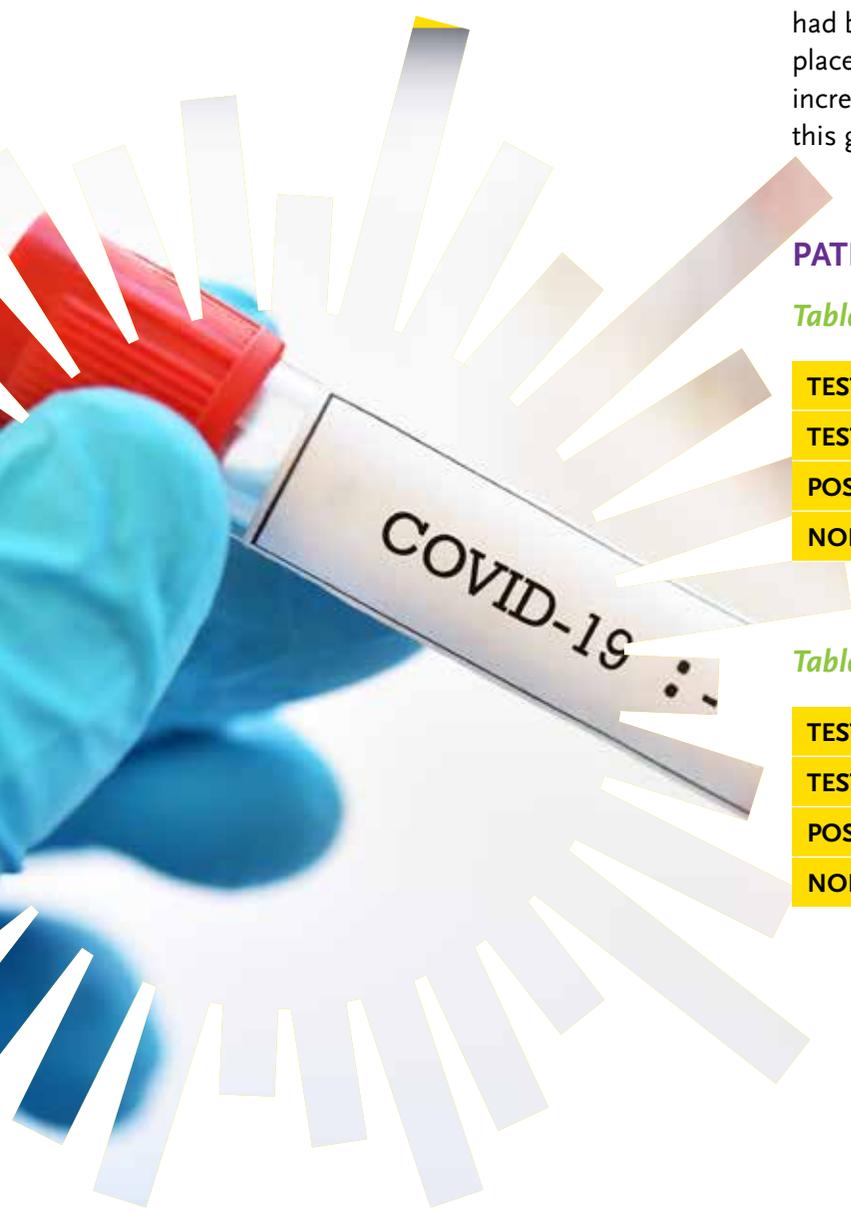
Patients reported a range of challenges in accessing services and treatment including:

- Cancellation of outpatient appointments with neurology services
- Cancellation of infusion/injection treatments (mainly affecting patients with MS/Migraine)
- Delays in commencing new treatments, changes in medication postponed
- Routine MRI scans postponed, delays in getting results from MRI
- Challenges in getting prescriptions renewed
- Cancellation of physiotherapy and other allied health services

A similar percentage of family carers (26%) reported a significant impact on access to services through their qualitative responses, raising most of the same issues as the patient respondents. An analysis of their comments showed that family carers tended to express more anxiety about the impact on the persons health and concern about when services would become available.



Testing and Covid-19



Both the patient and carer groups were questioned about whether the person with the neurological condition had been tested for COVID-19 and the outcome of testing. The majority had not been tested. This survey took place over three weeks in April 2020, concluding on April 30th. Since that date, rates of testing have significantly increased. It is likely that a repeat of the survey at the present time would reveal higher rates of testing among this group.

PATIENT RESPONSES

Table 6.1: Self report on direct experience of COVID-19 and testing

TESTING FOR COVID ₁₉ WHICH TURNED OUT TO BE NEGATIVE	5%
TESTED POSTIVE AND SELF ISOLATING AT HOME	1%
POSITIVE TEST FOR COVID AND TREATMENT IN A HOSPITAL OR OTHER CARE SETTING	0%
NONE OF THE ABOVE	94%

Table 6.2 Self report on direct experience of COVID-19 and testing

TESTING FOR COVID ₁₉ WHICH TURNED OUT TO BE NEGATIVE	2%
TESTED POSTIVE AND SELF ISOLATING AT HOME	0%
POSITIVE TEST FOR COVID AND TREATMENT IN A HOSPITAL OR OTHER CARE SETTING	2%
NONE OF THE ABOVE	96%

MOST CHALLENGING ASPECT OF COVID-19

Respondents were asked to comment on the most challenging aspect of COVID-19. Most identified being anxious about contracting the virus, some were concerned that they would be asked to return to the workplace and exposed to greater risk. Family carers were concerned about cocooning the patient while at the same time facing a return to work/school among other members of the family and managing this in the longer term. Many patient and carer respondents were experiencing multiple impacts of the lockdown, with concern about the wellbeing of elderly parents they could not visit as well as their own risk. For the majority of respondents, dealing with social isolation was a significant challenge. This survey took place before measures were announced that those cocooning could leave their homes to take daily exercise, at the time of this survey most reported a negative impact on their physical and psychological wellbeing of confinement to their homes.

This section revealed the extent to which families are struggling with the impact of COVID-19, with the person with a neurological condition also a parent worker or responsible for elderly relatives and now feeling intense concern about fulfilling these other roles while vulnerable because of their own chronic condition. Family carers were having to balance their concern for their family member while also worried about bringing the virus into the home through work/school/family visits into the future.

“Worsening condition due to lack of treatment, stress and anxiety”

“Lack of physiotherapy. Increased pain and reliance on pain medication”

“Just thinking what if something happens, what services would be available”

“Fear of contracting COVID19 and leaving my family without any support during my isolation/treatment”

“Afraid that if I contract COVID-19 I won't be able to go into hospital for my monthly infusion treatment which would leave me at risk of relapse”

“Worrying what will happen if I get a seizure”

“Needing Carers who also visit other houses”

“The worry and concern if we need healthcare at this time”

“Socially isolating means lack of support/respice for me as a carer”

“Lack of support as my family member's condition has deteriorated in tandem with restrictions”

“Trying to fill in all the gaps as we no longer have PA's coming into our home”

Ways in Which People with Neurological Conditions/Family Carers could be Supported at This Time

The most frequently reported recommendation was for more condition-specific information to be made available, including the potential risks for people with specific neurological conditions or on specific medications. The point was frequently made that there is a lot of advice and information on COVID-19 in general but people with neurological conditions do not feel that sufficient detailed information is available to them. Many noted they would like to be contacted by their neurology service, even by e mail or text to advise them on access to services and what to do in an emergency.

“Condition-specific information in an Irish context would be helpful. There is very good information available on how to avoid contracting COVID-19 but I would like to know what to do if I contracted COVID-19”

“Safe access to services (bloods/MRIs)”

“More up to date information delivered in a timely fashion and advice how to manage immuno-suppression drugs as restrictions get lifted”

“Clear instructions are needed in relation to treatment medication and possible risks”

“A text from the hospital/neurology service on what to do in an emergency”

“If I contract (COVID-19) how will being on a DMT affect my recovery”

“Just the care team to make a call to keep in contact”

“I think the main thing is to ensure specialist nurses remain in place and are not seconded. Its important to ensure they are available to support neurological patients and keep them out of hospital”



List of NAI members

Acquired Brain injury Ireland
Alzheimer Society of Ireland
An Saol
Aphasia Ireland
Ataxia Ireland
Aware
Bloomfield Health Services
Cheshire Ireland
Chronic Pain Ireland
Dystonia Ireland
Enable Ireland
Epilepsy Ireland
Headway
Huntington's Disease Association of Ireland
Irish Heart Foundation
Irish Hospice Foundation
Irish Motor Neurone Disease Association
Migraine Association of Ireland
Move4Parkinsons

Multiple Sclerosis Society of Ireland
Muscular Dystrophy Ireland
National Council for the Blind
Neurofibromatosis Association of Ireland
North West MS Therapy Centre
Parkinson's Association of Ireland
Polio Survivors Ireland
PSPA Ireland
Syringomyelia Support group of Ireland
Spinal Injuries Ireland
Spina Bifida Hydrocephalus Ireland
The Rehab Group

Associate Members

IBrain Tumour Ireland
Syringomyelia Chiara Malformation Support Group

Neurological Alliance of Ireland

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