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The impact of COVID-19 on community neurology patients

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RESEARCH

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ABSTRACT

Background

The COVID-19 pandemic has had a worldwide impact. People with neurological disorders are at an increased risk of severe infection and consequent mortality. In this study we investigated the impact of COVID-19 on community neurology patients in the absence of direct infection with the virus to see if their wellbeing was affected.

Aims

To determine whether and how the COVID-19 pandemic affected people with neurological disorders, in the absence of COVID-19 infection.

Methods

A prospective survey of patients with neurological conditions to evaluate the impact of the COVID-19 pandemic on their quality of life, physical and mental wellbeing, access to goods/services and areas of unmet needs relating to the pandemic. The survey was completed by 243 community neurology patients in Perth, Western Australia from April to June 2020.

Results

Most respondents reported that COVID-19 impacted their daily life (80.7 per cent) and family relationships (73.1 per cent). 10.3 per cent of patients had a substantial effect on their access to facilities such as the gym, and services such as physiotherapy; as well as access to finances (7 per cent) and care (5.8 per cent); whilst anxiety was increased to a minor degree in over half of patients (55.97 per cent). Unclear public health information and guidelines, social isolation and disruption to routine were also identified as difficulties.

Conclusion

Despite the absence of direct infection with COVID-19, many neurology patients experienced physical and emotional detriment as a result of the pandemic. This study identified the need for organisation and amendment to provisions of neurological services in preparation for future pandemics.

Key Words

COVID-19, neurology patients, pandemic.

What this study adds:

1. What is known about this subject?

Patients with COVID-19 infection may develop severe neurological problems whilst people with pre-existing neurological disorders have an increased risk of severe infection and consequent mortality.

2. What new information is offered in this study?

The physical and emotional wellbeing of neurology patients was affected by the COVID-19 pandemic in the absence of direct infection.

3. What are the implications for research, policy, or practice?

Community involvement and neurological services need to develop pandemic contingency plans to ensure improved access for neurology patients in the event of future epidemics and pandemics.

Background

People with neurological disorders are at an increased risk of severe COVID-19 infection and consequent mortality.[1-4]

Furthermore, patients with COVID-19 infection may develop severe neurological problems.[5,6] We propose that community dwelling patients with neurological disorders and disability may succumb to the effects of the pandemic interventions such as social distancing and isolation – which are essential strategies to contain the spread of COVID-19.[7] There is little data on the impact of COVID-19 on community neurology patients in the absence of direct infection with the virus.[8,9] To our knowledge this is the first study on the impact of COVID-19 on community neurology patients in Australia who do not have COVID-19. We are concerned that the public health outcome may adversely affect the wellbeing of these individuals. We therefore set out to investigate the consequences of the pandemic on community neurology patients in Perth, Western Australia. Social distancing, loss of routine and lack of exercise all have the potential to disrupt their lives and wellbeing.[10] We addressed this deficiency in knowledge by asking our patients of the consequences of the pandemic on their health and wellbeing. This data we hope will help our community plan and cope with future pandemics.[11]

Method

Informed consent

Informed consent was obtained from the subjects for their willingness to participate in the study. The study has ethics approval from the Neurodegenerative Disorders Research ethics board (NDR HREC 20-301). Respondents completed the survey from 7 April to 25 June 2020 corresponding with the beginning of phase 1 restrictions and the end of phase 3 restrictions respectively in Western Australia. Participation in the study was voluntary. None of our patients have or had COVID-19 infection.

Research instrument

A survey for patients with neurological conditions was developed in the English language to evaluate the impact of the COVID-19 pandemic on their overall quality of life. A questionnaire was developed specifically for the study. If the respondent was non-fluent in English, a translator was arranged. The questionnaire was divided into four sections: (i) Section A consisted of demography and diagnostics. (ii) Section B six questions relating to life, relationships and both physical and mental health. (iii) Section C five questions regarding accessibility to goods and services. (iv) Section D allowed participants to comment on overall impact and areas of unmet needs from the pandemic (see appendix A).

The questionnaire was given to the study subjects in person or by e-mail. Each question allowed a quantitative response via an impact score consisting of a selection of numbers, 0 (no impact) to 10 (significant impact), and a qualitative response via a comment section allowing justification for their numerical impact score choice. The final scores were categorized at five levels: low (0-5), medium (6-10) and high (11-15).

Study population

The study was a descriptive cross-sectional design, involving a solo neurologist's practice of community dwelling neurology patients in Perth, Western Australia.

Data analysis

Baseline characteristics and survey responses were analysed using descriptive statistics on de-identified data. The following subgroups were analysed: respondent information, impact on life, accessibility, and mental wellbeing, and finally analysis of comments. For each question, percentage of respondents was determined for each impact score (0-10) and statistical analysis was preformed to report the mean impact score and interquartile range (IQR).

Results

The survey was completed by 243 patients attending the neurology clinic for various conditions. The demographic of the respondents is presented in Table 1. The median age of participants was 61 years old (IQR=29). The majority of respondents were female (58 per cent) and surveys were most commonly completed by the patient (75.21 per cent) or by a spouse on behalf of the patient (15.70 per cent). The survey participants consisted of a variety of neurological diagnosis, with the most common being epilepsy (17.2 per cent), Alzheimer's disease (13.6 per cent) and a variety neurodegenerative conditions (12.8 per cent; see Appendix B).

Impact on life

Figure 1 shows the impact of COVID-19 on the life of respondents as proportions. COVID-19 impact on daily life and family relationships had a substantial proportion of respondents scoring 4–6, representing some impact (30.1 per cent and 26.0 per cent, respectively) – whilst the other categories of partner and/or carers, employment and medical condition were reported to have some impact (score 4–6) in less than 20 per cent of respondents for all categories (16.9 per cent, 10.2 per cent and 12.4 per cent, respectively). However, these three categories—partner and/or carers, employment and medical condition—had a larger proportion of respondents reporting no impact (43.2 per cent; 63.6 per cent, and 62.4 per cent, respectively);

whilst only 19.3 per cent of respondents reported no impact on daily life and 26.9 per cent on family relationships. Yet overall, a significant impact score of 10 as recorded for a smaller proportion of respondents in all categories; daily life (7.0 per cent; n=17), family relationships (6.6 per cent; n=16), partner and/or carers (6.2 per cent; n=15), employment (9.2 per cent; n=22), medical condition (2.9 per cent; n=7). The median level of impact recorded on a scale of 0 (no impact) to 10 (significant impact) was greatest at 5 for daily life and family relationships at 4, whilst median impact score on partner and/or carer was 2 (IQR of 6, 7 and 6, respectively). Employment and medical condition had a median impact score of zero (0) (IQR of 5 and 3, respectively).

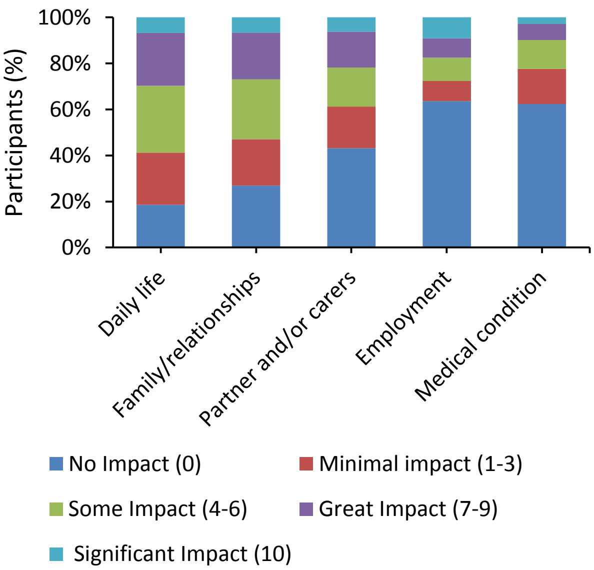
Table 1: Characteristics of the participants

Sex, *n* (%)	
Female	141 (58.02%)
Male	102 (41.98%)
Age, *Years*	
Median	61
IQR	29
Who completed survey for patient, *n* (%)	
Patient	182(75.21%)
Spouse	38 (15.70%)
Carer	13 (5.37%)
Adult child	4 (1.65%)
Other	5 (2.07%)
Neurological condition, *n* (%)	
Epilepsy/seizures	43 (17.20%)
Alzheimer's disease	34 (13.60%)
Neurodegenerative disorders[1]	32 (12.80%)
Migraine	29 (11.60%)
Neuropathy & related disorders	24 (9.60%)
Parkinson's disease	20 (8.00%)
Movement disorders	18 (7.20%)
Multiple sclerosis	10 (4.00%)
Cerebrovascular	5 (2.00%)
Tumours	5 (2.00%)
Miscellaneous[1]	30 (12.00%)

[1] For full list of neurodegenerative disorders and miscellaneous conditions see Appendix B.

Impact on daily life, family/relationships, partner and/or carers, employment and medical condition were assessed. Values are percentages of total responses from participants for each category (n=243 per category).

Figure 1: **Impact of COVID-19 on life of neurology patients**

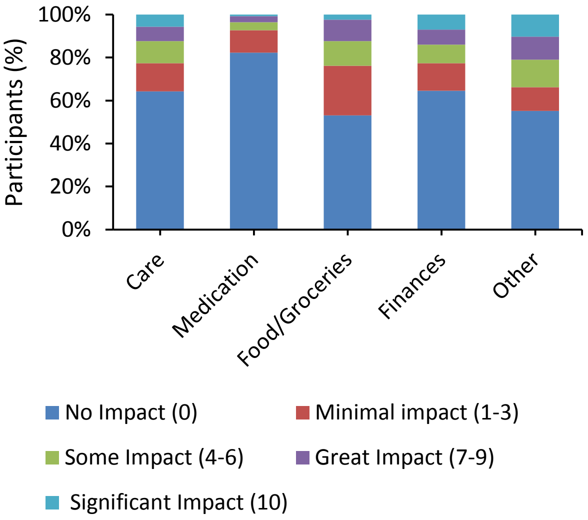


Impact on accessibility

Figure 2 displays the relative impact of COVID-19 on respondent's accessibility displayed as proportions.

Impact on accessibility to care, medication, food/groceries, finances and other were assessed. Other includes physiotherapy, OT, gym, pharmacy, nursing home, childcare. Values are percentages of total responses from participants for each category (n=243 per category).

Figure 2: Impact of COVID-19 on accessibility for neurology patients



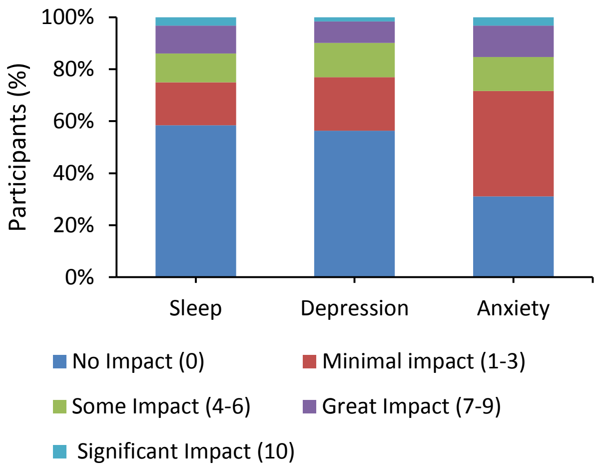
A substantial proportion of neurology patients surveyed reported no impact of COVID-19 on accessibility to care (64.2 per cent; n=156), medication (82.3 per cent; n=200), food/groceries (53.1 per cent; n=129), finances (64.6 per cent; n= 157), or other service (i.e. physio, gym) (55.1 per cent; n=133). Minimal impact was reported by patients for food/groceries in 23.1 per cent (n=56), care in 13.2 per cent (n=32), finances in 12.8 per cent (n=31), other in 11.1 per cent (n=27), and medication in 10.3 per cent (n=25). Great impact, classified as scores 7 to 9 (on a scale of 0 to 10) was reported in 10.7 per cent (n=26) of participants for access to ‘other’, followed by food/groceries at 9.9 per cent (n=24), care at 6.6 per cent (n=16), finances at 7.0 per cent (n=17) and a much smaller proportion for access to medication at 2.9 per cent (n=7). The category with the greatest number of respondents (10.3 per cent; n=25) reporting a significant impact was access to ‘other’ (i.e. physio, gym), followed by access to finances (7.0 per cent; n=17) and care (5.8 per cent; n=14). The median level of impact recorded on a scale of 0 (no impact) to 10 (significant impact) was 0 for all categories assessed – care, medication, food/groceries, finances, and other (IQR of 3, 0, 3, 0 and 5 respectively).

Impact on mental wellbeing

Regarding the impact of COVID-19 on anxiety, sleep, and depression in neurology patients – displayed in Figure 3 –

Impact on mental wellbeing parameters of sleep, depression and anxiety were assessed. Values are percentages of total responses from participants for each category (n=243 per category).

Figure 3: Impact of COVID-19 on mental wellbeing of neurology patients



Over half of the respondents reported no impact on depression and sleep (56.38 per cent and 58.44 per cent, respectively) and minimal impact on anxiety (57.61 per cent). Significant impact was reported at rates less than 5 per cent for anxiety, depression, and sleep (4.35 per cent, 1.65 per cent, and 3.29 per cent respectively). Highest levels of impact out of all three categories were seen for anxiety, (55.97 per cent). Levels of impact on depression and sleep were closely correlated. The median level of impact recorded on a scale of 0 (no impact) to 10 (significant impact) was zero (0) for both sleep and depression (IQR of 4 and 3 respectively), whilst median impact score for anxiety was slightly greater at 1 (IQR of 5).

Notable comments

The COVID-19 restrictions allowed our patients to have more rest, which helped their clinical state (Table 2, comment 1). Others noted the beneficial aspects and ease of Telehealth platforms that they had not used prior to the pandemic (Table 2, comment 4); this was not so for all patients (Table 2, comment 14). Many respondents noted Western Australia’s COVID-19 strategy and overall management of the pandemic in a positive nature (Table 2, comments 2 and 3). Some respondents noted the negative and detrimental aspects of the COVID-19 restrictions. Comments surrounded the complexity of the rules and regulations not always being transparent (Table 2, comment 10); family hardships because of limited access visits to nursing homes or rural locations; and reports of family members passing away and job loss (Table 2, comments 5, 8, 13 and 16). Others reported concerns about their mobility (Table 2, comments 11 and 15), paranoia in everyday life, or the COVID-19 concern for sanitisation (Table 2, comments 6, 7 and 9). There was a theme of decreased quality of life as a result of the pandemic restrictions (Table 2, comments 15 and 17). Comment 5 presented in Table 2 identifies the extraordinary impact that COVID had on a 66-year-old patient with Posterior Cortical Atrophy (PCA)—a rare variant of Alzheimer’s disease—resulting in cortical blindness; the patient experienced elevated anxiety as a result of the pandemic restrictions on her out-of-home activities and routine, including the inability to see family due to border restrictions.

Discussion

This study is the first of its kind to demonstrate the detriment that the coronavirus pandemic has had on the mental and physical wellbeing of community neurology patients via restrictions imposed to minimise the spread of the virus. The findings present an insight into the toll of the pandemic on the community, which was found to have not been shared equally across all people. We are witnessing a phenomenon whereby ‘social isolation’ has not been borne equally among all community neurology patients as a result of the pandemic, particularly for individuals who were physically and/or financially vulnerable.[8,10,11–14]

Overall, respondents reported a greater degree of impact on daily life and family relationships and less of an impact on partner and/or carer; whilst no substantial impact was seen across respondent's employment, and medical conditions. Impact of the pandemic on daily life was explained by restrictions altering their routine and community engagement activities. Family and relationship hardships were explained by inability to access nursing homes and rural locations, whilst others found the pandemic to inhibit or limit their contact with family members. As a result of the pandemic, patients being cared for at home have lost respite opportunities (i.e., day centres), making many feel they are alone and overwhelmed in caring for their loved ones.[15] Although there was an impact on employment Australia-wide, this was not reflected in this study probably as a result of Western Australia's shorter duration of lockdown and the age of the respondents surveyed. Their median age was 61 years; thus, a substantial proportion of patients may have been retired and not working, explaining the lower than expected impact on employment. We were unable to determine whether the patient's condition changed as a result of the restrictions induced by the pandemic or the natural history of their disease.

For the majority of our community neurology patients, accessibility to care, medication, groceries, finances, and other services such as the gym were not impacted by the pandemic. Despite this, 10.3 per cent of patients reported that COVID-19 had a substantial effect on their access to facilities such as the gym, and services such as physiotherapy, as well as access to finances (7 per cent) and care (5.8 per cent). Impaired access to the gym and physiotherapy has a profound impact on neurology patents, causing acceleration of mobility disability and disruption of routine.[16-18] Anxiety was increased to a minor degree in our patients, but sleep and depression were not. The pandemic has caused psychiatric distress.[19-22]

One of the strengths of our study was the collection of comments from our patients. Patients noted that the information communicated in the media regarding the pandemic and its associated guidelines were not clear; this issue was also reported by Wang et al.,[23] whereby patients with dementia struggled to access accurate information about the pandemic. Some people might have difficulties remembering procedures and understanding the public health advice, such as mask-wearing, social distancing and hand hygiene; thus, appropriate contingency plans need to be implemented for future pandemics to ensure information is effectively communicated to everyone in the community. For the majority of respondents, dealing with social isolation was a significant challenge, highlighting the need for community engagement opportunities that are safe during a pandemic and that existing services having a pandemic contingency to ensure access for all people in the community. The statement made by the patient with PCA is particularly noteworthy in that it highlights the extent that the pandemic can influence patients' lives and emphasises the difficulty in distinguishing a progressive deterioration from a neurodegenerative condition versus the impact of the pandemic restrictions.

Since the data was assembled for this publication we received an additional comment of importance which was made by a 49-year-old female with Down's Syndrome with cognitive and behavioural changes. Her carers noted that COVID-19 restrictions caused increased tension in her community home for both residents and staff. Carers were permanently at home in their community residence throughout lockdown. Lockdown resulted in changes in their daily routine – no work or outings, limited drives in which the subjects and carers were not allowed to leave the car, and the inability to see family and friends. This paper has found a common and widespread impact in care facilities for neurology patients, reinforcing the need to outline strategic plans for future epidemic and pandemic outbreaks for care facility residents and those patients cared for at home who are particularly vulnerable to these threats.[24–26]

The carers of patients with neurological disorders face similar difficulties to patients, but the impact is less severe.[27–28]

We identified patterns and suggestions for the design of COVID-19 public health policies, which might help in future pandemics. Our proposed future pandemic recommendations for neurology patients are outlined in Table 3. Although the sample size in our study is modest, sources of bias are present in our study: primarily selection bias, given that all patients originated from one community practice.

Conclusion

Our study reveals that physical and emotional wellbeing of neurology patients can be affected during a pandemic in the absence of direct infection. This provides a stimulus for the organisation and provision of neurological services in future pandemics.

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PEER REVIEW

Not commissioned. Externally peer reviewed.

CONFLICTS OF INTEREST

The authors declare that they have no competing interests.

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ETHICS COMMITTEE APPROVAL

Neurodegenerative Disorders Research Human Research Ethics Committee 20-301

Table 2: Notable comments

	Quotations	**Age (yrs)**	**Condition**	**Completed**
Positive				
1	Having one month off [from work] was good – my tremor is now less, [as I am] less rushed at work	65	Essential tremor	Patient
2	Pleased with our state's (WA) handling of the virus	65	Cavernoma	Patient
3	I'm very glad to be living in WA during this because we've handled it well	28	Sensory syndrome	Patient
4	Modern technology and the use of face to face platforms is brilliant for appointments in these times and with people who can't move around well. Mum was exhausted after our facetime meeting yesterday - It would have taken her days to recover if we had travelled to see you	97	Chronic pain state	Adult child
Negative				
5	Visual difficulties [due to my Posterior Cortical Atrophy] have made being at home all the time incredibly challenging. Limited topics of interest at home and news/general talk about the COVID-19 has caused additional anxieties. Difficult to distinguish between the general progressive decline of the disease and effects of COVID-19 – that is why we are visiting the Neurologist today. a) Absence of routine out-of-home activities/entertainment to maintain social relationship & engagement b) Intra- & Inter-state restrictions meaning No relatives can be visited (only via telephone).	66	PCA[a] [resulting in cortical blindness]	Spouse
6	Paranoia – wear gloves, mask and disinfect everything. Mainly due to information contradictions.	73	Meningioma	Patient
7	No quality of life – spend time at home in chair (not much else)	63	PSP[b]	Spouse
8	Death of Father. At that time had to be away from my own house for 3 weeks – living with relatives while grieving. Country borders closed so travel restricted; needed official document to go home	61	Sensory neuropathy	Patient
9	Less carers and unable to get out in the community			
10	Trying to understand the rules and restrictions. It is confusing as each state and territory within Australia has different rules and regulations in response to COVID-19.	23	Critical illness neuropathy	Patient
11	The greatest challenge I have experienced is my decreased ability to walk since lock-down, as I have been using my wheelchair (unable to walk more than 10 steps)	68	Movement disorder	Patient
12	Restricted access to nursing home of wife (has Alzheimer's Disease)	78	AD[c]	Patient
13	Having to deal with losing both my jobs & wondering how I will support my family			
14	Changes: Online/phone call appointments which I do not like, and avoid, which limits my access to help/services	21	CSF Rhinorrhoea	Patient
15	Rough on wheelchair dependency. Increased depression. Frustrated/short with those around him because of being house bound. Less mobility.	70	Movement disorder	Patient

16	I am concerned that life from now will forever be different. 3/5 Adult children lost jobs	47	Migraine	Patient
17	[The patient] has become very argumentative and very obsessive compulsive. I am blamed for anything that goes wrong. I have to explain what a lot of words mean. He is constantly wanting my time. Due to this I am retiring from my nursing duties.	77	Semantic dementia	Spouse

PCA: Posterior Cortical Atrophy believe; b. PSP: Progressive Supranuclear palsy; c. AD: Alzheimer's Disease

Table 3: Future pandemic recommendations for neurology patients

1. **Physical activity**	Governments to consider collaboration with care and health facilities to support physical activity at home for neurology patients.[29]
2. **Contingency for neurology patients in care facilities**	
3. **Contingency for neurology patients cared for at home**	
4. **Ensuring access to online services**	Appropriate facilities to communicate with health professionals (Telehealth access) and loved ones. Ensure access to online replacement for services such as physiotherapy and exercise training.
5. **Medical condition – specific information**	Including the pandemic associated risks and advice for people with special neurological conditions on specific medications.

Appendices

Appendix A: Survey

Impact of COVID-19 on community neurology patients

SUBJECT CONSENT

1. I, ____, have voluntarily completed the COVID-19 IMPACT SURVEY.
2. I hereby give my consent for my responses and comments to be analysed for research purposes.
3. I understand my responses and comments will be de-identified and used anonymously for research undertaken by the research team.
4. I agree to the results of the research being published.
5. I confirm I am over 18 years of age.

Signed:

Name (please print) ____________________________ Signature: ____________________

Date: ______________________________

FOR OFFICE USE ONLY.

Witnessed:

Name (please print) ____________________________ Signature: ____________________

Date: ______________________________

Appendix B: Medical conditions of participants

Condition	n		Condition	n
Adrenoleukodystrophy	1		Multiple system atrophy	3
AIDP post Neisseria meningitidis infection	1		Musculoskeletal pain and sciatica	1
APLAS (Seizures, memory loss)	1		Myasthenia Gravis (1 x ocular)	3
Ataxia	1		Neurological Symptoms	1
Autism spectrum disorder (1 w/ epilepsy)	2		Neuropathy	8
Brachial neuritis	1		Neurofibromatosis 1	1
Behavioural variant frontotemporal dementia	1		Non-fluency of speech, anosmia	1
Cavernoma (brainstem/ C6)	2		Periodic paralysis	1
Cerebral amyloid angiopathy	1		Pineal Cyst	1
Cerebral aneurysm	1		Progressive non-fluent aphasia	1
Cerebrovascular disease, brainstem strokes, ataxia	1		Post head injury	3

Cervical dystonia	1		Post-encephalitis & critical illness neuropathy	1
Chronic fatigue syndrome, fibromyalgia	1		Post-viral syndrome	1
Chronic pain state	1		Primary progressive aphasia	1
Cognitive difficulties	1		Previous stroke	1
Corticobasal syndrome	1		Progressive supranuclear palsy	7
CSF rhinorrhoea	1		Psychogenic movement disorder	1
Dementia (2 x semantic)	1		Radiculopathy Recurrent vestibular syndrome	1
Dysembryoplastic neuroepithelial tumor (left)	1		Restless leg syndrome (1 w/ meningioma)	4
Emerging extra-pyramidal Syndrome	1		Sensory syndrome	2
GATTA2 deficiency (Migraine, Seizures)	1		Shingles	1
Gilles dela tourettes	1		Small fibre neuropathy	1
Glossdynia	1		Speech apraxia, REM sleep behaviour disorder	1
Huntington's disease	1		Spinocerebellar ataxia	1
Hemifacial spasm	1		Syncope	1
Hypertrophic olivary syndrome Idiopathic intracranial hypertension.	1		Tauopathy	2
Leg pain	1		Tauopathy DBS	1
Leukodystrophy	1		Temporal Arteritis	2
Meige syndrome	1		Thalamic Astrocytoma (U-P shunts)	1
MELAS syndrome	1		Torticollis, lateral collis, anterior collis, major depression syndrome	1
Memory loss	2		Transverse myelitis	1
Meningioma	1		Tremor (Essential)	6
Mild Guillain-Barré syndrome	1		Trigeminal neuralgia	4
Moyamoya, L-MCA occlusion	1			