

# **LIVING WITH A NEUROLOGICAL CONDITION IN IRELAND**

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

**OCTOBER 2020**



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



government supporting communities

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## KEY FINDINGS

# 800,000 Irish People Are Living With Neurological Conditions

*Such as stroke, dementia, acquired brain injury,  
epilepsy, multiple sclerosis and Parkinson's disease*

**Latest research by the Neurological Alliance of Ireland**

### PATIENTS REPORTING THEIR ACCESS TO VITAL SERVICES IS NOW WORSE THAN DURING THE RECESSION

	% of people reporting they could not access this service	
	2011	2019
Neurologist	4%	10%
Nurse Specialist	11%	17%
Physiotherapy	9%	18%
Counselling	10%	20%

### WAITING TIMES TO SEE A NEUROLOGIST

**37%** waiting more than 12 months  
to see a neurologist for the first time  
(compared to **33%** in 2011)

Highest waiting times are in  
Munster (**41%** waiting more than  
12 months)

### OUT OF POCKET COSTS OF CARE

**45%** paying more than **€100** a  
month towards the cost of their  
care

Most significant expenditure on  
physiotherapy (**15%** spending  
more than **€100** a month)

### NEED BUT CANT AFFORD TO PAY FOR:

Neuropsychology **18%**

Physiotherapy **15%**

Counselling **17%**

# KEY FINDINGS

## Previous and Current NAI Surveys:

Percentage of Respondents Reporting they Cannot Access a Specific Service

	2011	2014	2018	2019
Neurologist	4%	7%	9%	10%
Nurse Specialist	11%	20%	15%	17%
Physiotherapist	9%	14%	18%	18%
Speech & Language Therapist	5%	13%	3%	5%
Occupational Therapist	9%	15%	12%	11%
Psychologist	16%	24%	19%	16%
Respite Care	4%	25%	7%	5%
Aid/appliance	9%	13%	11%	12%
Adaptation to the home	8%	25%	14%	12%

## FOREWORD AND COMMENT ON SURVEY FINDINGS

Welcome to the fourth in our series of survey reports on living with a neurological condition in Ireland. The Neurological Alliance of Ireland has carried out these nationwide surveys over a period of years, beginning in 2011, in order to support and inform our ongoing advocacy work on behalf of Irish people living with neurological conditions and their families.

Data collection to inform the 2020 survey was carried out in November and December 2019, before the onset of the COVID19 pandemic. The report examines access to neurological care services and a range of other supports among people with neurological conditions and family carers. For the first time in these surveys there is a specific focus on issues facing parents of a child with a neurological condition.

The report shows a worrying trend in relation to accessing key services when this is compared to previous surveys. Since 2011, the percentage of respondents reporting they could not access a service has doubled in relation to neurology and physiotherapy services.

A specific focus on out of pocket expenditure, expanding on an item in our 2018 survey, appears to confirm anecdotal concerns from our member groups that there is a strong reliance on individuals and families to contribute to the cost of their own care. The findings echo those of our previous surveys in reporting a fifth of family carers giving up work specifically in order to care for a person with a neurological condition and two thirds reporting that family finances have been significantly impacted as a direct result of the neurological diagnosis.

Issues in relation to medications also emerged in this survey with over a third reporting that were unable to access a medicine licensed for their condition and almost a third that they had been impacted by a generic substitute.

This survey in our series focused for the first time on parents of a child with a neurological condition. While the sample size was too small to make meaningful interpretations from the data, it is very clear that there are significant issues for this group in accessing services, particularly longer term care, which NAI is committed to explore further.

This survey was carried out before the unprecedented events of early 2020 with the outbreak of the worldwide coronavirus pandemic. It is clear that COVID19 has further exacerbated the struggle to access care experienced by people with neurological conditions.

Our COVID19 survey of over six hundred people with neurological conditions carried out in May 2020 highlighted the impact of lockdown on access to services with many individuals experiencing delays and postponements in vital treatments and neurorehabilitation services for their condition.

Our submission to the Oireachtas Committee on COVID19<sup>1</sup> pointed to the increased pressures placed by COVID19<sup>2</sup> on neurology and neurorehabilitation services which were already completely under-resourced.

As we present these survey findings, we do so in the realisation that the challenges experienced by people with neurological conditions have significantly increased due to the current pandemic and more than ever they need our strongest support and unified voice for change.



*Tom Scott,  
Chair Of NAI*

*Mags Rogers,  
Executive Director of NAI*



<sup>1</sup> COVID19: *The Impact on People with Neurological Conditions and Family Carers (May 2020)* Neurological Alliance of Ireland

<sup>2</sup> *Call for Priority Investment in Neurological Care in Ireland in the Fight Against COVID19: Submission to the Oireachtas Committee on COVID19 (July 2020)* Neurological Alliance of Ireland

# NEUROLOGICAL CONDITIONS IN IRELAND

Neurological conditions are those affecting the brain and spinal cord. They represent the leading cause of disability and the second leading cause of death worldwide<sup>3</sup>. Over 800,000 people in Ireland live with a neurological condition<sup>4</sup> with many experiencing significant and challenging impacts on almost every aspect of their lives as a result of their condition. As populations age across the developed world, more

people will develop neurodegenerative conditions and, thanks to advances in surgery and treatment, more people will live with acquired disabling neurological conditions into the future. The World Health Organisation has recognised that neurological conditions represent the greatest challenge to public health systems in developed countries worldwide. Ireland is extremely poorly prepared to meet this

challenge, both now and into the future. Underinvestment in the development of services means that most people living with neurological conditions in this country will struggle to get the level and type of care taken for granted in other developed countries.

The Neurological Alliance of Ireland, as the only umbrella organisation dedicated to representing people with

neurological conditions, has a critical responsibility to continue to highlight and address this situation through its ongoing work to promote the development of services and supports for all those affected by neurological conditions.

<sup>3</sup> Global, regional and national burden of neurological disorders 1990-2016; a systematic analysis for the Global Burden of Disease Study 2016. *Lancet: Neurology* 2019;18 459-480

<sup>4</sup> *Review of Neurology and Neurophysiology Services (2007) Report prepared for the National Hospitals Office, Health Services Executive*

# UNDERINVESTMENT IN NEUROLOGICAL CARE IN IRELAND

Ongoing failure to invest properly in services means that Irish people with neurological conditions struggle to get the care they need to support the early diagnosis, treatment and rehabilitation of their condition.

A national audit of neurology services<sup>5</sup> carried out by the NAI in partnership with Neurology Clinical Programme revealed large gaps in multidisciplinary staffing to support neurology services nationwide; including consultant neurologists and clinical nurse specialists, a lack of dedicated beds and long waiting times for access to diagnostics.

NAI continues to highlight the serious gaps in neurorehabilitation services throughout Ireland<sup>6</sup>. As a country, we have less than half the dedicated specialist rehabilitation beds needed for our population, as well as the lowest number of consultants in rehabilitation medicine in Europe. There are also huge gaps in community rehabilitation services including dedicated teams, residential and respite services.

Ongoing failure to invest properly in neurology and neurorehabilitation services continues to present an enormous challenge for individuals and their families living with these

conditions. It is also a significant contributory factor in critical issues facing our health system including growing outpatient waiting lists, overcrowding in accident and emergency departments and the continued problem of delayed discharges from acute care.

The Neurological Alliance of Ireland is calling for multi-annual investment to support the implementation of the neurorehabilitation strategy<sup>7</sup> and the models of care for epilepsy and

neurology. A three-year implementation framework<sup>8</sup> for the neurorehabilitation strategy was published in February 2019 but dedicated investment is needed during and extending beyond the three year implementation 2019-2021 given that the existing service infrastructure is chronically underdeveloped and under resourced.

<sup>5</sup> Report on National Survey Of Neurology Services (2015) Neurological Alliance of Ireland [https://www.nai.ie/assets/22/E622B527-41E1-4471-9EFDAE484E1745B2\\_document/NAI\\_Report\\_on\\_National\\_Services\\_2015\\_C.pdf](https://www.nai.ie/assets/22/E622B527-41E1-4471-9EFDAE484E1745B2_document/NAI_Report_on_National_Services_2015_C.pdf)

<sup>6</sup> Pre Budget Submission 2020 (July 2019) Neurological Alliance of Ireland website [https://www.nai.ie/go/resources/nai\\_documents/16-7-2019-nai-pre-budget-submission-2020](https://www.nai.ie/go/resources/nai_documents/16-7-2019-nai-pre-budget-submission-2020)

<sup>7</sup> National Policy and Strategy for the Provision of Neurorehabilitation Services in Ireland 2011-2015 (2011) Department of Health [https://health.gov.ie/wp-content/uploads/2014/03/NeuroRehab\\_Services1.pdf](https://health.gov.ie/wp-content/uploads/2014/03/NeuroRehab_Services1.pdf)

<sup>8</sup> National Strategy & Policy for the Provision of Neurorehabilitation Services in Ireland, From Theory to Action: Implementation Framework 2019-2021 (2019) Health Services Executive <https://www.hse.ie/eng/services/list/4/disability/neurorehabilitation/national-strategy-policy-for-the-provision-of-neuro-rehabilitation-services-in-ireland.pdf>

## THE CURRENT STUDY: BACKGROUND AND METHODOLOGY

This survey was developed by the Neurological Alliance through consultation with its member organisations and a group of patient advocates living with neurological conditions.

The survey was hosted by NAI on survey monkey during November and December 2019. Recruitment took

place through patient organisation websites and through social media, inviting responses to the survey. The 2019 survey repeated a number of questions in previous surveys around access to health services and other supports but also introduced a number of items in response to issues raised in the consultative process to inform the survey design. These included

questions on home care support, rental accommodation and out of pocket expenditure on healthcare and other supports. For the first time, a section was introduced for parents caring for a child under the age of eighteen.

The NAI wishes to sincerely thank all of those who gave their time to

complete such a lengthy and detailed questionnaire. We understand that many of the items continue to explore the difficult and challenging aspects of living with a neurological condition and NAI acknowledges the commitment and support of all those who shared their experiences.

## ACCESS TO SERVICES: FINDINGS AND ANALYSIS

Each group of respondents were offered a series of answer choices in relation to their requirement for and ability to access a range of supports and services for their neurological condition.

### Patient Responses

The highest percentage of patient respondents reporting they needed a service but could not access it were in relation to counselling (20%) physiotherapy (18%), nurse specialist (17%), neuropsychology (17%) and psychology (16%) services.

**Table 1.1. 1: Access to Services: Patient Respondents**

	I CAN ACCESS THIS SERVICE AND IT IS SUFFICIENT FOR MY NEEDS	I CAN ACCESS THIS SERVICE, BUT IT IS NOT SUFFICIENT FOR MY NEEDS	I NEED THIS SERVICE, BUT I CANNOT GET IT	NOT SURE/ DON'T KNOW	NOT APPLICABLE/I DON'T NEED THIS SERVICE
Consultant Neurologist	55%	30%	9%	4%	2%
Neuropsychology	6%	6%	17%	41%	30%
Nurse Specialist	36%	17%	17%	13%	17%
MRI Scan	58%	9%	7%	11%	15%
Physiotherapy	26%	18%	18%	15%	23%



**Table 1.1. 1: Access to Services: Patient Respondents (Continued)**

Speech and Language Therapy	11%	3%	5%	11%	70%
Occupational Therapy	14%	7%	11%	17%	51%
Psychology	8%	6%	16%	26%	44%
Respite Care	1%	0%	5%	10%	84%
Aid, Appliance or Specialist Equipment for my neurological condition	8%	5%	12%	16%	59%
Adaptation to my home	9%	2%	11%	10%	68%
Personal Assistant Services	2%	2%	5%	13%	78%
Day Service	2%	1%	3%	8%	86%
Social Worker	3%	2%	7%	13%	75%
Counselling	9%	9%	20%	24%	38%
Neurorehabilitation Services	3%	1%	13%	26%	57%
Home Care Support	2%	3%	8%	12%	75%
Case Manager	2%	1%	7%	24%	66%
Palliative Care	1%	1%	1%	4%	93%

## Family Carer Responses

A high percentage of family carers reported they could not access counselling (48%) or neurorehabilitation services (40%). Over one third reported that they could not access Psychology (38%) or Neuropsychology (33%) services. As with the patient respondents, the highest single out of pocket expenditure was private health insurance (53%). Over one fifth of family carers were paying entirely out of their own pocket for neurologist (28%), MRI scan (28%) and GP services (25%). Private health insurance was the most significant out of pocket expenditure with 29% of carers reporting paying more than €100 a month. The other significant out of pocket expenses was a paid carer in the home (19%). 40% of carers were spending more than €100 on out of pocket expenditure on healthcare.

What is your experience at the moment in accessing the following services/ supports for your family member's neurological condition?

*Table 1.1.2 Access to Services: Family Carer Responses*

	WE CAN ACCESS THIS SERVICE AND IT IS SUFFICIENT FOR OUR NEEDS	WE CAN ACCESS THIS SERVICE BUT IT IS NOT SUFFICIENT FOR OUR NEEDS	WE NEED THIS SERVICE BUT WE CANNOT GET IT	NOT SURE/ DON'T KNOW	NOT APPLICABLE, WE DON'T NEED THIS SERVICE
Consultant Neurologist	47%	32%	6%	9%	6%
Neuropsychology	7%	13%	33%	37%	10%
Nurse Specialist	21%	21%	27%	14%	17%
MRI scan	16%	6%	16%	28%	34%
Physiotherapy	15%	46%	15%	9%	15%
Speech and Language Therapy	18%	28%	18%	15%	21%
Occupational Therapy	35%	35%	8%	2%	20%
Psychology	6%	9%	38%	28%	19%
Respite Care	12%	15%	18.5%	18.5%	36%
Aid, Appliance or Specialist Equipment for my neurological condition	43%	18%	9%	9%	21%
Adaptation to my home	21%	9%	18%	27%	25%

*Table 1.1.2 Access to Services: Family Carer Responses (continued)*

Personal Assistant Services	6%	15%	18%	21%	40%
Day service	6%	16%	16%	28%	34%
Social Worker	2%	12%	25%	34%	27%
Counselling	6%	6%	48%	28%	12%
Neurorehabilitation Services	3%	3%	40%	33%	21%
Home care support	3%	34%	13%	22%	28%
Case Manager	0%	12%	21%	46%	21%
Genetic Testing	6%	3%	19%	44%	28%
Genetic Counselling	3%	6%	12%	49%	30%
Palliative Care	6%	6%	6%	19%	63%

## Parents of a Child with a Neurological Condition

Over one fifth of respondents reported that they needed services but could not access them including neuropsychology (28%), occupational therapy (21%), adaptation to their home (21%), home care support (21%) and counselling for the child (24%) and family members (36%).

*Table 1.1.3 Access to Services: Parent of a Child with a Neurological Condition Respondents*

	WE CAN ACCESS THIS SERVICE AND IT IS SUFFICIENT FOR OUR NEEDS	WE CAN ACCESS THIS SERVICE BUT IT IS NOT SUFFICIENT FOR OUR NEEDS	WE NEED THIS SERVICE BUT WE CANNOT ACCESS IT	NOT SURE/ DON'T KNOW	NOT APPLICABLE, WE DON'T NEED THIS SERVICE
Consultant Neurologist	44%	28%	5%	8%	15%
Neuropsychology	6%	3%	28%	44%	19%
Nurse Specialist	33%	13%	20%	7%	27%
MRI scan(s)	37%	15%	18%	15%	15%
Physiotherapy	24%	30.5%	9%	6%	30.5%
Speech and Language Therapy	25%	15.5%	19%	0%	40.5%
Occupational Therapy	24%	34%	21%	0%	21%
Psychology	12%	27%	15%	12%	34%
Respite Care	0%	6%	18%	27%	49%
Aid, Appliance or Specialist Equipment	21%	18%	6%	24%	31%
Adaptation to our home	9%	3%	21%	18%	49%



**Table 1.1.3 Access to Services: Parent of a Child with a Neurological Condition Respondents (continued)**

Special Needs Assistant	46%	12%	6%	9%	27%
Play Therapy	3%	6%	19%	22%	50%
Social Worker	18%	18%	6%	6%	52%
Counselling for the child with a neurological condition	6%	12%	24%	28%	30%
Counselling for other family members/carers	2%	5%	36%	36%	21%
Neurorehabilitation Services	0%	3%	15%	33%	49%
Home care support	0%	3%	21%	24%	52%
Case Manager	6%	6%	15%	30%	43%
Assessment of Need (under Disability Act)	13%	6%	15.5%	40.5%	25%
Genetic testing	12.5%	10%	12.5%	26%	39%
Genetic counselling	13%	0%	13%	32%	42%
Palliative care	3%	0%	0%	3%	94%

## ACCESS TO SERVICES: ANALYSIS

Adult respondents were questioned about the length of time they had waited to see a neurologist from the time of onset of their symptoms. 37% reported waiting more than 12 months, up from 29% in the 2018 survey.

When this was broken down by region, Munster had the highest proportion of respondents waiting more than twelve months. A similar percentage of respondents reported a significant impact of long waiting lists between neurology appointments with Leinster and Connaught showing almost equal rates of response and Munster slightly lower. Over a fifth of respondents in Leinster and Munster reported a significant impact of long waiting times for MRI scans but the percentage in Connaught was 44%. Both these issues of increasing waiting times between neurology appointments and long waits for MRI emerged in the first patient experience survey of neurology services carried out by the NAI in 2018<sup>9</sup>.

It is clear that there is growing pressure on neurology services with waiting

lists for an outpatient appointment now at their highest ever. The number of people waiting for an outpatient appointment rose from 13,493 in 2015 to 21,990 in the same month in 2020, while the number waiting more than twelve months rose from 2,418 to 8,960, more than a threefold increase<sup>10</sup>. In 2015, the NAI carried out the first detailed survey of neurology centres, examining staffing levels, dedicated beds and access to diagnostic testing. The survey revealed significant staffing shortages across all neurology centres<sup>11</sup>, lack of sufficient dedicated beds and particular issues in relation to non-emergency MRI scans. The NAI plans to replicate and extend this survey in the coming months in order to assess the extent to which neurology services have received additional resources to keep pace with increasing levels of referral and activity over the past five years.

Access to individual specialist services and supports is an area which has been examined in successive NAI surveys since 2011. One of the most significant findings from the 2019

survey is an increase in the percentage of respondents reporting they cannot access these services since the earliest survey in 2011. At that point Ireland was experiencing a serious economic recession with curtailment of health spending in all areas, including recruitment and capacity building. The finding that access to critical services such as consultant neurology, nurse specialists and physiotherapy appears to have deteriorated SINCE that period is a cause for significant concern.

The percentage of family carers reporting they cannot access specific services has tended to be higher than that reported by patients and this is also the case in the current survey. This may reflect greater needs among the patient population where a family carer is responding on their behalf. It is of note that 40% of carers in this survey reported they could not access neurorehabilitation services. This is much higher than previous surveys and may reflect a greater awareness and understanding of neurorehabilitation and the gaps in service provision due

to campaigning by NAI and its member organisations.

There is understandable reluctance to extrapolate from the current sample to the wider population of parents of children with neurological conditions due to the extremely small sample size in this survey. It is however evident that access to services is a very significant issue for this group, once again nurse specialist, neuropsychology and allied health are among the services which respondents report they cannot access. This group also reported experiencing long waiting times between neurology appointments and for MRI scans, suggesting that paediatric neurology services are also struggling to meet demand. One positive finding appears to be prompt access to consultant neurology for a diagnosis in contrast to self-report from adult service users, but of course this is not a like for like comparison given that a paediatric population is involved.

<sup>9</sup> Report on the First Patient Experience Survey of Neurology Services in Ireland (2018) Neurological Alliance of Ireland website [https://www.nai.ie/go/resources/nai\\_documents/14-12-2018](https://www.nai.ie/go/resources/nai_documents/14-12-2018)

<sup>10</sup> Outpatient Waiting Lists by Speciality [www.ntpf.ie](http://www.ntpf.ie)

<sup>11</sup> Report on National Survey of Neurology Services (2015) Neurological Alliance of Ireland website [https://www.nai.ie/go/resources/nai\\_documents/15-2-2016-summary-findings-from-first-national-audit-of-neurology-services-in-ireland](https://www.nai.ie/go/resources/nai_documents/15-2-2016-summary-findings-from-first-national-audit-of-neurology-services-in-ireland)

# OUT OF POCKET EXPENDITURE: FINDINGS & ANALYSIS

## Patient Responses

Respondents were asked about whether they were paying for any healthcare supports out of their own pocket and the amount of this expenditure on a monthly basis (a) in relation to individual services and supports and (b) overall, as a monthly total of out of pocket expenditure. The services with the highest percentage of respondents reporting paying entirely out of their own pocket were GP services (54%), private health insurance (66%), MRI scan (37%), consultant neurologist (35%) physiotherapy (28%) and medications (22%).

Private health insurance was the single highest area of out of pocket healthcare expenditure with 40% of respondents reporting paying more than €100 a month.

45% of respondents reported that they were paying more than €100 IN TOTAL in terms of out of pocket expenditure on healthcare on a monthly basis.

*Table 1.2.1 Out of Pocket Expenditure (Individual Services) Patient Responses*

	I PAY ENTIRELY OUT OF MY OWN POCKET FOR THIS SERVICE	I PAY OUT OF MY OWN POCKET FOR ADDITIONAL HOURS/ SESSIONS	I RECEIVE THIS SERVICE FREE OF CHARGE	I NEED TO PURCHASE THIS SERVICE BUT CANNOT AFFORD IT	NOT APPLICABLE TO ME, I DON'T NEED THIS SERVICE
Speech and Language Therapy	5%	1%	9%	4%	81%
Occupational Therapy	6%	1%	15%	10%	68%
Psychology	12%	1%	6%	19%	62%
Physiotherapy	28%	8%	19%	14%	31%
Neurologist	35%	3%	48%	6%	8%
GP Visit	54%	2%	40%	1%	3%
Aid, Appliance or Specialist Equipment for my neurological condition	15%	1%	11%	6%	67%
Paid Carer in the Home	2%	2%	3%	4%	89%
Medication for my neurological condition	22%	6%	65%	2%	5%



*Table 1.2.1 Out of Pocket Expenditure (Individual Services) Patient Responses (continued)*

Private Health Insurance	66%	2%	2%	18%	12%
Neurorehabilitation Service	6%	1%	4%	13%	76%
Neuropsychology	5%	0%	3%	18%	74%
Adaptation to my home	12%	2%	4%	11%	71%
Respite Care	2%	0%	1%	3%	94%
Adapted wheelchair accessible transport	7%	1%	3%	3%	86%
Personal Assistant Services	2%	2%	2%	5%	89%
MRI Scan	37%	7%	26%	5%	25%
Day Services	1.5%	1.5%	3%	2%	92%
Counselling	19%	2%	9%	17%	53%
Case Manager	0%	0%	4%	8%	88%



**Table 2.2.2 Out of Pocket Expenditure (Amount Per Month by Individual Service) Patient Responses**

	LESS THAN €20 PER MONTH	€21-€60 PER MONTH	€61-€100 PER MONTH	MORE THAN €100 PER MONTH	NOT SURE OF THE COST TO ME	I RECEIVE THIS SERVICE FREE OF CHARGE	NOT APPLICABLE TO ME, I DON'T NEED THIS SERVICE
Speech and Language Therapy	2%	2%	3%	3%	6%	11%	73%
Occupational Therapy	2%	0.00%	2%	2%	10%	11%	73%
Psychologist	1%	2%	5%	6%	11%	6%	69%
Physiotherapy	3%	8%	11%	15%	11%	15.5%	36.5%
GP Visit	17%	23%	8%	4%	8%	34%	6%
Neurologist	7%	15%	6%	5%	13%	45%	9%
Aid, Appliance or Specialist Equipment for my neurological condition	5%	4%	2%	3%	12.5%	8.5%	65%
Paid Carer in the Home	0%	0%	1%	4%	4%	4%	87%
Medication for my neurological condition	14.5%	14.5%	4%	7%	7%	47%	6%
Private Health Insurance	1.5%	8.5%	13%	40%	12%	3%	22%
Neurorehabilitation Service	0%	2%	0%	2%	9%	5%	82%
Neuropsychology	1%	1%	1%	2%	15%	3%	77%



**Table 2.2.2 Out of Pocket Expenditure (Amount Per Month by Individual Service) Patient Responses (continued)**

Adaptation to my home	2%	1%	0%	3%	16%	3%	75%
Respite Care	0%	0%	0%	1%	6%	2%	91%
Adapted wheelchair accessible transport	1%	1%	2%	2%	4%	2%	88%
Personal Assistant Services	1%	1%	1%	3%	4%	2%	88%
MRI Scan	9%	6%	3%	3%	19%	26%	34%
Day Services	0%	1%	0%	0.5%	4%	1.5%	93%
Counselling	2%	4%	5%	8%	10%	10%	61%
Case Manager	0%	0%	0%	0%	8%	5%	87%

**Table 2.2.3 Out of Pocket Expenditure (Total Per Month) Patient Responses**

Less than €20 per month in total out of my own pocket	8%
€21-60 per month	13%
€61-100 per month	14%
More than €100 per month	45%
Not sure	8%
Not applicable to my situation, I don't have to contribute out of my own pocket for services/supports for my neurological condition	12%

## Family Carer Responses

*Table 2.2.4 Out of Pocket Expenditure (Individual Services) Family Carer Responses*

	WE PAY ENTIRELY OUT OF OUR OWN POCKET AS A FAMILY FOR THIS SERVICE	WE PAY OUT OF OUR OWN POCKET FOR ADDITIONAL HOURS/ SESSIONS	WE RECEIVE THIS SERVICE FREE OF CHARGE	WE NEED TO PURCHASE THIS SERVICE BUT CANNOT AFFORD IT	NOT APPLICABLE, WE DON'T NEED THIS SERVICE
Speech and Language Therapy	6%	16%	34%	16%	28%
Occupational Therapy	3%	3%	62%	4%	28%
Psychology	10%	14%	7%	24%	45%
Physiotherapy	20%	16%	34%	17%	13%
Neurologist	28%	7%	48%	10%	7%
GP visits for the person with a neurological condition	25%	0%	72%	0%	3%
Aid, Appliance or Specialist Equipment for the person with a neurological condition	6%	19%	38%	6%	31%
Paid carer in the home	6%	12%	15%	19%	48%
Medication for their condition	12%	6%	82%	0%	0%



*Table 2.2.4 Out of Pocket Expenditure (Individual Services) Family Carer Responses (continued)*

Private Health Insurance	53%	3%	0%	31%	13%
Neurorehabilitation Services	3.5%	3.5%	7%	38%	48%
Neuropsychology	13%	10%	0%	37%	40%
Adaptation to our home	14%	24%	7%	10%	45%
Respite Care	10%	6%	19%	10%	55%
MRI scan for the person with a neurological condition	28%	3%	28%	6%	35%
Day Service	13%	6%	13%	10%	58%
Counselling for the person with a neurological condition	19%	13%	7%	32%	29%
Case Manager for the person with a neurological condition	4%	0%	18%	26%	52%

**Table 2.2.5 Out of Pocket Expenditure (Amount Per Month by Individual Service) Family Carer Responses**

	LESS THAN €20 PER MONTH	€21-€60 PER MONTH	€61-100 PER MONTH	MORE THAN €100 PER MONTH	NOT SURE OF THE COST TO US	WE RECEIVE THIS SERVICE FREE OF CHARGE	NOT APPLICABLE, WE DON'T NEED THIS SERVICE
Speech & Language Therapy	0%	3%	6%	6%	16%	44%	25%
Occupational Therapy	3%	0%	3%	3%	14%	58%	19%
Psychologist	0%	4%	0%	4%	39%	15%	38%
Physiotherapy	0%	3%	0%	10%	26%	43%	18%
Neurologist	3%	13%	0%	6.5%	16%	55%	6.5%
GP visits for the person with a neurological condition	6%	9.5%	9.5%	0%	3%	69%	3%
Aid, Appliance or Specialist Equipment for the person with a neurological condition	4%	4%	4%	0%	14%	32%	42%
Paid carer in the home	0%	0%	7%	19%	12%	8%	54%
Medication for their neurological condition	6.5%	6.5%	3%	6.5%	6.5%	64.5%	6.5%
Private health insurance	0%	3%	19%	29%	13%	0%	36%



**Table 2.2.5 Out of Pocket Expenditure (Amount Per Month by Individual Service) Family Carer Responses (continued)**

Neurorehabilitation Services	0%	0%	0%	4%	32%	8%	56%
Neuropsychology	0%	0%	0%	0%	42%	4%	54%
Adaptation to our home	3%	3%	0%	7%	28%	7%	52%
Respite Care	0%	4%	0%	8%	12%	24%	52%
MRI scan for the person with a neurological condition	11%	0%	0%	8%	35%	15%	31%
Day Service	0%	4%	4%	8%	15%	8%	61%
Counselling for the Person with a Neurological Condition	4%	0%	0%	12%	24%	12%	48%
Case Manager for the Person with a Neurological Condition	0%	0%	0%	4%	33.5%	8.5%	54%

**Table 2.2.6 Out of Pocket Expenditure (Total Per Month) Family Carer Responses**

Less than €20 per month in total out of our own pocket	3%
€21-60 per month	15.5%
€61-100 per month	19%
More than €100 per month	40.5%
Not sure	9%
Not applicable to our situation, we don't have to contribute out of our own pocket for services/supports for our family member's neurological condition	13%

## Parents of a Child with a Neurological Condition

### Out of Pocket Expenditure

26% of parents were paying more than €100 out of their own pocket on private health insurance, 17% on wheelchair accessible transport and 13% more than €100 a month on speech and language therapy. 47% of parents were paying more than €100 a month in total on out of pocket expenditure on healthcare.

*Table 2.2.7 Out of Pocket Expenditure (Amount Per Month by Individual Service) Parent of a Child with a Neurological Condition Responses*

	LESS THAN €20 PER MONTH	€21-€60 PER MONTH	€61-100 PER MONTH	MORE THAN €100 PER MONTH	NOT SURE OF THE COST TO US	WE RECEIVE THIS SERVICE FREE OF CHARGE	NOT APPLICABLE, WE DON'T NEED THIS SERVICE
Speech & Language Therapy	6%	3%	3%	13%	3%	34%	38%
Occupational Therapy	10%	3%	0%	7%	13%	44%	23%
Psychologist	3%	0%	3%	7%	19.5%	19.5%	48%
Physiotherapy	7%	7%	0%	10%	6.5%	26.5%	43%
Neurologist	10%	0%	0%	4%	10%	52%	24%
GP visits	17%	13%	0%	0%	3%	60%	7%
Aid, Appliance or Specialist Equipment	16%	10%	0%	0%	16%	13%	45%
Paid carer in the home	3.5%	0%	3.5%	0%	14%	0%	79%
Medication for their neurological condition	20%	13.5%	0%	3%	0%	50%	13.5%





*Table 2.2.7 Out of Pocket Expenditure (Amount Per Month by Individual Service) Parent of a Child with a Neurological Condition Responses (continued)*

Private health insurance	0%	6.5%	19%	26%	6.5%	0%	42%
Neurorehabilitation Services	0%	0%	4%	0%	10%	7%	79%
Neuropsychology	3%	0%	0%	0%	14%	7%	76%
Adaptation to our home	0%	0%	0%	6.5%	28%	6.5%	59%
Respite Care	0%	0%	4%	0%	18%	7%	71%
MRI scan(s)	0%	0%	7%	0%	21.5%	46.5%	25%
Special Needs Assistant	0%	0%	0%	0%	10%	55%	35%
Play therapy	0%	4%	0%	0%	14%	0%	82%
Case Manager	0%	0%	0%	0%	11%	15%	74%
Counselling for child with a neurological condition	0%	4%	0%	0%	25%	14%	57%
Counselling for other family members/carers	0%	0%	0%	7%	26%	0%	67%
Wheelchair accessible transport	0%	3%	3%	17%	7%	0%	70%

*Table 2.2.8 Out of Pocket Expenditure (Total Per Month) Parent of a Child with a Neurological Condition Responses*

Less than €20 per month in total out of our own pocket	6%
€21-60 per month	6%
€61-100 per month	9%
More than €100 per month	47%
Not sure	19%
Not applicable to our situation, we don't have to contribute out of our own pocket as a family for services/supports for my child's neurological condition	13%

## OUT OF POCKET EXPENDITURE ON HEALTHCARE: ANALYSIS

The issue of out of pocket expenditure on healthcare has been included in successive surveys in response to concerns of both NAI members and individual patient advocates that individuals and families continue to have to pay out of their own pocket to obtain access to important services for their neurological condition. This finding emerged once again from the current survey, with almost half of patient respondents reporting paying more than €100 a month for individual services such as neurology, physiotherapy and MRI scans. The percentage of respondents contributing significantly out of their own pocket for vital services, and the nature of those supports, are largely consistent across the three surveys from 2014 to 2019 and include GP, private health insurance, neurology, physiotherapy and MRI scans. While GP and private health insurance costs are a reality for many of us, out of pocket expenditure on allied health and other services represents an additional burden on people with neurological conditions and their families.

40% of family carers reported paying more than €100 in out of pocket healthcare expenses with the highest areas of expenditure on private health insurance and home care (one fifth of family carers were paying more than €100 a month for paid home care). The most significant costs for parents of children with a neurological condition were speech and language therapy, private health insurance and wheelchair accessible transport with almost half spending more than €100 a month on out of pocket contributions to healthcare expenses.

One of the significant drawbacks of the current survey, on reflection, was the failure to offer additional higher categorisation for total out of pocket expenditure per month. The highest amount that could be identified by respondents was “more than €100 a month”. The cumulative cost to purchase a number of services is no doubt significantly higher than €100 a month. Efforts should also have been made to ascertain levels of out of pocket expenditure EXCLUDING

spending on private health insurance. Finally, it would be informative to assess the amount and type of out of pocket expenditure for those with private health insurance. Many health insurance plans allow customers to recoup some of the cost of outpatient consultant visits and services such as physiotherapy but these seldom cover the full cost of such appointments.

A comparison of those working full time and those who gave up work because of their neurological condition within the patient sample found little significant difference in the percentage of those paying over €100 a month in out of pocket expenditure on healthcare (Of those working full time 50% reported paying more than €100 a month versus 38% of those not working as a direct result of their neurological diagnosis). While much more systematic research is needed, it may be that securing access to services through personal contributions in whole or part is a necessary and required expenditure faced by individuals and their families, with little choice in reaching into their

own pockets to fund access to vital supports. Of significant concern is the relatively high percentage (almost one fifth) of respondents in the patient sample reporting that they need supports such as neuropsychology (18%) and counselling (17%) but cannot afford them. These percentages are much higher in the family carer sample with a high proportion of carers reporting they need but cannot afford neurorehabilitation services (38%), neuropsychology (37%), counselling for the person with a neurological condition (32%) and case management services (26%).

The overall findings suggest that out of pocket expenditure is a significant issue for people with neurological conditions and their families and the total cost and resulting financial burden needs to be examined more systematically.

# EMPLOYMENT, BENEFITS AND ENTITLEMENTS: FINDINGS & ANALYSIS

## Patient Responses

A significant proportion of respondents (41%) had a medical card. 68% had a long-term illness card and 29% were in receipt of disability allowance. 33% of respondents reported they were not eligible for a medical card while 20% had never applied. A similar pattern is seen in terms of disability allowance, 31% were not eligible, 35% had never applied. 38% of respondents reported they had to give up work as a direct consequence of their neurological condition, 29% were working full time, 16% part time.

*Table 3.1.1 Benefits and Entitlements Patient Responses*

	Yes	No I am not eligible	No I was refused	Applying for at the moment	I have never applied
GP only card	9%	37%	5%	1%	48%
Medical Card	41%	33%	6%	1%	19%
Disability Allowance	29%	31%	3%	2%	35%
Long Term Illness Card	68%	13%	2%	2%	15%

*Table 3.1.2 Employment Status Patient Responses*

I had to give up work as a direct result of my neurological condition	38%
I have never worked outside the home	4%
I am retired	5%
I am currently in a rehabilitative training programme	0%
I am currently on sick leave due to my neurological condition	8%
Working full time at the moment	29%
Working part time at the moment	16%

# EMPLOYMENT, BENEFITS AND ENTITLEMENTS: FINDINGS & ANALYSIS

## Family Carer Responses

Only a small percentage of family carers in the survey were receiving full (8%) or part rate (16%) carers allowance. 41% were in receipt of the carers support grant (formerly called the respite grant).

55% of family carers reported that they were currently working outside the home. 24% of respondents had given up work in order to care for the person with a neurological condition. 59% of respondents reported that the family income had fallen significantly since the onset of their family member's neurological condition.

*Table 3.1.3 Employment Status Family Carers*

	YES	NO	NOT APPLICABLE TO MY SITUATION
Are you currently working outside the home?	55%	37%	8%
Were you working outside the home before the onset of your family member's neurological condition	82%	12%	6%
Did you have to give up work as a result of their neurological condition	24%	61%	15%
If you are still working, did you have to reduce your hours as a result of caring for your family member?	30%	30%	40%
Has the family's income fallen significantly since the onset of their neurological condition	59%	29%	12%

*Table 3.1.4 Benefits and Entitlements Family Carer Responses*

	YES, I AM CURRENTLY RECEIVING THIS BENEFIT	I HAVE NEVER APPLIED FOR THIS BENEFIT	APPLYING FOR AT THE MOMENT	I APPLIED FOR THIS BENEFIT BUT I WAS TURNED DOWN
Full rate carers allowance	8%	75%	4%	13%
Part rate carers allowance	16.5%	71%	0%	12.5%
Carers Support grant (Respite grant)	41%	55%	0%	4%
Carers Benefit	13%	83%	0%	4%

## Parent of a Child with a Neurological Condition

One third of family carers of a child with a neurological condition reported receiving full rate carers allowance (34%), 22% were receiving part rate carers allowance. 58% were receiving the respite care grant and 67% domiciliary care allowance. Half (50%) had never applied for carers allowance, 38% had never applied for the respite grant and 23% had never applied for domiciliary care allowance.

**Table 3.1.5 Employment Status: Parent of a Child with a Neurological Condition Responses**

	YES	NO	NOT APPLICABLE TO MY SITUATION
Are you currently working outside the home?	39%	60%	1%
Have you ever worked outside the home?	91%	3%	6%
Did you have to give up work specifically to care for your child with a neurological condition?	55%	33%	12%
If you are still working, did you have to reduce your hours in order to care for your child with a neurological condition?	38%	12%	50%

**Table 3.1.6 Employment Status: Parent of a Child with a Neurological Condition Response**

	YES, I AM CURRENTLY RECEIVING THIS BENEFIT	I HAVE NEVER APPLIED FOR THIS BENEFIT	APPLYING FOR AT THE MOMENT	I APPLIED FOR THIS BENEFIT BUT I WAS TURNED DOWN
Full rate carers allowance	34%	50%	8%	8%
Part rate carers allowance	22%	67%	5.5%	5.5%
Carers Support grant (Respite grant)	58%	38%	4%	0%
Carers Benefit	19%	75%	6%	0%
Domiciliary Care Allowance	67%	23%	7%	3%

## ANALYSIS

Over one third of patient respondents reported giving up work as a direct result of their neurological condition while over half (59%) of family carers in this sample reported that the family income had fallen significantly since their family member was diagnosed with a neurological condition. Similar findings across successive NAI surveys point to the need for a more in-depth study of the implications of being diagnosed with a neurological condition on income and financial wellbeing. The evidence of significant out of pocket expenditure on healthcare highlighted in this survey, combined with high rates of under and unemployment due to neurological disability, point to the risk of a significant financial impact of neurological conditions which is seldom highlighted. Many neurological conditions affect those of working age facing heavy financial commitments and there is a need for greater understanding of the impact on the financial wellbeing and ability to access services among both individuals and families as a consequence of a neurological diagnosis.

## RENTAL ACCOMMODATION, HOME CARE: ANALYSIS & FINDINGS

### Patient Responses

15% of patient respondents were in rental accommodation. Concerns about the cost of rental accommodation and potential loss of rental accommodation were reported by approximately 10% of

total respondents to the survey. The majority of respondents were not recipients of home care support, response rates in relation to these items are too low to draw meaningful findings.

*Table 4.1.1 Accommodation: Patient Responses*

	Yes	No	Not applicable to my situation
Currently living in rental accommodation	15%	52%	33%
Cannot find suitable rental accommodation	6%	21%	73%
Can find suitable rental accommodation but cannot afford it	10%	18%	72%
Worried I could lose my current rental accommodation	10%	21%	69%

**Table 4.1.2 Home Support: Patient Responses**

	YES, THIS REFLECTS MY EXPERIENCE	NO, THIS IS NOT MY EXPERIENCE	NOT APPLICABLE TO MY SITUATION
My home care hours are not sufficient for my needs	8%	4%	88%
The type of home care support I have is not suitable for a person with a neurological condition	6%	5%	89%
My home care support is not reliable	5%	5%	90%
I am on a waiting list for home care	3%	4%	93%
I have been turned down for additional home care hours when I requested them	5%	5%	90%

## Family Carer Responses

In contrast to the patient sample, a higher proportion of family carers were in receipt of home care support. Of these, 47% reported that their home care hours were insufficient, 32% had been turned down for additional hours and for 31%, the home care support provided was from their perspective not suitable for a person with a neurological condition. One fifth (20%) reported that their home care support was not reliable.

**Table 4.1.3 Home Care: Family Carer Responses**

	YES, THIS REFLECTS MY EXPERIENCE	NO, THIS IS NOT MY EXPERIENCE	DON'T KNOW/ NOT SURE	NOT APPLICABLE TO MY SITUATION
Our home care hours are not sufficient	47%	0%	9%	44%
The type of home care support we have is not suitable for a person with a neurological condition	31%	13%	9%	47%
Our home care support is not reliable	20%	20%	7%	53%
We are on a waiting list for home care	16%	13%	10%	61%
We have been turned down for additional home care hours when I requested them	32%	6.5%	6.5%	55%



## Parent of a Child with a Neurological Condition

*Table 4.1.4 Home Care: Parent of a Child with a Neurological Condition Responses*

	YES, THIS REFLECTS MY EXPERIENCE	NO, THIS IS NOT MY EXPERIENCE	NOT APPLICABLE TO MY SITUATION
Our home care hours are not sufficient	23%	0%	77%
The type of home care support we have is not suitable for a child with a neurological condition	11%	3%	86%
Our home care support is not reliable	11%	4%	85%
We are on a waiting list for home care	13%	0%	87%
I have been turned down for additional home care hours when I requested them	4%	7%	89%

*Table 4.1.5: Accommodation: Parent of a Child with a Neurological Condition Responses*

	YES	NO	NOT APPLICABLE TO MY SITUATION
Currently living in rental accommodation	22%	41%	37%
Cannot find suitable rental accommodation	7%	27%	66%
Can find suitable rental accommodation but cannot afford it	4%	24%	72%
Worried we could lose our current rental accommodation	14%	17%	69%

## HOME CARE, RENTAL ACCOMMODATION: ANALYSIS

The majority of respondents were not in receipt of home care but 11% of those receiving this service felt it was not suitable for a child with a neurological condition or was not reliable. 13% were currently on a waiting list for home care.

22% were in rented accommodation, 14% were concerned they could lose their current rental accommodation. The percentage of the patient sample availing of home care in this survey was extremely low and therefore we could not sufficiently examine issues in relation to home care among this group.

Concerns in relation to home care were very significant among the family carers sample however, with over 40% of family carers reported their home care hours were not sufficient, while a third had been turned down for additional support. A third felt that the support they receive is not appropriate for a person with a neurological condition. These findings in relation to levels of home care provision and its suitability, echo those of the 2018 survey and provide further support for the development of a statutory home care scheme. As outlined in the NAI response to the public consultation on this issue<sup>12</sup>, it is vital that such a scheme provides for the particular needs of people with neurological conditions and their families.

The percentage of patient respondents living in rental accommodation is very low and this probably reflects the age range of most respondents (40-60 years). Parents of a child under eighteen years were more likely to report living in rental accommodation. While there is some indication of issues in relation to cost and security of rental accommodation, this is an area that requires further detailed examination and a larger representative sample size in order to draw any meaningful conclusions.

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<sup>12</sup> NAI response to the Public Consultation on a Statutory Scheme for Home Care (2017)  
Neurological Alliance of Ireland website [https://www.nai.ie/go/resources/nai\\_documents/26-9-2017-nai-response-to-home-care-consultation](https://www.nai.ie/go/resources/nai_documents/26-9-2017-nai-response-to-home-care-consultation)

# MEDICATION: FINDINGS & ANALYSIS

Table 5.1.1: Access to Medicines: Patient Responses

	YES TO A LARGE EXTENT	YES TO SOME EXTENT	NOT EXPERIENCING THIS ISSUE	NOT RELEVANT TO MY SITUATION
Significant cost to me of paying for medications for my condition out of my own pocket	13%	26%	45%	16%
Negative experience when prescribed a generic substitute	10%	17%	51%	22%
Aware that there is a licensed medication available for my condition that I don't have access to	12%	19%	42%	27%
Long waiting times between neurology appointments	39%	28%	23%	10%
Long waiting times for MRI scans	24%	16%	41%	19%

Over a third of patient respondents highlighted challenges in relation to accessing or utilising medicines. Over one third (39%) reported being impacted by the cost of medications, 31% that they were unable to access a licensed medication for their condition and 27% had been negatively impacted by prescription of a generic substitute. The issue of access to medicines is one that will be explored in more detail

in future surveys as there are clear indications from this survey to support the concerns highlighted in a series of reports in relation to approval and access to medicines in Ireland<sup>13,14</sup> and concerns raised by NAI member groups in relation to delayed reimbursement, resulting in lack of access to new treatments or significant costs to patients paying out of their own pocket for these medications.

<sup>13</sup> *Steering a course to avoid the drug iceberg: The challenge of accessing new and innovative medicines in Ireland and call for a national strategy: A multi stakeholder perspective (2018) Irish Platform for Patients, Science and Industry (IPPOSI) & Medical Research Charities Group (MRCCG)*

<sup>14</sup> *Steering a course to avoid the drug iceberg: The challenge of accessing new and innovative medicines in Ireland and call for a national strategy: A multi stakeholder perspective (2018) Irish Platform for Patients, Science and Industry (IPPOSI) & Medical Research Charities Group (MRCCG)*

## SPECIAL CONSIDERATIONS

### Experiences of Parents of a Child with a Neurological Condition

The small sample size prevents any meaningful generalisation from the survey findings in relation to this group of respondents. However, it is clear that there is considerable need to better understand the challenges facing parents of a child with a neurological condition. Access to services is clearly a significant issue, the percentages of parents reporting they needed a service but could not access it was higher than that for the patient sample and in relation to a greater number of individual services.

The current survey involved only an initial pilot attempt to capture some of the needs of this group. There is clearly much more systematic work to be done around survey design and recruitment to better understand the issues facing children with neurological conditions and those who care for them.

### Family Carers

Most of the focus on family carers in this version of the “Living with a Neurological Condition” survey focused on access to services and out of pocket expenditure from a family carers perspective, rather than on the wellbeing and experience of family carers themselves. Previous NAI survey’s examining the experience of family carers have highlighted a number of aspects which are echoed in the current survey, most notably the percentage of carers giving up work to care for an adult with a neurological condition (24% gave up work, 30% reduced their hours). In the case of family carers of a child with a neurological condition this figure is even higher (55% gave up work, 38% reduced their working hours in order to care for a child with a neurological condition).

## CONCLUDING COMMENTS FROM THIS REPORT

### Moving Forward: Supporting and Strengthening our Advocacy Through Research

In contrast to the high prevalence of neurological conditions, with an estimated 800,000 Irish people living with a neurological condition, research and statistics on their needs and experiences has historically been very limited. A report published by the Neurological Alliance in the UK<sup>15</sup>, termed this group the “invisible patient” highlighting the need for better data and more research to understand and respond to the needs of people with neurological conditions across the health system. In Ireland, the problem is compounded by the lack of prevalent studies even of relatively common neurological disorders, pressure on neurology services affecting the capacity of clinicians to engage in research together with the relatively low profile and prioritisation of neurological conditions both in an Irish and international context.

This picture is changing, with Irish neurological charities playing a crucial role in funding and driving research into individual neurological conditions and acting as hubs to commission research as well as supporting patient engagement at all stages of the research process. There is increasing recognition that public funding for research into neurological conditions has been disproportionately low despite the high prevalence of these conditions and their impact on the individual and wider society.

Later in 2020, NAI will launch its three-year Strategic Plan (2020-2022) which includes a commitment to develop a research strategy within the umbrella. This is in recognition of the critical need to ensure that our advocacy efforts are strengthened and supported by high quality systematic research developed and delivered in partnership with our members and other stakeholders, most importantly those living with neurological conditions and their families.

<sup>15</sup> *The invisible patients: revealing the state of neurology services (2015) Neurological Alliance UK*

# APPENDIX

## PROFILE OF RESPONDENTS

### Adult respondents living with a neurological condition

The majority of respondents to the survey were adults diagnosed with a neurological condition (71%). A majority of these were female (72%) and the highest single category of respondents had been living with their condition for more than ten years (41%). Most were living with family (74%) and over half (53%) of respondents were from the East of the country. Over one third of respondents (37%) reported waiting more than 12 months to see a neurologist from when they first noticed their symptoms. The neurological conditions most frequently represented in the survey were multiple sclerosis (29%), Parkinson's disease (28%), migraine (17%) and epilepsy (12%).

**Table 6.1.1 Profile of Respondents**

An adult living with a neurological condition	71%	286
A family member caring for an adult (over 18 years) who has a neurological condition	15%	61
A family member caring for a child (under 18 years) who has a neurological condition	14%	56

**Table 6.1.2 Neurological Condition: Patient Responses**

Acquired Brain Injury	2%
Brain Tumour	1%
Dystonia	1%
Epilepsy	12%
Migraine	17%
Multiple Sclerosis	29%
Muscular Dystrophy	1%
Myasthenia Gravis	1%
Parkinsons Disease	28%
Post Polio Syndrome	3%
Stroke	2%
Rare Neurological Condition not included in list above	3%

**Table 6.1.3 Age: Patient Responses**

Less than twenty years old	0%
Twenty to forty years old	27%
Forty to sixty years old	62%
More than sixty years old	11%

**Table 6.1.4 Gender: Patient Responses**

Male	28%
Female	72%

**Table 6.1.5 Region: Patient Responses**

Leinster (counties Dublin, Kildare, Carlow, Kilkenny, Laois, Longford, Louth, Meath, Offaly, Westmeath, Wexford, Wicklow)	53%
Munster (counties Clare, Cork, Kerry, Limerick, Tipperary, Waterford)	31%
Connaught (counties Galway, Leitrim, Mayo, Roscommon, Sligo)	7%
Ulster (counties Cavan, Monaghan, Donegal)	9%

**Table 6.1.6 Length of Time Living with Condition: Patient Responses**

Less than one year	3%
One to three years	11%
Three to six years	20%
Six to ten years	19%
More than 10 years	41%
Don't Know/Not Sure	2%
I was born with my condition	4%

**Table 6.1.7 Length of Time from Noticing Symptoms to First Neurology Appointment**

Less than 3 months	16%
3-6 months	16%
6-12 months	20%
More than 12 months	37%
Not applicable/I did not need to see a neurological specialist for my condition	4%
Don't know/Can't remember	7%

**Table 6.1.8 Living Situation: Patient Responses**

Living Independently alone	15%
Living with Family	74%
Living independently in shared accommodation with others (e.g. flatmates/friends)	7%
Living independently with support from personal assistants or paid carers	3%
In residential setting	1%
In nursing home	0%

### Family Carer of an adult with a neurological condition

Family carers accounted for 15% of respondents to the overall survey. A majority of these were female (91%). The largest category (47%) were spouses or partners of the person with a neurological condition. The highest percentage of respondents were in the age range forty to sixty years (52%), 26% were caring for a person within that same age range. The neurological conditions most frequently represented in this section of the survey were progressive supranuclear palsy (19%), Parkinson’s disease (17%) and epilepsy (17%) Less than a third of carers (31%) had other caregiving responsibilities.

**Table 6.2.1 Family Members Neurological Condition: Family Carer Responses**

Alzheimers Disease/Dementia	5%
Acquired Brain Injury	14%

Ataxia	0%
Brain Tumour	0%
Dystonia	0%
Chronic Pain	0%
Epilepsy	17%
Huntingtons Disease	8%
Motor Neurone Disease	11%
Migraine	3%
Multiple Sclerosis	3%
Muscular Dystrophy	0%
Myasthenia Gravis	0%
Neurofibromatosis	0%
Parkinson's Disease	17%
Post Polio Syndrome	3%
Progressive Supranuclear Palsy	19%
Spina Bifida	0%
Spinal Injury	0%
Stroke	0%
Currently awaiting a diagnosis	0%
Rare neurological condition not included in the above list	0%

**Table 6.2.2. Region: Family Carer Responses**

Leinster (counties Dublin, Kildare, Carlow, Kilkenny, Laois, Longford, Louth, Meath, Offaly, Westmeath, Wexford, Wicklow)	57%
Munster (counties Clare, Cork, Kerry, Limerick, Tipperary, Waterford)	29%
Connaught (counties Galway, Leitrim, Mayo, Roscommon, Sligo)	11%
Ulster (counties Cavan, Monaghan, Donegal)	3%

**Table 6.2.3 Relationship to Carer: Family Carer Responses**

I am a parent of the person with a neurological condition	24%
I am a spouse/partner of the person with a neurological condition	47%
I am an adult carer for a parent with a neurological condition	29%

**Table 6.2.4 Gender of Carer: Family Carer Responses**

Male	9%
Female	91%

**Table 6.2.5 Age of Carer: Family Carer Responses**

Less than twenty years old	0%
Twenty to forty years old	9%
Forty to sixty years old	52%
More than sixty years old	39%

**Table 6.2.6 Age of Family Member with a Neurological Condition: Family Carer Responses**

Less than twenty years old	5%
Twenty to forty years old	18%
Forty to sixty years old	26%
More than sixty years old	51%

**Table 6.2.7 Additional Caregiving Responsibilities: Family Carer Responses**

Yes	31%
No	69%



**Table 6.2.8: Hours Per Day Spent Caring: Family Carer Responses**

Less than 3 hours	26%
3-5 hours	12%
5-10 hours	18%
More than 10 hours a day	44%

### Family Carers of a Child with a Neurological Condition

Our 2019 survey for the first time included a section for family carers of a child (under eighteen years) with a neurological condition. The sample size was very low at 56 respondents (representing 14% of the total respondents to the survey) therefore there can be very limited generalisation from the findings. Nevertheless, the purpose of this section was to introduce this population into our surveys for the first time and attempt to capture some of the issues impacting on them.

Future surveys will aim to improve promotion and take up by this group as well as consultation with parents to inform survey design (in this survey the items were adapted from the patient and family carer sections). The majority of respondents (42%) were from the East of the country.

One third of the carers (29%) had been caring for their child from six to ten years. The majority were parents of children with epilepsy (46%) and spina bifida/hydrocephalus (18%). One third reported seeing a neurologist less than 3 months after they first noticed symptoms. Sixty one per cent were providing care for more than ten hours a day. 76% had other caregiving responsibilities. Over half (55%) had given up working, 38% were working reduced hours to care for their child with a neurological condition.

**Table 6.3.1 Length of Time as a Carer: Parent of a Child with NC Responses**

ANSWER CHOICES	RESPONSES
Less than one year	14%
One to three years	8%
Three to six years	13%
Six to ten years	29%
More than 10 years	22%
Don't Know/Not Sure	0%
They were born with their condition	14%

**Table 6.3.2 Child's Neurological Condition: Parent of a Child with NC responses**

ANSWER CHOICES	RESPONSES
Acquired Brain Injury	9%
Brain Tumour	3%
Epilepsy	46%
Hydrocephalus	18%
Muscular Dystrophy	6%
Spinal Injury	0%
Meningitis	0%
Guillain Barre syndrome	0%
Rare neurological condition not included in the list above	9%
Currently awaiting a diagnosis	9%

**Table 6.3.3. Length of Time Between Symptom Onset and First Appointment with a Neurologist**

ANSWER CHOICES	RESPONSES
Less than 3 month	34%
3-6months	9%
6-12 months	6%
More than 12 months	24%
Diagnosed at birth or pre-natal stage	12%
Not relevant, they have not seen a neurological specialist	15%
Don't know/Can't remember	0%

**Table 6.3.4 Hours per Day Spent Caring: Parent of a Child with NC Responses**

Less than 3 hours	3%
3-5 hours	12%
5-10 hours	24%
More than 10 hours a day	61%

**Table 6.3.5: Additional Caregiving Responsibilities: Parent of a Child with NC responses**

Yes	76%
No	24%

**Table 6.3.6 Age of Carer: Parent of a Child with NC responses**

Less than twenty years old	3%
Twenty to forty years old	27%
Forty to sixty years old	70%
More than sixty years old	0%

**Table 6.3.7: Region: Parent of a Child with NC responses**

Leinster (counties Dublin, Kildare, Carlow, Kilkenny, Laois, Longford, Louth, Meath, Offaly, Westmeath, Wexford, Wicklow)	43%
Munster (counties Clare, Cork, Kerry, Limerick, Tipperary, Waterford)	36%
Connaught (counties Galway, Leitrim, Mayo, Roscommon, Sligo)	15%
Ulster (counties Cavan, Monaghan, Donegal)	6%

# NAI MEMBER ORGANISATIONS

*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*

*Spinal Injuries Ireland*

*Spina Bifida Hydrocephalus Ireland*

*The Rehab Group*

## **Associate Members**

*Brain Tumour Ireland*

*Syringomyelia Chiara Malformation  
Support Group*

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