



Psychological Support for People with Neurological Conditions in West Wales

Executive Summary

This paper sets out the psychological support needs of people living with neurological conditions in West Wales. Cognitive dysfunction and mental health issues experienced by people are explored, and numbers estimated for how many people this affects in the Hywel Dda Health Board area.

Cognitive dysfunction affects the majority of people living with neurological conditions. The impact of cognitive dysfunction is often very severe, resulting in relationship breakdown, loss of work or other valued social roles and consequently social isolation. With appropriate interventions, these could often be avoided. We estimate that over 6000 people living with neurological conditions in Hywel Dda are affected, 2000 of these severely.

However, neuropsychology services are typically aimed solely at people with acquired brain injury or stroke. In other neurological conditions, cognitive damage may occur more gradually, but the need for psychological assessment, treatment and advice on compensatory strategies is the same. Currently one neuropsychologist in Swansea provides a service for ABMU and Hywel Dda health boards. She is not able to give the service required.

Levels of mental ill health amongst people with neurological conditions are very high – 40-50% of the group will have ongoing anxiety and depression. The main cause of the depression does not go away. Yet mental health services are not well equipped to deal with the issues presented, and people go untreated and unsupported.

Recommendations

A full list of recommendations is given on p12 of this report. It is essential that the neuropsychology service from Murryston is expanded to meet the needs of people with a high level of cognitive dysfunction in Hywel Dda.

Other recommendations include improved information provision about mental health services and counselling support; developing a pathway so that people can be referred to the most appropriate support for them, and working in partnership with the voluntary sector to facilitate peer support.

The health board may wish to establish a working group with representation from health, social care and voluntary groups to better ascertain the services required and how to meet needs. It is vital that services are improved for the quality of life for people living with neurological problems in Hywel Dda.

Introduction

This paper sets out the psychological support needs of people living with neurological conditions in West Wales. Cognitive dysfunction and mental health issues experienced by people are explored, and numbers estimated for how many people this affects in the Hywel Dda Health Board area. The impact of psychological issues arising from neurological conditions is looked at in terms of the quality of life of people with neurological conditions. Case studies from a range of people with different conditions give examples of how people are affected.

The paper goes on to consider the support currently available in West Wales, and the different types of support which may be required in order to address this complex but very important issue. Recommendations for next steps are made.

Rationale and Methodology

The West Wales Neurological Alliance (WWNA) carried out a survey in 2010 of the experiences of people with neurological conditions in West Wales in accessing health and social care services. One of the findings of this was that numbers of people who had access to psychological or emotional support services was very low at 4%. In addition, there were several statements such as the one below which highlighted the need for additional support:

“When first diagnosed, psychological counselling is needed as the life you knew was ended... Depression occurs, this can be hazardous to relationships. It cost me my marriage, I have now come to terms with it without any help.”

In 2012 the WWNA therefore began to take forward work to outline the psychological support needs of people with neurological conditions, with the aim of improving the support available.

A questionnaire on cognitive and emotional issues was completed by the various neurological patient organisations which form WWNA (see Appendix 1 for the list of these), and a plenary session was held in January 2013 which brought out many common themes. The report has therefore been written based on the experiences of neurological patient organisations working in West Wales. It is an indication of the types of needs and the range of people affected rather than academic research. Where numbers are used, these are estimates based on statistics used by patient organisations.

Cognitive dysfunction in people with neurological conditions

It is commonly understood that certain neurological events, such as traumatic brain injury or stroke, will cause cognitive problems. Services exist to support the rehabilitation of people who have experienced these. However, it is also true that other neurological conditions cause very significant cognitive dysfunction. Often this occurs in a gradual decline, such as in MS, Parkinsons

or Ataxia; sometimes it occurs after a specific illness or event, such as in Hydrocephalus.

Representatives of the WWNA member organisations were surprised at the very high degree of overlap in the cognitive symptoms experienced by the different conditions. It was clear that the majority of neurological conditions cause significant or major cognitive problems for a high proportion of those living with the conditions. It was also a common experience that medical professionals tend not to take these symptoms very seriously, despite people living with these symptoms stating that they are very difficult to manage.

The symptoms which were common to all or nearly all conditions are as follows:

- Forgetting or unlearning tasks
- Poor short-term memory
- Poor long-term memory (particularly in Epilepsy)
- Reduced ability to reason
- Poor concentration
- Disorientation – difficulty finding the way in familiar or unfamiliar routes
- Information processing difficulty
- Spatial awareness problems
- Remembering and mixing up names and objects
- Word finding problems
- Emotional lability
- Hypersensitivity to light, noise, busyness, chemicals, odours and touch (particularly in ME)
- Impulsive behaviour
- Drug side effects, e.g. disinhibition and impulsive behaviour and psychotic symptoms with some Parkinsons' treatments
- Mood swings
- Non-optical problems with visual focus - some people acquire dyslexia
- Non-vestibular vertigo
- Easily startled or panicked by movement or noise
- Significant personality change

These have a major impact on the ability of people to function in everyday situations and, in turn, have a detrimental impact on close relations.

Impact of living with cognitive dysfunction

The impact on quality of life for individuals who are trying to live with such cognitive problems is considerable. Employment is likely to be affected by issues such as poor memory and concentration, and difficulty processing information and thoughts. In some conditions these are a significant factor in people leaving employment.

Cognitive problems are hidden impairments, which are difficult for friends, family and colleagues to understand. It is very difficult for a family member or colleague to separate the issues caused by the condition from the individual's

personality. This creates relationship problems in people's vital relationships. Issues such as emotional lability, mood swings and impulsive behaviour can be difficult to live with and may be a factor in high relationship breakdown rates. MS for instance has a marriage breakdown rate over four times that of the general population.

The impact therefore on family members of these symptoms is very significant. Family and carers often describe these symptoms as being more difficult to cope with than providing support due to physical disability.

For people who have spatial awareness problems or a reduced ability to process risk factors, leaving the home on their own may be difficult. This may lead to over reliance on a carer, or social isolation if limited assistance is available. Sometimes family can become very protective, which in turn can be limiting.

Cognitive problems that can result from neurological conditions are often downplayed by medical professionals in importance compared to physical impairment. Again, this is perhaps because they are hidden symptoms. However, patient surveys reveal how important cognitive factors are for quality of life. For instance, In the ME Association's UK wide 'Managing My ME' survey (2010) of patients' experiences / views: *"Muscle Fatigue was ranked as the symptom that affected respondents the most. This was followed by cognitive dysfunction, then pain, then sleep problems... (then) mobility problems."*

Access to healthcare

A linked issue is access to healthcare. Cognitive problems in neurological conditions can have two particular impacts in this regard.

- Attending appointments. People who face challenges with their memory and their paperwork are likely to forget health appointments and fail to attend them. In some cases, this may lead to their removal from a list to be seen, followed up or treated. It is important to consider how best to ensure that people with cognitive problems as a result of their neurological condition are not disadvantaged in this respect.
- Advocacy. Patient organisations often see that people who live alone and have no one to support them are likely to struggle to make their wishes heard. People will often become less able to speak for themselves – maybe due to cognitive issues, or loss of confidence and motivation. Again, it is important that systems of regular review are in place to support people who live alone and are more vulnerable. They are less likely to report a change in need and circumstances.

Impact of living with cognitive dysfunction: Case studies

Mabel, 72, lives in Cardiff. She developed epilepsy at the age of 45. Since her diagnosis Mabel has not been allowed to go out on her own. Her family are afraid that she might have a seizure and hurt herself. In recent years she has started forgetting where she put things and gets very confused. Her family are

very protective of her. However she gets frustrated that she cannot do the things she used to enjoy. When she was younger, Mabel was an active member of the local church and looked after her grandchildren. This was stopped once she developed epilepsy. The impact of this has meant that she has become more and more isolated, relying totally on her family for her needs. This has led to her becoming withdrawn and frustrated that her life has changed so much because of the epilepsy. Mabel says that “the only pleasure I get is when I come to the local support group”. Her husband doesn’t like going to the group. However he is comfortable knowing that if she is ill people around her will know what to do and contact him.

Ann, 47, lives in Carmarthen. She has had MS for 11 years. In recent years she has developed some cognitive problems which have become difficult to cope with. She says that she has forgotten about the oven being on a few times, and has come back home to find it dangerously hot. She is signed off work and can’t see herself going back as she found the concentration required of her exhausting. When out of the house, she finds she cannot cope well in unfamiliar situations, and therefore avoids going anywhere she doesn’t know well. This is making her husband and children very frustrated as it is limiting them too. She says, ‘this is the most difficult thing about the illness – no-one understands what it’s like, they think you’re just being stupid. It hits how you see yourself.’

Indication of numbers of people with neurological conditions affected by cognitive problems in West Wales

We have estimated numbers on the following basis:

- Prevalence rate of the different neurological conditions, multiplied by
- Numbers of people in Hywel Dda HB area (372,320), multiplied by
- Percentage of people with particular neurological conditions who have cognitive impairment.

These numbers not intended to be researched, academic figures, but they do provide an indication of the numbers of people who may require support in the Hywel Dda area.

For instance, prevalence rate of MS in the UK is 0.164%. About $\frac{3}{4}$ of people with MS have some cognitive dysfunction, and about $\frac{1}{4}$ have serious cognitive dysfunction. Therefore numbers of people affected in Hywel Dda would be:

$$0.164\% \times 372,320 \times \frac{3}{4} = 458$$

$$\text{Numbers seriously affected} = 152$$

‘Severely affected’ is defined here as where cognitive issues cause significant impairment and have a major impact on quality of life. ‘Affected’ means there is some impact on functioning.

For the conditions represented by WWNA where we had adequate evidence to estimate, we would estimate the following numbers:

Condition	Number in HD	Number affected	Severely affected
Parkinsons	800	800	240*
ME/CFS	1100	1000	275
MS	600	450	150
Sp.Bif/Hydroceph.	120	120	Not available
Epilepsy	5600	3920	1680
Total	8173	6171	2345

*The figure of 240 shows the 30% of people with Parkinsons who have dementia. All people with Parkinsons are likely to have severe cognitive functioning problems later in the disease course.

These figures do not include family and carers, whose quality of life is affected, often severely, by the cognitive issues of the person they support.

Emotional support needs

It is common for people living with neurological conditions to have depression and anxiety problems. This is frequently the most difficult aspect of living with the condition to cope with, both for people with the condition and family and carers.

Why depression and anxiety occur

There are two main reasons for this. Firstly, there are 'physical' factors which relate to particular diseases. Depression and anxiety may occur due to brain damage in areas of the brain which regulate mood. Lack of dopamine in Parkinson's, for instance, may be a causal factor; and there are very high rates of severe depression following deep brain stimulation treatment. In Hydrocephalus, depression is very common following shunt surgery. Fatigue and pain, both experienced by the majority of people living with neurological conditions, may contribute to depression. Various drug treatments may have a depressive side effect.

Secondly, there is reactive depression and anxiety caused by living with the limitations of long term illness. There are many factors in this. Bereavement reactions occur when ill health takes away key parts of someone's identity, such as their roles in work or at home, or activities that they loved to do. Relationship breakdown is common, and if leaving the house becomes a problem (for issues of mobility, spatial awareness or continence, for instance), then social isolation can result, which leads to further depression and anxiety. These issues will apply to the majority of people living with neurological conditions at different times and stages, and will frequently apply to their family and carers too. Diagnosis and its aftermath is a particularly difficult time, as the case study below illustrates:

"My name is John, I'm 66 years old and was diagnosed with Parkinsons 14 years ago. My wife was horrified when accompanying me to Parkinsons Clinic to see drooling people in wheelchairs and shuffling shells of people on zimmers. She assumed that I would soon be in the same state. Being told that many couples break up because of PD did

not help her state of mind. She states--I did not sign up for Parkinsons when we got married and I am not a carer. Despite some very ineffective and short term psychiatry and medication which had bad side effects and 3 attempts to take her own life she soldiers on, full of anxiety and concerned about the future, with no further help on offer.”

Due to the above factors, the nature of depression and anxiety needs to be seen differently amongst people with neurological conditions compared to the general population – *the cause does not go away*. Managing mental health issues is likely to be a constant battle over the course of living with the disease. There is also likely to be a tension as to the causative factor – is it neurological damage or reaction to a personal situation?

Depression and anxiety rates

It is difficult to find reliable information on depression and anxiety rates in neurological conditions. The UK MS Register, which is based in Swansea and whose dataset includes all MS patients in Hywel Dda, has published figures which show that 54% of people with MS have ongoing anxiety problems, and 46% have ongoing depression problems (MS Register, 2012). Estimates in Parkinson’s are that 40 – 50% of people have depression and anxiety (Cummings, 1993). Lifetime prevalence in epilepsy has been estimated at between 6% and 30% in population-based studies and up to 50% among patients receiving secondary care (Kanner, 2003). Little other evidence was available but anecdotally the rates of depression in all conditions represented in WWNA was equally high.

Suicide rates and suicidal ideation amongst people with neurological conditions

Suicide rates are not well researched for all neurological conditions. The findings most relevant are the following papers. All point to a substantially increased likelihood for suicidal ideation, suicidal attempts and actual suicides compared to the general population.

Rates and risk factors for suicide, suicidal ideation, and suicide attempts in chronic epilepsy.

Jones JE, Hermann BP, Barry JJ, Gilliam FG, Kanner AM, Meador KJ
Department of Neurology, University of Wisconsin-Madison, Madison, WI, USA. 2003

Studies of causes of death among people with epilepsy suggest that the lifetime prevalence rate of suicide is elevated. Although not all of the studies have reported an increased risk for suicide, the collective data yield an average rate of approximately 12% among people with epilepsy, compared with 1.1-1.2% in the general population. The increased risk for suicide

appears to affect children and adolescents as well as adults. Rates of suicide attempts have also been reported to be elevated among people with epilepsy.

The neuropsychiatry of multiple sclerosis

Kate Jeffries, 2006

Suicidal ideation is very common in multiple sclerosis (Box 3↓). [Feinstein \(2002\)](#) studied 140 consecutive patients attending a multiple sclerosis clinic in Canada and found a lifetime prevalence of suicidal intent of 28.6%; 6.4% of the sample had actually attempted suicide. In addition, people with multiple sclerosis have a significantly increased rate of suicide compared with the general population and patients with other neurological disorders ([Sadovnick et al. 1991](#); [Stenager et al. 1992](#)). As yet, there is no study proving a link between suicide and depression in multiple sclerosis, although such an association is likely to exist.

The neuropsychiatry of depression after brain injury

Simon Flemingera, Donna L. Olivera, W. Huw Williamsb & Jonathan Evans, 2003

There appears to be about a three to fourfold increased risk of suicide after TBI, (*TBI is defined as after stroke or acquired brain injury*) although much of this increased risk may be due to pre-injury factors in terms of the characteristics of people who suffer TBI. About 1% of people who have suffered TBI will commit suicide over a 15-year follow-up.

Existing cognitive, emotional and mental health support available in West Wales

This is an overview of different types of services and support available, and to what extent these are available in West Wales.

Neuropsychology

Clinical neuropsychology is the application of neuropsychological knowledge to the assessment, management, and rehabilitation of people who have suffered illness or injury (particularly to the brain) which has caused neurocognitive problems. In particular they bring a psychological viewpoint to treatment, to understand how such illness and injury may affect and be affected by psychological factors.

Neuropsychology support tends to be focused on cases of acquired brain injury (ABI) and Stroke. Clearly people who have experienced this need neuropsychology support. However, there are also a number of other conditions such as those highlighted in this report which are equally in need of this type of support. The mechanism of brain damage may be different in (for example) Epilepsy or Hydrocephalus compared to that of stroke, but the need for knowledgeable assessment, treatment and advice on compensatory strategies is the same.

In West Wales, access to neuropsychological support for neurological conditions is absolutely minimal. The neuropsychologist at Morriston, Dr Tanya Edmonds (who provides a service on her own for ABMU and Hywel Dda health board areas) may take occasional referrals in extreme cases where a health professional refers them. However, this is a drop in the ocean compared to the numbers of people whose cognitive issues impact hugely on their lives.

Primary Care

Counselling is frequently offered through primary care services. Typically this will involve referral by the GP for CBT style counselling of short duration, usually up to six sessions. This can be an important part of the support options needed. However, there are some issues with this provision:

- No information is available (at least that we are aware of) to say where this support is available
- CBT approaches can be useful, but with individuals who have cognitive deficits, the required ability to change thought patterns may be harder to attain.
- CBT approaches may fail to assess underlying cognitive damage which would require a different treatment approach.
- Many people have ongoing problems with depression and anxiety (due in part to cognitive damage), which a short course of counselling is unlikely to affect.

Mental health services

Mental health services aim to support people with long-term and acute mental health issues to avoid harm to themselves and others, keep people in the community, and support rehabilitation from mental ill health where possible.

West Wales Neurological Alliance is not aware of the mental health services in Hywel Dda. Anecdotally, many people living with neurological conditions do not seek referral to mental health services. We are aware of no joint working between mental health services and specialist nurses or neurologists. Condition specific pathways, where they exist, often do not suggest referral to mental health services. Also, we are not sure what the criteria are for a GP or specialist nurse to make a referral to mental health services.

It may be the case that mental health services have a positive role to play in assisting people with neurological conditions to manage their mental health. However, there is a need for more information and awareness of what can be offered through these services.

Health psychologists

Health psychologists may play a role in assessing and treating the psychological side of illness. Such professionals might be beneficial in supporting people with neurological conditions, although we do not have any evidence that this is used elsewhere. We are not aware whether there are any health psychologists in the Hywel Dda area, or whether any are currently providing a service to people with neurological conditions.

Specialist Nurses

Specialist nurses play a vital role in supporting people with different neurological conditions in managing their condition. Regarding mental health and emotional issues, they will be able to provide a listening ear. They are often trusted by people as a point of continuity in their care over a number of years. A few have training in listening skills and CBT approaches. They may be able to provide basic information on compensatory strategies for cognitive deficits, e.g. memory aids.

However, it would be a mistake to think that specialist nurses have adequate expertise to provide appropriate support for the cognitive and emotional needs of people with neurological conditions. This is for a few reasons:

- Several conditions are not covered by specialist nurses
- They are not able to adequately interpret cognitive assessments and would therefore not usually undertake them
- They do not have the time to spend long periods either home visiting or on the phone to meet emotional support needs
- They do not have the counselling skills to enable people to work through difficult issues.

Community Resource Teams and Chronic Condition Neurology Service

Many of the same observations about specialist nurses will apply to members of the above teams. Some professionals in these teams will provide emotional support and will have varying degrees of skills to do so. A specialist OT in the CCNS in Carmarthenshire will be able to advise on compensatory strategies for cognitive issues, but is not able to undertake cognitive assessments. The CCNS is only available in Carmarthenshire currently. We are not aware of any mental health professionals being part of these teams.

Local peer support groups

Peer support groups have a potentially significant role to play in supporting people with neurological conditions in these issues. Peer support groups, whether structured (e.g. expert patient) or informal (local drop-in socials) will:

- Help normalise the experience of living with cognitive difficulties
- Enable learning from peers regarding compensatory strategies, which is often a more effective technique than learning from professionals
- Reduce social isolation, often forming strong mutually supportive relationships.

However, there is a real problem in running such groups in a rural area like Hywel Dda – geography and transport. People who are severely affected by their condition may find it very difficult to leave home without a carer, and so will be dependent on transport provided. Few (if any) of the neurological patient groups in West Wales have their own transport, and many of the groups have struggled in recent years to encourage adequate attendance to their meetings. Peer support is therefore not as developed as it might be in Hywel Dda.

National Charities

National charities will often have a helpline which is there for emotional support as well as information. Some charities have a 'buddy scheme', or a local worker (such as MND Association Visitors) who provide emotional support to people, and will often do home visits. These are an important means of support. Again, due to the sparse population and difficulty training such volunteers, these services may be less well developed in West Wales.

Recommendations

No one approach will be able to meet the huge and varied needs outlined in this paper. A multi-faceted partnership approach between the health board and voluntary groups will be required. The health board may need to set a working group up to gain further evidence before committing to a plan. The following measures are ones that the West Wales Neurological Alliance would like to see implemented:

1. An enhanced neuropsychology service, possibly with a clinical psychologist who has an interest in neuropsychology based in Hywel Dda, who works under the governance of the neuropsychologist in Morriston.
2. Clear information provision on primary care counselling support and how to access it.
3. Clear information provision on mental health services and the criteria for accessing them.
4. Development of a pathway for cognitive and emotional support in neurological conditions which allows for escalating a case from primary care, CRT or specialist nurse to mental health services or neuropsychological support. Training in the pathway would need to be given to primary care, community teams and specialist teams.
5. Consider how to ensure that people with neurological conditions can be supported to attend appointments, and not to be removed from treatment if they fail to attend.
6. Consider how to ensure that particularly vulnerable people with neurological cognitive issues can receive regular healthcare reviews.
7. Consider deployment of a mental health nurse or health psychologist, trained in cognitive dysfunction issues, in the CCNS service.
8. Working with the local neurological alliance, support development of peer support mechanisms in Hywel Dda.
9. Work with the local neurological alliance to raise awareness of the support available from national charities to GPs and key health professionals.

Conclusion

This is a complex and difficult area for which no easy solutions exist. However, the impacts of cognitive problems and mental ill health on people living with neurological conditions are very detrimental to quality of life and wellbeing. The health board has a responsibility to do what it can to meet these needs, and we call on it to work in partnership with West Wales Neurological Alliance to develop services and support to do this.