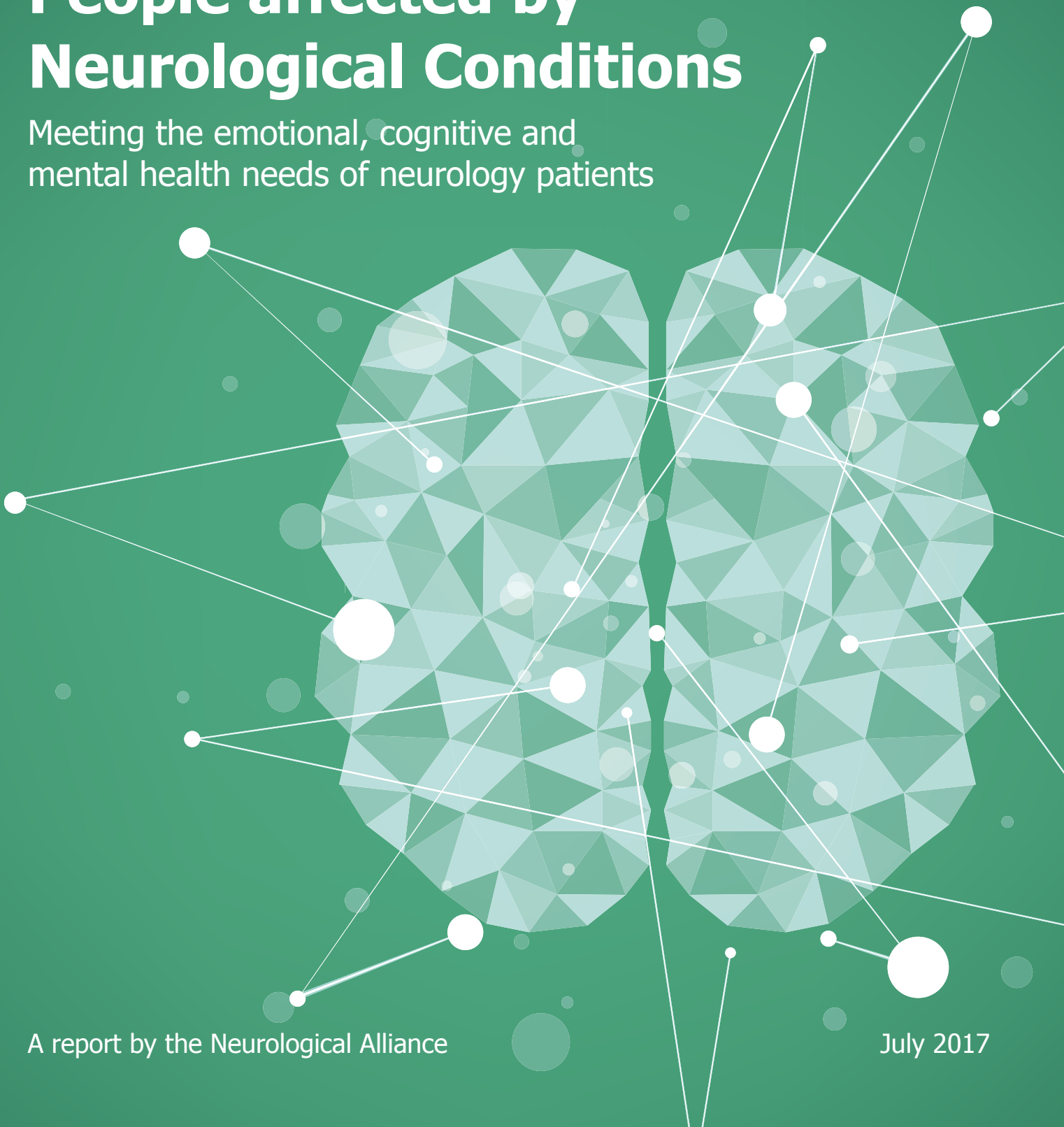


# Parity of Esteem for People affected by Neurological Conditions

Meeting the emotional, cognitive and  
mental health needs of neurology patients

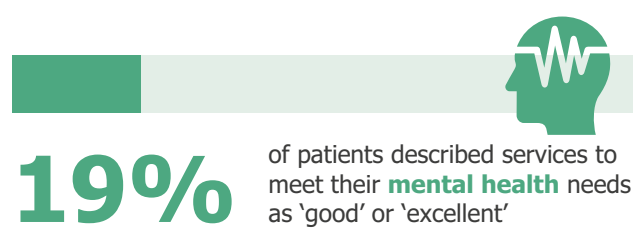
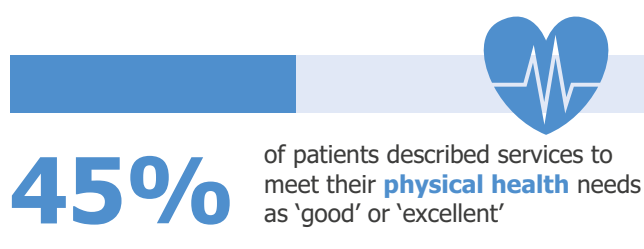


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## INTRODUCTION

45% of patients taking part in the Neurological Alliance's 2016 patient experience survey described the services to meet their physical health needs as 'good' or 'excellent'. This is in itself a disappointing satisfaction rate, but more worrying is the finding that for services to meet their mental health needs, the percentage of survey respondents rating services as 'good' or 'excellent' fell to just 19%.<sup>1</sup> This suggests parity of esteem – the principle by which mental health is valued equally with physical health – is a long way from being a reality for neurology patients. To date this has been a neglected policy area, even within policy on neurological conditions.



For this report we have gathered together stories from patients about their experience of having a neurological condition alongside mental health, emotional or cognitive needs. These stories highlight how mental health needs associated with neurological conditions can impact considerably upon patient outcomes, especially where timely and appropriate diagnosis and interventions are not available. A co-morbid mental health condition can often lead to reduced ability to self-manage a physical condition, manifesting itself in poorer adherence to treatment plans and lower attendance at medical appointments. This contributes to more acute episodes, poorer clinical outcomes and higher mortality rates.<sup>2</sup> A lack of early detection, treatment and intervention for emotional, cognitive and mental health needs associated with neurological conditions not only lowers health outcomes, it can reduce quality of life and increase disability. In children it can often be a factor in lower educational attainment. Patients report that the combination of a neurological condition and mental health condition can bring them to crisis point. In some cases, not recognising and treating a co-morbid mental health condition can lead to inpatient admissions, early and unnecessary residential care, and in extreme cases homelessness, offending and imprisonment.<sup>3,4</sup>

The impact of poor care for co-morbid mental health needs of patients with neurological conditions reaches beyond the experience of the individuals

themselves. Families and carers of people with mental health needs associated with neurological conditions often struggle to cope emotionally themselves. For example, cognitive and mental health issues in individuals with multiple sclerosis have also been shown to be correlated with caregiver distress and reduced quality of life.<sup>5</sup> A study by the Motor Neurone Disease Association found that one of the main concerns of carers was how they would cope mentally.<sup>6</sup> In parallel, the costs to the health service of treating mental health alongside a long-term condition represents a significant amount of spend for the NHS – around 12–18%<sup>7</sup> of the long-term conditions budget. The King's Fund argues that, *'this considerable sum is not spent optimally, because health and social care are largely organised separately for physical and mental illness.'*<sup>8</sup> There are also wider economic impacts of having a comorbid mental health condition, for example, increased unemployment and reduced productivity.

The best available evidence suggests that patients with mental health needs make up a sizeable proportion of the total neurological patient population, which has now reached 12.5 million cases in England, or 59,000 cases per Clinical Commissioning Group (CCG).<sup>9</sup> The prevalence of neurological conditions is likely to continue to increase as people live longer. NHS expenditure on neurological conditions amounted to £4.4 billion in 2012/13, which represents an expenditure increase of 200% since 2003.<sup>10</sup>

# INTRODUCTION

Despite this increasing prevalence and cost to the health service, neurology is not a high priority for the NHS. In policy terms it is hidden within the wider long-term conditions policy agenda meaning there are few specific neurology-related incentives within the NHS accountability frameworks.<sup>11</sup> This has contributed to local commissioners being largely disengaged from neurology. It is therefore perhaps unsurprising that the mental health needs of neurology patients have been given little attention, given the low priority afforded to neurology overall.

While there has been little focus on neurology within national policy making, mental health has increased in prominence in the last decade in the wake of high profile campaigns such as Time for Change and Heads Together, as well as better availability of evidence about the prevalence within the population (one in four people will have a mental health condition at some point in their lives<sup>12</sup>) and high costs to the NHS of mental health conditions. The Mental Health Five Year Forward View sets out a number of service improvement initiatives for mental health. Through this new strategy, overall, mental health services will benefit from additional investment of £1bn per year by 2020/21.<sup>13</sup> Despite this increased focus on mental health, however, our patient experience survey suggests that, to date, patients with neurological conditions are not benefitting from improvements.

The Neurological Alliance, working in partnership with the Division of Neuropsychology at the British Psychological Society, as well as a number of member patient organisations, has undertaken a piece of research to understand more about the experience of neurology patients accessing services to meet



## Neurological conditions

**NEUROLOGICAL CONDITIONS** are disorders of the brain, spine or nerves. They are a diverse group of conditions which can have a range of causes including genetic factors, traumatic injury, and infection. The term covers a wide range of conditions from progressive illnesses such as Motor Neurone Disease and Alzheimer's to relapsing remitting conditions such as epilepsy or migraine. The term also covers sudden onset injuries to the brain including those which may occur from a road traffic accident or a stroke. There are also many rare neurological conditions such as Multiple System Atrophy and Guillain Barre Syndrome.

their mental health, emotional and cognitive needs. As part of this research, we considered how the mental health, emotional and cognitive needs of patients with neurological conditions are distinct from the mental health needs of the general population, and what this means for commissioning and service delivery. Focussing on England, in this report we present our findings and explore the range of interventions and tools that could better support neurology patients with mental health needs. We conclude with a series of recommendations which aim to improve services and make parity of esteem a reality for neurological patients.

Types of neurological conditions <sup>14</sup>	Estimated prevalence in England
Intermittent (e.g. epilepsy, migraine)	7.4 million
Progressive (e.g. Parkinson's, dystonia, motor neurone disease)	2.6 million
Stable with changing needs (e.g. fibromyalgia, transverse myelitis)	2.2 million
Sudden onset (e.g. acquired brain/spine injury, encephalitis)	350,000

## EXECUTIVE SUMMARY

### **Emotional, cognitive and mental health needs of neurological patients have tended to be invisible, even within policy on neurological conditions.**

The NHS Constitution includes a commitment to achieving 'parity of esteem' to ensure that the system can 'improve, prevent, diagnose and treat both physical and mental health problems with equal regard.'<sup>15</sup> Parity of esteem is the principle by which mental health is prioritised equally with physical health. To date there has been little consideration of how 'parity of esteem' applies to people with neurological conditions and how to deliver on this commitment for them. This is despite the significant impact of mental health, emotional and cognitive needs associated with a neurological condition on patients, carers, the NHS and wider economy.

### **The likelihood of having a comorbid mental health condition may be even higher for neurology patients than for the long-term conditions patient population overall.**

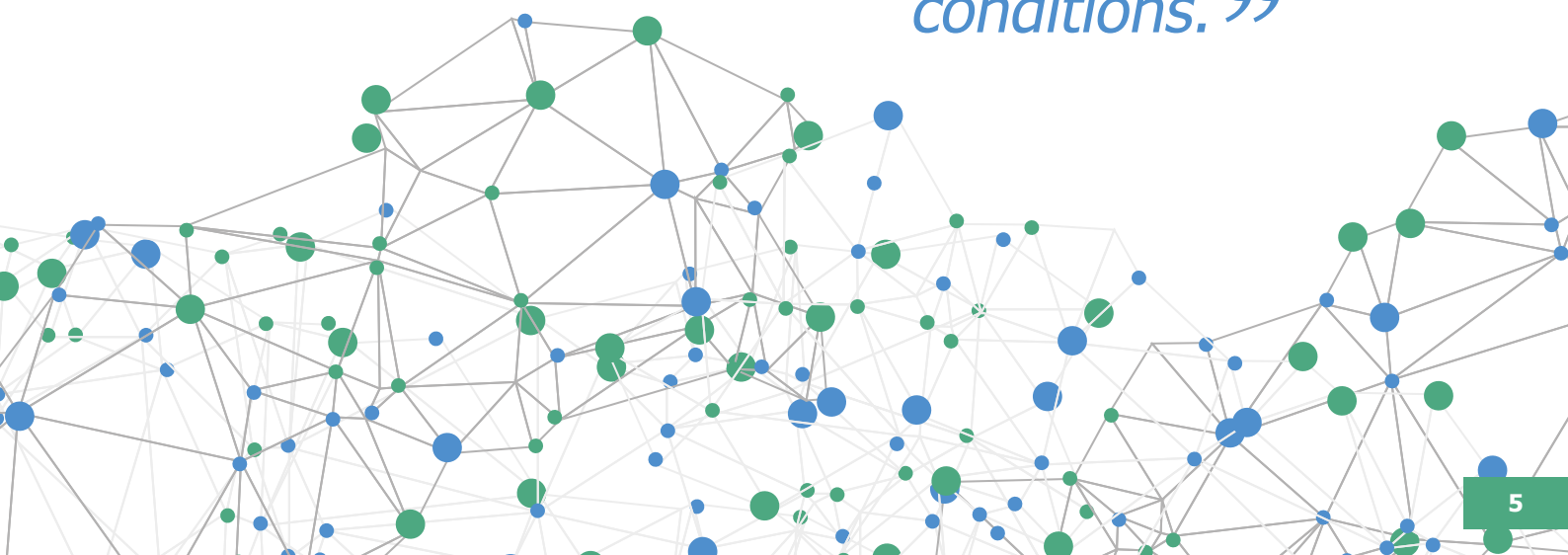
GP survey data shows that people with neurological conditions experience the highest levels of difficulty with anxiety and depression and have the highest comorbidity with mental health conditions out of all long-term conditions.<sup>16</sup> Prevalence data from a range of studies also highlights a high level of need for the majority of neurological conditions, often with around 50% of patients affected, and sometimes more.<sup>17</sup> The families and carers of this group of patients may also have distinct mental health needs.

### **There is often a complex interplay between neurological conditions and comorbid mental health conditions.**

As neurological conditions relate to the brain and nervous systems there is an increased complexity in the interaction between physical needs and broader emotional, cognitive and mental health needs. It can be difficult to unpick where the neurological condition ends and where a mental health condition begins or how the two interplay with each other. Providing accurate diagnosis and effective treatment for emotional, cognitive or mental health needs in this context can be challenging.

.....

*“To date there has been little consideration of how 'parity of esteem' applies to people with neurological conditions.”*



# EXECUTIVE SUMMARY

## Current services are characterised by disjointed pathways, poorly coordinated care and variation across the country.

Our work indicates gaps in the availability of, and access to, specialist neuropsychological and neuropsychiatric support within multidisciplinary teams. This is particularly notable within community based services. Availability of psychological support in general can also be an issue and we found that those with neurological conditions are often not able to access mental health services as their condition is seen as organic. For those who are accepted by mental health services, they often find that these services are not appropriately tailored to meet their specific needs. Signposting to information or other self-management resources to support emotional, cognitive and mental health needs is often poor.

## Specially designed services that bring together neurology and mental health are required to achieve the best outcomes for patients.

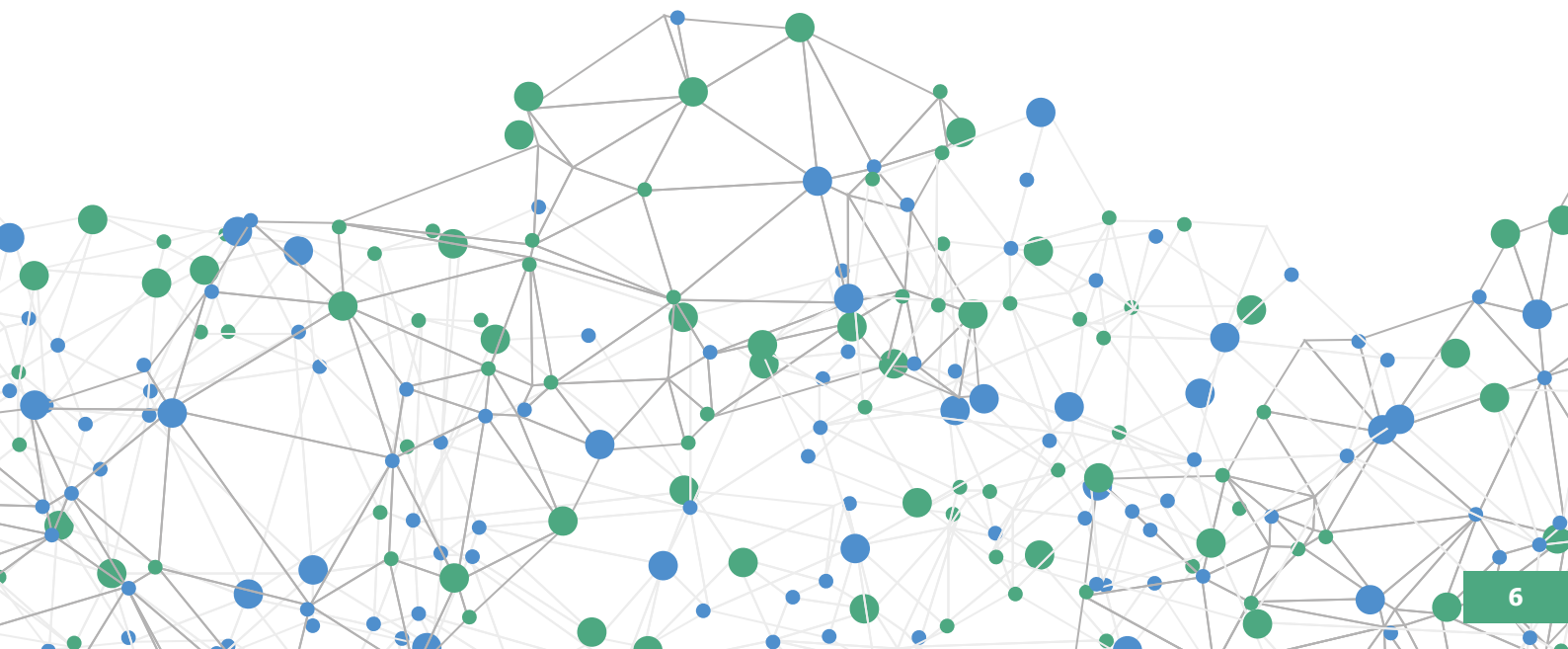
With effective psychological triage within the neuroscience pathway, it can be determined which individuals would be suitable for mental health services and which individuals need specialist psychological interventions to meet the needs of their condition. Information and self-management can also play an important role in meeting mental health needs, and patient organisations have a lot of resources available in this regard. Cognitive, emotional and mental health needs of neurology patients should be considered at the time of diagnosis, with screening included in ongoing care.



## Recommendations

- 1 Clarify commissioning responsibilities for neurology and mental health
- 2 Standardise NICE guidance relating to neurological conditions to address emotional, cognitive and mental health needs
- 3 Invest in specialists and specialist training
- 4 Improve access to information, care planning and coordination of care for neurology patients

In [chapter 4](#) we provide more detail about what action is needed to achieve these recommendations.



## 1.1 Policy context for mental health and neurology

Parity of esteem is the principle by which mental health is given equal priority to physical health. It is a major policy objective for the NHS. The NHS Constitution includes a commitment to achieving parity of esteem to ensure that the system can 'improve, prevent, diagnose and treat both physical and mental health problems with equal regard.'<sup>18</sup>

Progress towards this objective is a commitment in the Government's 2017–18 Mandate for NHS England.<sup>19</sup> The 2017 update on progress against the Five Year Forward View dedicates a whole chapter to mental health.<sup>20</sup> The Five Year Forward View for Mental Health, the national strategy for improving mental health services, makes system-wide commitments to redesign mental health services including community, acute and crisis care, children and young people's mental health services as well as putting in place prevention initiatives.<sup>21</sup> Overall mental health services will benefit from additional investment of £1bn per year by 2020/21.<sup>22</sup>

Around 46% of people with a mental health condition also have a long-term physical health condition and around 30% of people with a long-term condition also have a mental health condition – around 4.6 million people. This makes people living with long-term conditions two to three times more likely to experience mental health issues than the general population.<sup>23</sup> Despite these trends, historically services have not been set up to meet mental health needs alongside needs from a physical long-term health condition.

There are recent policy commitments aiming to address the lack of integration between mental and physical health. The Five Year Forward View for the NHS published in 2014 sets out an ambition for removing traditional boundaries between physical and mental health services (as well as social care) to ensure a whole person approach to care.<sup>24</sup> The Five Year Forward View for Mental Health has committed to targeting the expansion of access to psychological therapies, stating that two-thirds of the additional people receiving services will have co-morbid physical and mental health conditions or persistent medically

unexplained symptoms.<sup>25</sup> The NHS England statement on pilot sites for this work does not, however, include neurological conditions.<sup>26</sup>

In policy and service delivery terms, neurological conditions sit under the long-term conditions umbrella. This is problematic for several reasons. Firstly, not all neurological conditions are long-term in nature. Secondly, even for the majority of neurological conditions that are long-term, being wrapped up in the long-term conditions agenda means neurology is competing for attention with some of the biggest spend areas and most prevalent conditions, such as diabetes. Thirdly, in terms of co-morbid mental health conditions, neurology is also often very different from other long-term conditions. As we explore later in this report:

- The likelihood of having a comorbid mental health condition may be even higher than for the long-term conditions patient population overall.
- There is a complex interplay between mental health and a physical neurological condition.
- Providing accurate diagnosis and effective treatment for emotional, cognitive or mental health needs can be challenging.
- Specially designed services that bring together neurology and mental health are therefore often required to achieve the best outcomes.

It is well documented by the Neurological Alliance (and others) that neurology is not a high priority for the NHS. There are few neurology-related incentives within the NHS accountability frameworks and commissioners are largely disengaged from neurology.<sup>27</sup> This is despite both prevalence and spend on neurological conditions increasing.<sup>28</sup>

## PARITY OF ESTEEM AND NEUROLOGICAL CONDITIONS

Just as neurological conditions can be 'invisible' within policy on neurological services, emotional, cognitive and mental health needs have been relatively 'invisible' within policy on neurological services. Although there has been growing attention on mental health in national policy making, key reports on neurological services have tended not to consider this issue. For instance, the national audit office<sup>29</sup> and public accounts committee<sup>30</sup> reports on services for people with neurological conditions did not cover mental health. Equally major reports on mental health such as the 'Five Year Forward View For Mental Health', described above, do not draw out the needs of neurological patients.

There are, however, some encouraging signs that this is slowly starting to change. Until recently neurological conditions were grouped with mental health and dementia within the strategic clinical network structures. Mental health, dementia and neurology remain as a grouped programme of work within the Intelligence Network at Public Health England. Although it is worth noting these work streams are largely separate. The recent community neurology guidance to commissioners highlighted the mental health needs of the patient group.<sup>31</sup> The recognition is overdue and through this new report, the Neurological Alliance is seeking to raise the profile of the specific needs of this subset of neurology patients.

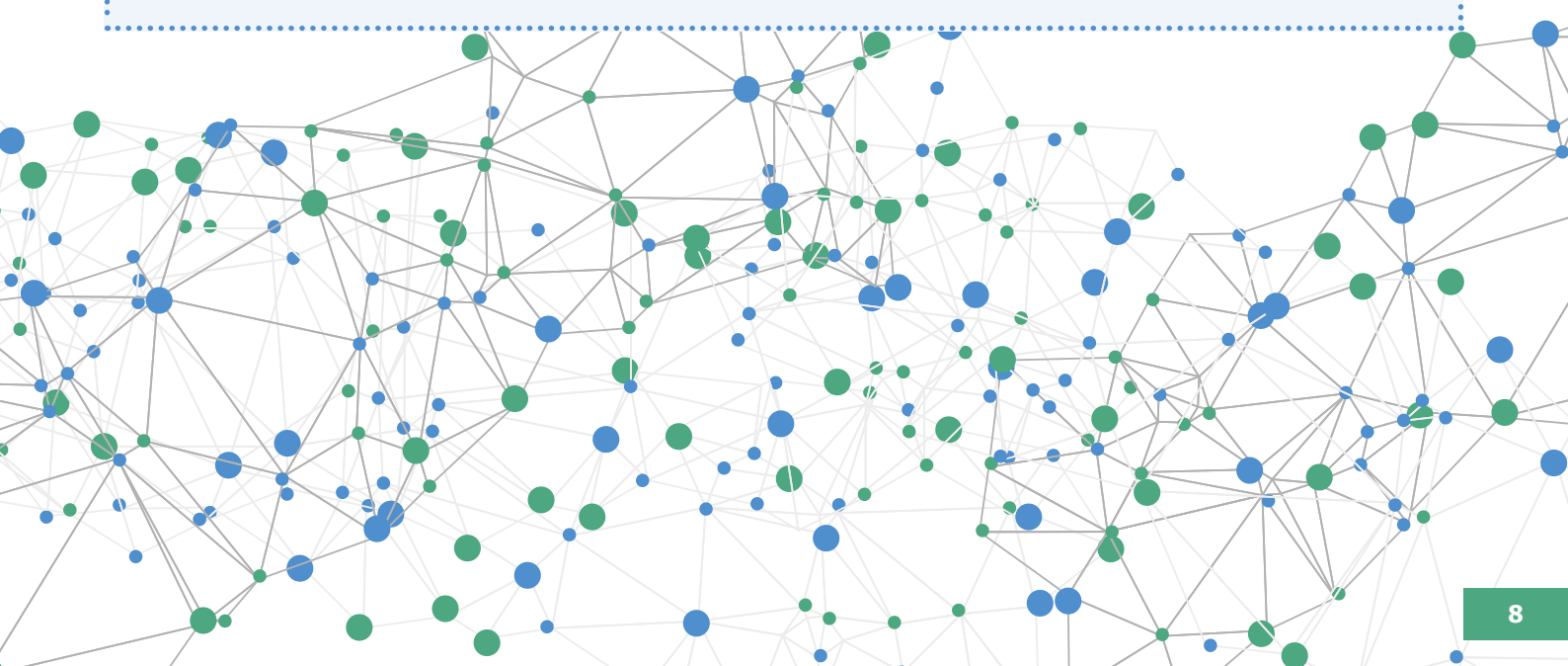


### G's story

**I WAS DIAGNOSED WITH PARKINSON'S IN 2012.** For about three or four years before, I struggled with anxiety and I just couldn't understand why I was feeling this way. I had a real constant feeling of panic and it was extremely challenging, especially at work as I was a teacher. Now I know the anxiety was part of my Parkinson's, as the mental health symptoms can show before the physical aspects.

As my Parkinson's progresses, I'm finding my anxiety really goes up and down and I find my emotions are harder to deal with. My self-esteem and my confidence can be rock bottom and it is an absolute effort to get things done during the day. I talk to my GP, I talk to my neurologist but I feel that the mental health issues, like the anxiety and depression are often not taken into account. I'm never offered any talking therapies.

For good mental health support – I shouldn't have to keep asking for it. It should be taken into consideration as part of the norm, just like the physical symptoms of Parkinson's. What goes on for me physically as part of my condition is talked about, but what about managing my mental health? For me, mental health is the least addressed part of my Parkinson's. It wasn't addressed at diagnosis, and it still isn't today. I feel I muddle my way through the day emotionally.





# PARITY OF ESTEEM AND NEUROLOGICAL CONDITIONS

## 1.2 The level of emotional, cognitive and mental health needs amongst those with neurological conditions

52% of patients who took part in our 2016 neurology patient experience survey reported having one or more co-morbid condition alongside their neurological condition. The most frequently cited co-morbid conditions were mental health, anxiety or depression. While these results are not generalisable to the wider neurology patient population, they give an initial indication of the level of mental health, emotional and cognitive needs.

There is little nationally collected data on the mental health needs of people with neurological conditions as a whole. GP survey data suggests that people with neurological conditions experience the highest levels of anxiety and depression and have the highest comorbidity with mental health conditions out of all long-term conditions.<sup>32</sup> Studies have shown that children with complex neurological conditions are up to eight times more likely to have the significant emotional, behavioural and cognitive problems than other children in the general population.<sup>33</sup> Good data also exists within some specific condition areas, which shows that often more than 50% of patients have emotional, cognitive and mental health needs.<sup>34</sup> It is, however, difficult to compile

data on rare conditions where population numbers can be small. It should also be noted that, due to the difficulties with diagnosis outlined below, there may be both over and under-reporting of neurological conditions and mental health conditions.

In order to try and estimate the level of need, we have brought together some of the best available data from research studies on presence of cognitive, emotional problems and co-morbid depression and anxiety for a variety of conditions and presented this below. If we collate the data covering MS, MND, epilepsy, dementia, Parkinson's and stroke, we estimate that up to 1.2 million people with these conditions may be affected by cognitive or emotional issues.

### Autism



79% of autistic adults have a **mental health problem** at some point in their lives.<sup>35</sup>



66% of autistic adults with no learning disability have considered **suicide**.<sup>37</sup>



70% of autistic children have a **mental health problem**.<sup>36</sup>



41% of autistic children have **two mental health problems**.<sup>36</sup>

### Dementia



**Depression** is more common among people with dementia; 20 to 40% of whom may have depression, particularly those who have vascular dementia or Parkinson's dementia.<sup>38</sup>



**Anxiety** is more common in people with dementia than those without, affecting between five and 20%. Like depression, anxiety is thought to be more common in vascular dementia, and probably also in Parkinson's dementia.<sup>39</sup>

# PARITY OF ESTEEM AND NEUROLOGICAL CONDITIONS

## Epilepsy



**Depression** is the most frequent comorbid psychiatric disorder in epilepsy. Its prevalence has been estimated to range between 20% and 50% of patients.<sup>40</sup>



**Depression** reported in 6–9% patients in remission, 20–30% of those having **seizures** and with lifetime prevalence estimated at 55%.<sup>41</sup>



The prevalence of **mood and anxiety disorders** in children with, for example, complex epilepsy, was 52% in a clinical sample and similar in population samples.<sup>42</sup>

## Functional Neurological Symptom Disorder

**Functional neurological symptoms** can also exist alongside organic neurological conditions. A large study from Scotland by Stone, J., Carson, A. Duncan, R. et al (2012) involving 2,467 patients with neurological conditions (e.g. epilepsy, multiple sclerosis, movement disorders, brain tumours, stroke), found an average of 12% of those patients across the whole sample also had **co-existing functional symptoms**.<sup>43</sup>



## Migraine



**Depression** is three times more common in people with migraine or severe headaches than in healthy individuals.<sup>44</sup> 47% of young people with recurrent headaches experience **psychological/psychiatric problems**.<sup>45</sup>

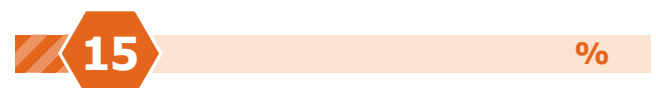


**Suicidal risk** was assessed as high in 20%.

## Motor Neurone Disease



The literature suggests that up to 35% of people living with MND will experience some degree of **cognitive change**<sup>46</sup> – that can range from mild to severe.



Up to a further 15% will have an additional **frontotemporal dementia**, meaning around 50% of people with MND are likely have some sort of cognitive change.

## Multiple Sclerosis



An estimated 50% of those with MS will experience **depression**.<sup>47</sup>



43–70% will experience **cognitive problems** associated with the condition.<sup>48</sup>

# PARITY OF ESTEEM AND NEUROLOGICAL CONDITIONS

## Multiple System Atrophy



40–80% of people with MSA will experience **depression**.<sup>49</sup>

## Transverse Myelitis



In a Johns Hopkins University study, 60% of Transverse Myelitis patient deaths were due to **suicide**.<sup>50</sup>

## Parkinson's



At any given time, up to 40% of people with Parkinson's will have **depression**.<sup>51</sup>



Up to 40% will experience **anxiety**.



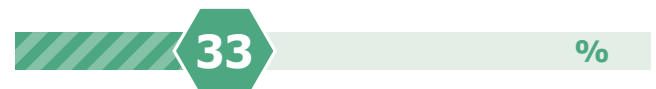
Up to 50% will experience mild **psychotic symptoms**.

However, mental health issues in Parkinson's are often underdiagnosed because some symptoms, particularly fatigue and insomnia, may be considered to be part of Parkinson's.<sup>52</sup>

## Stroke



56% of stroke patients experience significant **reasoning and planning difficulties (executive dysfunction)**.



33% of stroke patients have a **behaviour disorder alone (hypoactivity, disinterest)**.



22% of stroke patients have a **cognitive syndrome** alone.<sup>53</sup>

## Tourette Syndrome



The lifetime prevalence of any **psychiatric comorbidity** among individuals with Tourette Syndrome was 85.7%



57.7% of the population had **two or more psychiatric disorders**.<sup>54</sup>

## Traumatic Brain Injury



As many as 65% of moderate to severe TBI patients report long-term problems with **cognitive functioning**.



15% of TBI patients have persistent problems, which often include **cognitive deficits**.



The prevalence of **depression** after TBI was from 12.2% to 54%.<sup>55</sup>

## 1.3 How Parity of Esteem applies to Neurological Conditions

In common with other long-term conditions, coping with the diagnosis, symptoms and impact of a neurological condition can lead to depression, anxiety and low mood. 70% of respondents to our 2016 neurology patient experience survey stated that they were restricted in their activities frequently, most or all of the time.<sup>56</sup>

This can play out in different ways, for example, it may impact on an individual's independence, leading to social isolation, which in turn may cause depression. Many people with neurological conditions are unable to work which can cause anxiety and stress due to financial difficulties. Stigma linked to some neurological conditions can also trigger anxiety. Some neurological conditions are progressive conditions. Coping with the anticipated loss of physical and cognitive function and ultimately premature death, increase the likelihood of depression, anxiety and low mood.

In the case of neurological conditions, however, there is often additional complexity to the interactions between physical and mental health which can play out in several different ways.

People with neurological conditions may be affected by changes in the brain which directly affect their emotions, cognitive abilities and executive functioning. For instance, it may seem that someone is affected by depression when in fact they are affected by 'emotional lability' – a change in the brain which can cause someone to become more tearful, or to laugh inappropriately. Or it may be that someone seems to be affected by anxiety because they are forgetting things, not concentrating well or demonstrate general apathy or equally disinhibition when in fact these are cognitive changes linked to the neurological condition. Psychological disorders, emotional and behavioural symptoms, and cognitive difficulties in children with neurological conditions can often be the earliest presenting complaints.<sup>57</sup>

Conversely, those with progressive conditions affecting cognitive function such as dementia may see their depression overlooked as just part of the condition. Changes in emotions, cognitive and executive functioning caused by the condition may also exist alongside depression or anxiety. This has an effect on the nature of treatment which will be required. Mental health issues occurring independently of the neurological condition may also exacerbate it, for example, anxiety is a well known seizure trigger in epilepsy. Patients with severe mental illness, such as schizophrenia, may be at increased risk of acquired brain injury, which may in turn exacerbate mental health symptoms.

Neurological conditions can also make communication more difficult. For example, dysarthria can make it difficult to speak and aphasia can make it difficult to select the correct words or sounds when one is speaking, and it can also make it challenging to understand what other people are saying, or to read or write. This can have a range of consequences for someone's mental health. It can make it harder to identify the mental health needs of an individual in the first place, can increase the risk of people withdrawing socially (e.g. if it is 'too tiring' to talk), and can make it more difficult to deliver appropriate interventions (e.g. it can make it harder to conduct talking therapies or to access online information or peer support).

In some cases a patient may present with seeming mental health issues which may reflect an undiagnosed neurological condition. For example,

# PARITY OF ESTEEM AND NEUROLOGICAL CONDITIONS

hyperactivity, inattention and memory problems in children can be caused by an underlying and treatable neurological condition, but without specialist assessment the child may be prescribed treatments for ADHD. Another example would be the prescribing of antidepressants to a child who is mistakenly assumed to have a psychotic illness but where a frontal brain tumour is present.

Conversely a patient may be misdiagnosed with a neurological condition and display 'neurological' symptoms, such as blackouts, sleep problems or weakness, but they are not caused by structural changes in the brain. These are known as functional or dissociative conditions, and are caused by problems with how the nervous system is functioning and how the brain fails to send and receive messages correctly. For example, someone may exhibit all the symptoms of an epileptic seizure but the attack will be non-epileptic.

Medications that are commonly used to treat neurological conditions can often have side

effects including mental health issues. For example, the side effects of taking dopamine agonist medications for Parkinson's and other neurological conditions such as restless leg syndrome can cause compulsive behaviours such as hypersexuality or shopping addiction.

One of the reasons the mental health, cognitive and emotional needs of neurology patients requires particular consideration is the complex interplay between mental and physical health in this patient group. It can be difficult to unpick where a neurological condition ends and where a mental health issue begins. This can often lead to misdiagnosis. Providing accurate diagnosis and effective treatment for emotional, cognitive or mental health needs in this context can be challenging and may often require specialist expertise or training.

We explore in [chapters 2](#) and [3](#) the extent to which services for mental health are meeting the specific needs of the neurological patient group.

”

## H's story

**MY NIGHTMARE WITH RESTLESS LEG SYNDROME (RLS)** started approximately eight years ago.

A feeling in my legs that was so hard to explain. Sympathy and understanding was readily available for me through my family... [but] it does not help when at 3am in the morning you are crying with frustration and every 'normal' person is fast asleep and your alarm clock is soon to go off for a full day at work ahead. By no means am I a lonely person, but in the middle of the night I feel alone...

Over the years I have given many different medications to try which have given minimal or no relief at all. I have been referred to three different neurologists in three different hospitals. A neurologist prescribed Clonazepam which seemed to ease my symptoms, unfortunately I was not advised of the dependency factors with this and before I knew, I was addicted to this drug, taking up to eight times the daily dose.

Many years of lack of sleep has made me feel too scared to go to bed at a decent time. Anxiety has become a major factor during my day to day life. I have been offered and tried, talking therapies and antidepressants to work on my anxiety but I have found that [antidepressants] make other situations more exaggerated and deepens anxiety levels. I am still very confused as to whether RLS causes anxiety and inability to sleep well or if anxiety causes RLS to flare up. It all seems to be a vicious circle.

## 2.1 Disjointed patient pathways and poor coordination of care

Parity of esteem for neurological conditions cuts across traditional service boundaries, reflecting the complexity of the neurological patient group. The graphic below was produced by the husband carer of MW (patient story on [page 18](#)), a patient with Huntington's Disease.

It represented his family's experience of navigating the vast array of services and professionals involved in meeting his wife's multiple care needs. Like many other neurology patients, he found mental health provision to be separate from neurology services, with neurology not providing a clear pathway into other clinical specialisms or services. Similarly, GPs can often be unsure of the mental health services available to neurology patients and how to access these. This is not an isolated case; we have found many patients and their carers are being left to join up the dots between services often at an extremely stressful time in their lives and without any knowledge of what may be available for their needs.

Disjointed pathways are compounded by poor coordination of neurological patient care. The Neurological Alliance's 2016 patient experience survey found that 85% of respondents had not been offered a care plan; an essential tool in ensuring all of a patient's needs are considered together in order to develop a coordinated plan to support an individual. It is also important that patients have a named healthcare professional who can lead and support coordination of their care but 43% of patients taking part in our patient experience survey said they were unsatisfied with the information they received about a named health care professional. Furthermore, 20% of respondents felt their health care professionals never work together.<sup>58</sup>



# A PICTURE OF CURRENT SERVICES

## 2.2 Variation in services across the country

The Division of Neuropsychology recently interviewed clinical leads within regional neuroscience centres to investigate neuropsychology services at both tertiary and community level. The mapping process uncovered a postcode lottery in the availability of neuropsychology for patients in different areas of the country with some locations lacking adequate staffing or even having no provision at all.

Similarly, the MND Association recently undertook its own survey of access to neuropsychology and neuropsychiatric pathways and referral points across England, Wales and Northern Ireland for people affected by MND with suspected cognitive impairment and frontotemporal dementia. There was huge variation within the three nations, with very few pathways or referral opportunities and subsequent treatment and intervention available.<sup>59</sup>

On average there is one neuropsychologist based in a neuroscience centre per 600,000 people in the population. The range is from 1 for 200,000 people in the population to 1 for 1,500,000 indicating that some areas may be significantly under-staffed.<sup>60</sup> The majority of neuropsychology teams stated that, with more resources, they could easily increase the level of services they offer and the number of patients they see, pointing to a degree of unmet need.

Specialist services also vary in their accessibility with only five services out of 21 interviewed able to accept referrals from GPs and in contrast six limiting referrals only to neurology or neurosurgery consultants directly within the neuroscience centre.<sup>61</sup>

The mapping also indicated particular gaps in community level services for the emotional, cognitive and mental health needs of the neurological patient group.<sup>62</sup> Several clinicians highlighted that there was no community neuropsychology and sometimes no neuro-rehabilitation, while for others services were only available in one small part of a region or were highly restricted. To address this some neuroscience centres are taking an active role in supporting community rehabilitation by bringing community staff under their management or working directly with community partners to develop services.



### John's story

**JOHN WAS 56 WHEN DIAGNOSED WITH MOTOR NEURONE DISEASE.** He continued to be able to walk, but had weakness in his arms and hands. However, shortly after diagnosis his wife noticed that his behaviour was changing. He became apathetic and reluctant to leave the house. He did not want to talk to family members. It had been assumed at diagnosis that he had a mild cognitive impairment. However, his behaviour worsened and he began to gorge food inappropriately given some weakness in his swallowing. After further tests, it was found that he had frontotemporal dementia, that can be present in up to 15% of people with Motor Neurone Disease. However, there were no care pathways into the provision of neuropsychology for John, and the best advice that his family was offered was to keep all the kitchen cupboards locked for the duration of his illness. John did not benefit from any key interventions relating to his behaviour. The course of his disease progressed rapidly, with further self-imposed isolation from his family. He died 19 months after being diagnosed with MND.

## A PICTURE OF CURRENT SERVICES

A national audit of neuropsychiatric services in the UK showed that current neuropsychiatric service provision remains patchy and is limited to only a few regional or national specialised centres.<sup>63</sup> More recent unpublished work from The Faculty of Neuropsychiatry, Royal College of Psychiatrists showed an increase in specialised secondary and tertiary neuropsychiatry services and staffing but that this remained at approximately one third of the recommended service provision.<sup>64</sup> A number of centres do not have adequate access to MDT staff or resources to provide a range of necessary treatments.

Charities supporting those with neurological conditions are often playing a vital role in pump priming services or paying for individual patients to access private services. A critical issue for the patient group is often the difficulty of reaching services

that are not local, especially with the severity of symptoms in relation to some conditions. As a result model options such as virtual clinics and intensive sessions are highly relevant where they are available.

In terms of provision for children with co-morbid neurological and mental health conditions, there are 17 Specialist Paediatric Neurosciences Centres in England that provide specialist paediatric neurosciences services through a multidisciplinary approach to the diagnosis and management of a range of neurological disorders. Internal mapping carried out by the Division of Neuropsychology in neuroscience centres identified that the level of neuropsychology staffing in most paediatric neurology services was low and in particular there were gaps around rehabilitation. We also found that currently many local teams lack resources to support this group of children.<sup>65</sup>

### 2.3 Local mental health services are often unsuitable or are reluctant to accept neurology patients

At a local level our research has uncovered difficulty of making referrals into mental health services, for instance to IAPT (Improving Access to Psychological Therapies). In a significant number of cases, referrals of patients with neurological conditions would not be accepted as the patient's issues are seen as primarily physical.<sup>66</sup>

Whilst in some cases this may be correct, in other cases it will not be and can result in a lack of access to mental health services for those with neurological conditions. We also found cases where the referring clinician had to reframe adjustment issues as anxiety or depression to get people in.

A recent parliamentary question response suggested that the expansion of IAPT under the Five Year Forward View for Mental Health may mean better access for neurology patients.<sup>67</sup> However, for patients who are accepted, local mental health services often struggle to meet the specific needs of this patient group. Patients may be taken on but into a service that is unable to provide for their needs which may prove counter-productive. Our patient stories – about a person with autism and

a person with Huntington's Disease – illustrate the sometimes tragic consequences of a one-size-fits-all intervention. It should be noted that our research did highlight some examples of working arrangements being developed between the more specialist neuropsychology services and IAPT, perhaps emphasising the importance of a targeted service.<sup>68</sup>

Similarly, for children, general tier three child and adolescent mental health services (CAMHS) or community paediatric teams tend not to have relevant experience. Specialist knowledge of the effects of brain disorders, systemic illness, long-term conditions and disabilities are needed. Access to professionals who understand the subtle but profound and impairing impact of frontal lobe dysfunction in children in particular is essential.



## A PICTURE OF CURRENT SERVICES



### Karen's story

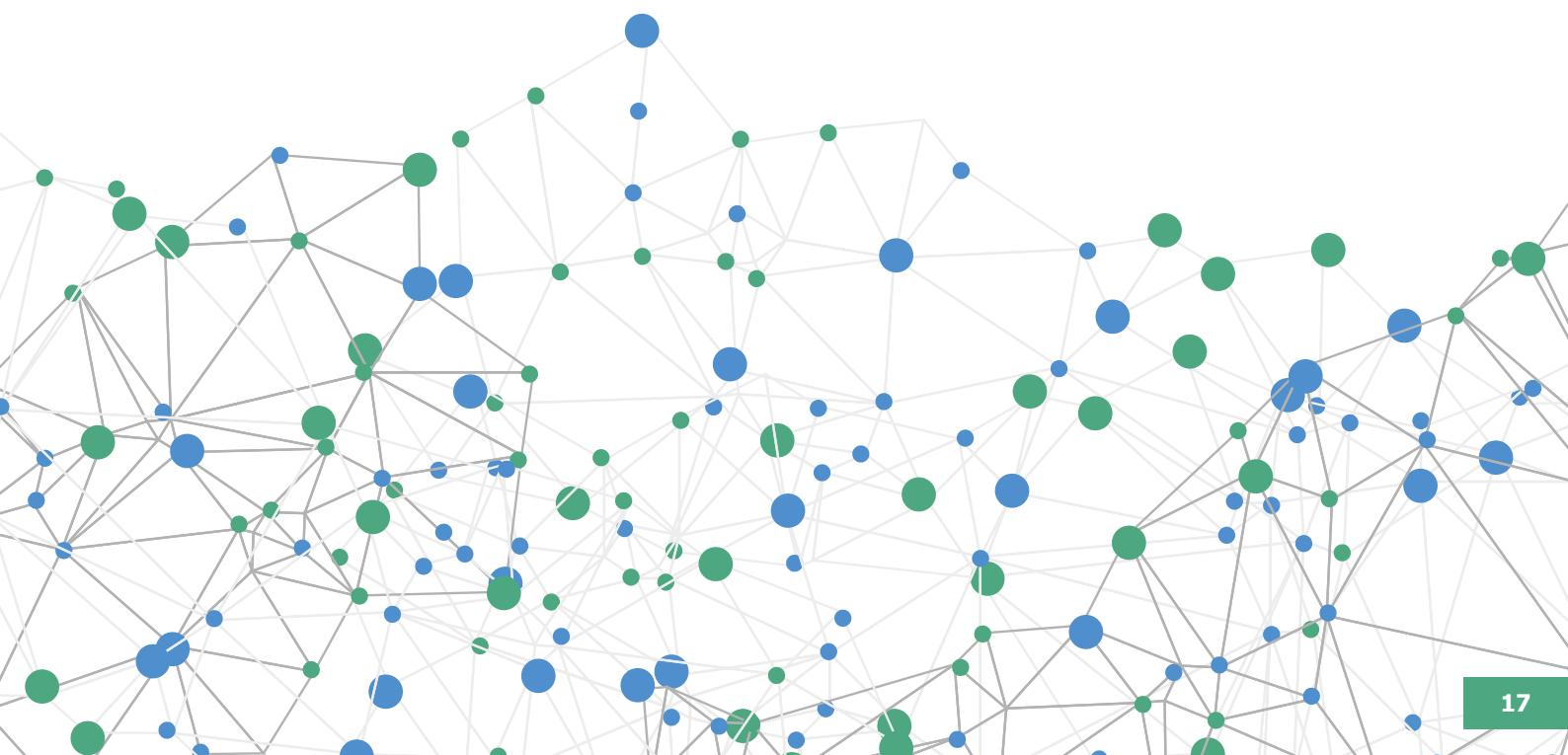
**CHARLIE, MY DAUGHTER** was a very quiet, good little girl, but as she grew up and approached double figures I noticed she became quite withdrawn, and wasn't at all happy. She felt like an outsider, but desperately wanted to be like everyone else. She started to self-harm.

We tried to help her ourselves at first, but knew she needed specialist help. She spent periods in psychiatric units – which was more aimed at containment rather than treatment and the doctors just weren't able to help her in any way. I can see now, that's because they were treating her mental health and ignoring her autism – so no wonder nothing worked.

There was one doctor who was brilliant and managed to get through to her. He saw immediately that her autism was stopping her from getting the help that she needed. He understood, but he had nothing to offer her. Over many years doctors offered completely inappropriate treatments – group talking therapy, for example. For someone who cannot express their feelings, and totally lacks emotional understanding or social skills that was unbearable, and we knew it wouldn't work.

Despite these battles and dark moments Charlie kept her (very literal!) sense of humour. She loved music. Music spoke to her in a way that people didn't. Likewise animals – they loved unconditionally and didn't mind her conforming to social norms and holding a conversation. These two passions led her to become an accomplished drummer and get a BTEC in animal care and management. We were so proud. But the depression and anxiety never went away. At that time she told me that she had been thinking about ending her life since she was thirteen. It was heartbreaking, but came as no surprise, we knew how unhappy she was, but no matter how much love and support and attention we gave, it didn't help. She was at the centre of our family's world, her grandparent's, her sister's, mine. We all rallied so hard for so long.

But in January 2016, aged just 25, she did end her life. She saw no way out other than to kill herself. We were left devastated and completely empty.



## A PICTURE OF CURRENT SERVICES

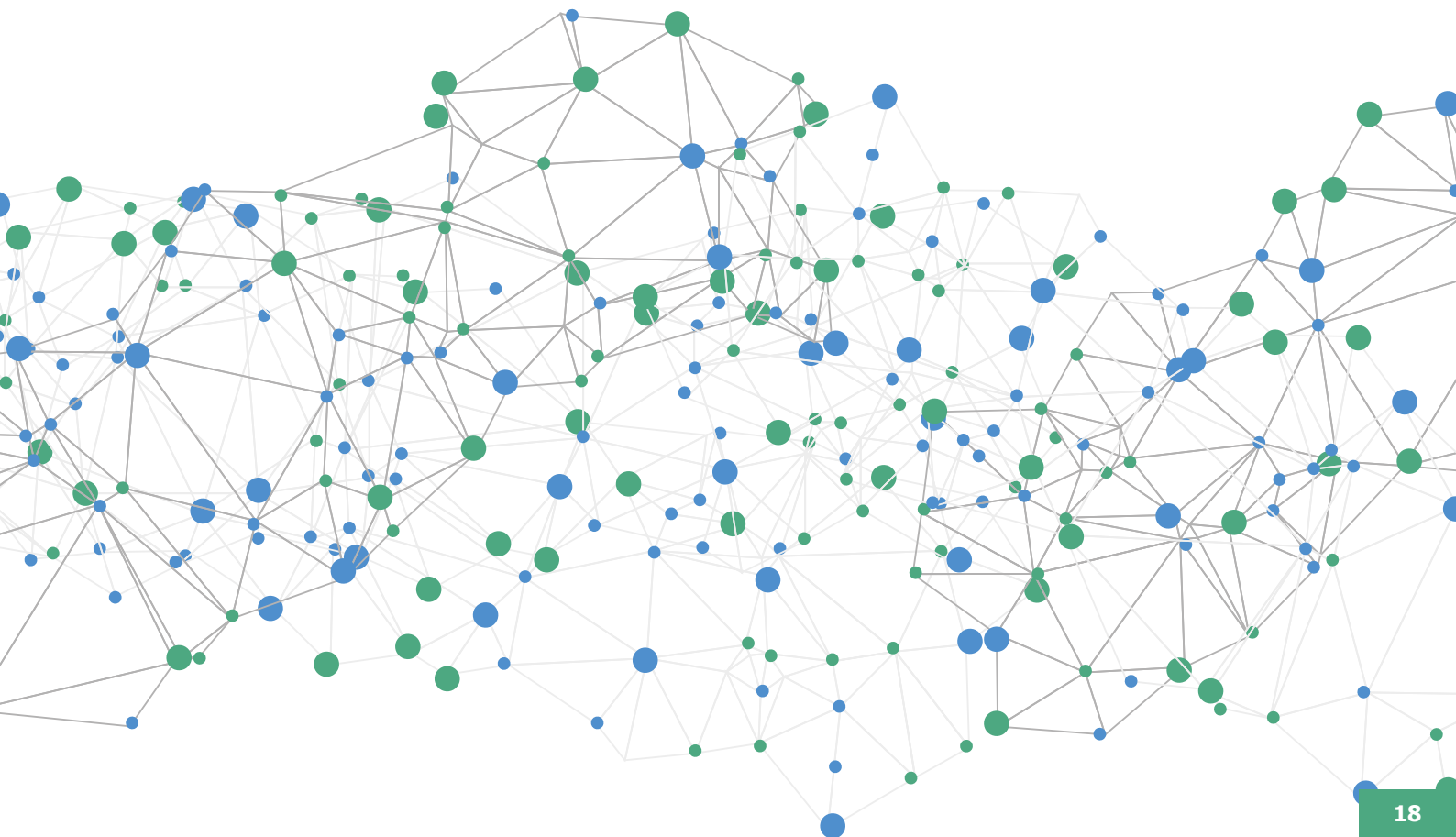


### MW's story

**PATIENT MW WAS DIAGNOSED WITH HUNTINGTON'S DISEASE IN 2008** and as the disease progressed her mixture of symptoms became increasingly complex. Initially, there was regular monitoring in the community from Adult Mental Health, with good communication between this service and MW's neurologist. Re-organisational changes and cost-cutting in 2012 meant that this arrangement was disrupted; MW was discharged from Adult Mental Health without consultation with her neurologist. Following a breakdown in MW's mental health a short time later she was held under section 3 of the Mental Health Act (MHA) in an acute mental health unit for over seven months where she was largely isolated from many of the other health services she was accessing while in the community (neurology, physiotherapy, speech and language, dietician).

Her physical health inevitably declined as a result and eventually MW was transferred to the Royal Hospital for Neuro-Disability, which MW's husband describes as an exemplar of the kind of multi-disciplinary team approach that patients with MW's such complex needs require. Very sadly MW passed away in June 2015 while still a patient of the Royal Hospital for Neuro-Disability. She had not been able to return home in the intervening year following her sectioning under the MHA. MW was 43 years old and a mother to two young children.

Following a complaint by MW's husband, independent investigators have confirmed that detention of MW under section could have been avoided with ongoing monitoring in the community and co-ordination with her neurologist. It was clear at the time of MW's discharge from mental health services that the service had a poor understanding of her condition, believed that it was 'neurological' therefore not mental health, and took the decision in isolation to other services. In addition, findings include that there was also no structure set up to provide an multi-disciplinary team model of care across the mental health trust and the wider NHS.



## A PICTURE OF CURRENT SERVICES

### 2.4 Not enough focus on screening, prevention, or intervention

The estimated balance of care between assessment and intervention for neuropsychology teams in neuroscience centres is on average 75:25.<sup>69</sup> Some of this is through choice as neuroscience centres can link into community services, but it is sometimes through necessity due to lack of resources.

At the other end of the range were a couple of services able to provide a roughly 50:50 balance of care. One neuropsychologist noted: *'We could easily double our service: we could offer outpatient support and therapeutic support in general. There is also a limit to what follow-up we can provide.'*<sup>70</sup> In terms of follow-ups, many services provided these through creative use of existing resources but without official funding. In several cases the research found gaps in neuropsychological input into inpatient rehabilitation in neurosciences centres.

Research by the Division of Neuropsychology also found a particular gap in ability of offer preventative

work with patients. Another neuropsychologist said that, *'If we were able to do more preventative work earlier then adjustment issues could be handled effectively. Working out whether someone has adjustment or cognitive issues correctly is really important. The wrong diagnosis can have a big impact on their life as you may think you are living with cognitive problems when you are not.'*<sup>71</sup> Equally, regular screening of neurology patients for mental health, emotional and cognitive needs does not routinely happen. Many neurological conditions change over time meaning mental health needs can change in parallel. This is particularly true for progressive conditions.

### 2.5 Signposting to information is poor

63% of patients responding to the Neurological Alliance's 2016 Patient Experience survey reported they were dissatisfied with information they had received about sources of emotional support.

This compares to 45% of patients who were unsatisfied with information they received about their neurological condition.<sup>72</sup> This suggests that whilst many patients are signposted to third party information provided by patient groups where they may often find good quality information and advice available, some patients may take time or struggle to access this, particularly sources of information about mental health. As one patient, diagnosed in 2015

commented: *'Before my diagnosis I had never heard of Transverse Myelitis, most of my information was obtained from the internet via my family, and later by myself. I was very scared and had a lot of anxiety. No psychological support was offered.'*<sup>73</sup> This is a missed opportunity given information, along with targeted self-management support, can be an important tool in preventing the emergence or escalation of mental health issues in neurology patients.

### 3.1 Mental health needs should be considered at different stages in the course of a neurological condition

This section provides an overview of what 'good' looks like in terms of meeting the emotional, cognitive and mental health needs of patients with neurological conditions.

#### Onset and diagnosis

For all those affected by neurological conditions, receiving an accurate diagnosis should include being provided with advice and support on how to cope with the potential cognitive, emotional and mental health impact of that diagnosis. How this is provided will vary according to the condition and the level of need. It may range from a full neuropsychological assessment to the provision of good quality information and support. For example, a full assessment may be needed in order to know which form of dementia someone is affected by or where in the brain epilepsy is located and how it is affecting cognitive function. Equally, in sudden onset conditions such as stroke or head injury, there may be additional emotional needs such as aggressive or unrestrained behaviour, or cognitive impacts such as loss of ability to process information. It is important that family and carers are included in the process of diagnosis as they will often have valuable input and information to add on the individual's experience of the condition, they will also play a role in helping communicate the diagnosis.

#### As part of treatment

A psychological or psychiatric assessment is often carried out before brain surgery. The interactions between medication and mental health conditions should also be considered before starting and during treatment.

#### Rehabilitation and ongoing care

Sometimes issues may only emerge over time if someone struggles to adjust to a condition or develops additional symptoms as a condition progresses. Patients may therefore need access to support for emotional, cognitive or mental health needs whether via further assessment and specialist support, integrated rehabilitation, or the provision of good quality information to enable self-management. Normally a member of the wider care team will need to identify this and make an onward referral. This is particularly important in the case of a progressive condition where cognitive changes are highly likely and where coping strategies can be developed. It is also important to acknowledge the need for palliative and end of life psychological care for some individuals with neurological conditions and their families, and this should also be provided within the individual's neurological care pathway. Hospices, particularly those with specialised knowledge of neurological conditions, are well placed to do this, and engagement in early stages of an illness is often beneficial.

Several NICE guidelines for neurological conditions include a recommendation to provide an annual or regular screening for cognitive, emotional or mental health needs. Screening can be carried out by a specialist or practice nurse, GP, member of a community health team or as part of a condition review with a neurologist. However, for the process to work effectively the professionals involved will require training and understanding in how needs which are identified can be met and either how to provide this support directly or how to make the right onward referral and in some cases prescription.

## WHAT DOES 'GOOD' LOOK LIKE?

### 3.2 Psychological support and intervention needs to be integrated with neurological care and support

There is now a wealth of evidence highlighting the importance of coordinated, person-centred care.<sup>74</sup> National Voices' Narrative for Person Centred Coordinated Care includes the need for professionals to communicate with each other, patients only having to tell their story once, and that all of an individual's needs are taken into account.

Similarly, the House of Care provides a framework for implementing person centred care support planning.<sup>75</sup> This is particularly pertinent for neurology patients where care often includes multiple professionals covering community, primary, secondary and tertiary care settings, as illustrated in the diagram on [page 22](#). It therefore follows that support for emotional, cognitive and mental health needs of neurology patients should be provided in the context of a multi-disciplinary framework to enable seamless care for both physical and mental health needs. Given some individuals might be extremely distressed or disabled, this also provides a continuity of care within a service environment which understands their needs.

A care coordinator is essential in this context. The MND Association has taken an active role in ensuring these arrangements are in place for their patient group, as outlined in the text box opposite.

Family and carers might also be involved in therapeutic interventions; research has shown that involving family member in therapeutic work has demonstrated benefits in wellbeing for the affected individual, as well as for the family members/caregivers.<sup>76</sup>

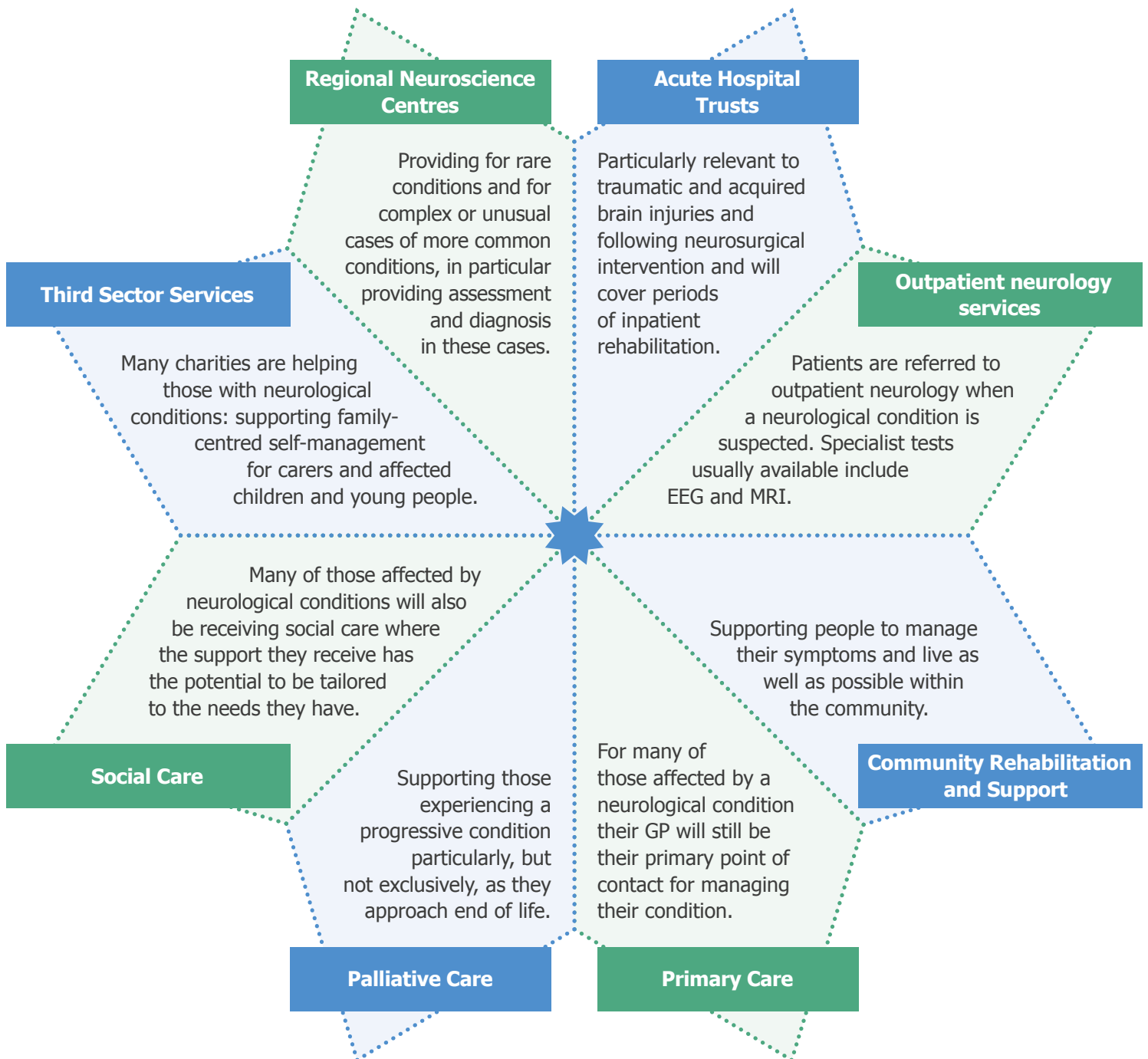


#### MND Association Care Centre and Network Programme

**THE NICE GUIDELINE FOR MND** notes the importance of a multi disciplinary team approach in the management of the condition, with well coordinated care. It does not however make any recommendation about how or who should coordinate that care. The MND Association through its 'care centre and network' programme makes some funding available to regional centres of excellence for the funding of a clinical care coordination role, so that care can be seamless between the speciality neurological team at the services, and between provision in the community, whether through a dedicated multi-disciplinary team or through hospice and palliative care services.

# WHAT DOES 'GOOD' LOOK LIKE?

## The range of services accessed by neurology patients in England



## WHAT DOES 'GOOD' LOOK LIKE?

### 3.3 Delivering parity of esteem for those with neurological conditions requires a distinct approach which goes beyond mental health services

Where a neurological condition does not present too many additional complexities, an adapted or targeted version of community mental health services can be effective in supporting people experiencing depression, anxiety or other mental health issues.

With effective psychological triage within the neuroscience pathway, it can be determined which individuals would be suitable for mental health services (primary care or secondary care) and which individuals would need a specialist psychological intervention to meet the needs of their condition. This approach ensures effective use

of service resources as well as helping individuals to access appropriate services quickly and more conveniently (e.g. closer to home, community services). Where an individual has more complex needs, specific neurological mental health services are required. This includes services provided by neuropsychiatrists and neuropsychologists.



#### Neuropsychiatrists and neuropsychologists

**NEUROPSYCHIATRISTS AND NEUROPSYCHOLOGISTS** specialise in treating psychiatric and psychological issues in patients with neurological presentations.

A neuropsychiatrist is a medical doctor who has trained in the field of psychiatry and has a special interest and training in functional neurological disorders and/or the behaviour and psychological effects of neurological diseases or injury to the brain. Some neuropsychiatrists have additional levels of training in general medicine, often including neurology. As they are medically trained, neuropsychiatrists will approach treatment from a medical point of view and can prescribe and manage medications as well as oversee any other relevant treatment modalities which often include, but are not limited to, psychological therapies.

A neuropsychologist is a psychologist who specialises in the functions of the brain, particularly memory, concentration and problem solving. Their work involves testing and assessing the psychological problems people may experience following an injury or neurological disorder, and helping them in their rehabilitation. Unlike a neuropsychiatrist, a neuropsychologist is not usually a medical doctor. With a background in psychology, a neuropsychologist can help patients to decide whether a psychological approach such as cognitive behavioural therapy may be helpful.

# WHAT DOES 'GOOD' LOOK LIKE?

## 3.3.1 Neuropsychological assessment and interventions

Neuropsychological assessments are an objective way of quantifying and characterising the cognitive, behavioural and emotional effects of the changes in brain function that can occur after damage, or with disease, affecting the brain. A neuropsychological assessment uses a psychosocial model looking both at cognitive and emotional status of a patient sometimes through tests, and also fully exploring their personal and social context which will affect how their condition

affects their daily life. An assessment is not just based on the problems or deficits someone may face, clinical neuropsychologists will also look to identify the strengths of the patients and should involve family and carers in the process. All of this is put together into a 'formulation' and the clinician may also discuss strategies for coping with or compensating for aspects of the condition with the patient and the wider family or carers. The psychological formulation

### **Cognitive and Behavioural Therapies:**

These are the most common psychological therapies in the NHS at the moment. They help individuals to identify, modify or tolerate unhelpful or irrational thinking processes and behaviours. The most common form is Cognitive Behaviour Therapy (CBT), although more contemporary '3rd generation' cognitive therapies such as Acceptance and Commitment Therapy (ACT), and Mindfulness based therapies have emerged (which would seem to be particularly adaptive for individuals with a variety of health related problems). Standard CBT involves looking at how unhelpful thoughts have a negative influence on emotions, physical state and behaviour. The CBT approach aims to help individuals change unhelpful thinking patterns, to reduce emotional, physical and behavioural symptoms of common mental health conditions such as depressions and anxiety. CBT can also directly focus on helping individuals to increase their activity levels.

**Mindfulness therapies:** These aim to help individuals to become more aware of their own personal experiences (e.g. thoughts, feelings, physical sensations, perceptions) and to develop mental skills which can stop us from getting 'caught up' in unhelpful or distressing personal experiences. Unlike CBT, Mindfulness does not aim to change the ways in which we think, but teaches us how to tolerate those psychological experiences which can be distressing. Acceptance and Commitment Therapy (ACT) utilises mindfulness as a key component in helping people to reconnect with forgotten or hidden personal values and to 'disentangle' us from unhelpful psychological and

behavioural patterns. The aim of ACT is to help people live their lives in the most purposeful way possible and develop psychological flexibility. This is usually associated with a greater sense of personal contentment, even if there are ongoing difficulties in people's lives. Mindfulness and ACT approaches would seem to be particularly relevant for individuals with long-term neurological conditions, who have to live with chronic disability and unpredictability of their condition.

**Motivational Interviewing (MI):** This intervention aims to help people develop their motivations to live their lives in a more meaningful way (i.e. by focussing upon personal values and behaviour change). It is an approach which is easily incorporated into other types of therapies (particularly CBT and ACT) and its principles are shared with other types of behaviour therapies.

**Positive psychology:** This refers to approaches which focus more upon an individual's strengths and motivations to help people improve the quality of their lives, rather than focussing upon the symptoms of psychological distress.

**Counselling:** This is a general term for approaches which facilitate conversations with people, to help them explore their thoughts, feelings, motivations and behaviours and to make meaningful changes in their lives. Counselling is often associated with the value of the 'therapeutic relationship' between the therapist and the client, which is contingent upon therapist empathy, respect and non-judgemental attitude.



## WHAT DOES 'GOOD' LOOK LIKE?

will also be used to inform wider care provided by a multidisciplinary team in hospital or the community where it can improve the outcomes achieved.

The assessment itself can be an extremely therapeutic process for the individual and their family as they will be able to explore and discuss the implications of the condition, potential strategies

for coping and process the diagnosis. There are also a range of psychological interventions that may be used to treat people with neurological conditions. The evidence base for effectiveness and efficacy of different psychological therapies comes mostly from research trials within a mental health context, although there is a growing evidence base within physical health specialities.

### 3.3.2 Neuropsychiatric assessment and interventions

A neuropsychiatric assessment is essentially a psychiatric assessment tailored to neurological conditions. It will therefore particularly focus on cognitive, behavioural and physical aspects of the disorder as well as the 'standard' components of a psychiatric assessment that comprehensively covers psychological and social factors. Consequently, it

will often incorporate neuropsychology reports, alongside neurology test results such as imaging and blood tests. As such, neuropsychiatrists are able to bring together and integrate information neurology, psychology and other related disciplines. A neuropsychiatric assessment will also consider the impact of medications (and

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#### K's story

**I'M PRETTY SURE I'VE TRIED EVERY MEDICATION OUT THERE** to help Chronic Migraine, with each medication I began to lose hope. At the beginning of each new drug, I held the belief that it would get rid of my headaches, that I would find a 'cure'. As each drug failed to do so I was in despair. Why me? Why was I the one who had to suffer so much? For a long period of time I was very down, I had lost my spark and enthusiasm for life; all I could think about was a life in pain, with never-ending headaches. I started to close up about my feelings and didn't feel comfortable talking to people about how I was feeling as I did not want to worry them. I was so sad, some days I felt like just giving up, questioning why I should go on if I am to live a life of pain and suffering...

It was then I was luckily referred to a neuropsychologist at Great Ormond Street Hospital. These sessions were a God-send; talking to an objective individual who would not worry like my family and friends. They helped me to find ways of coping in times of darkness, ways of thinking in the present rather than the future – where I had been thinking about things I had no control over. I was advised to write any thoughts or questions I had into a little book. At first I thought this was a silly idea, something only little kids do. But one day I was desperate and just grabbed the nearest notepad and jotted down all my thoughts. I found that little things such as writing my thoughts in a book helped my negative thoughts decrease leaving space to replace them with positive ones.

I found that opening up about my thoughts and feelings helped a lot. I started talking to my close friends, one in particular, which lifted a weight off my shoulder; the thoughts flew away as they left my mouth. Having someone to confide in means so much more than you think, talking to people really does help. I no longer felt alone. I was starting to come to terms with my chronic illness, working out mechanisms to cope with it. Knowing that I am surrounded by people who love and care about me, who want to listen to my problems and do anything they can to help, reassures me that I am not alone. No one can take the pain away from you, but having a strong support system halves the weight you have to carry.

## WHAT DOES 'GOOD' LOOK LIKE?

other treatments, e.g. deep brain stimulation for Parkinson's disease) given for a neurological condition on an individual's cognition, emotion and mental health. Neuropsychiatrists undertake a wide range of work, and some will specialise in particular disorders or areas (e.g. brain injury or functional neurological disorders).

Neuropsychiatrists work across a wide range of locations in both inpatient and outpatient settings within general and psychiatric hospitals. In acute settings they can see cases in A&E and, more

commonly, on inpatient neurology and general medical wards – for example, acute presentations of functional neurological disorders or suspected limbic encephalitis which can often present with complex psychiatric symptoms. The psychiatrist will therefore contribute to assessments of whether the symptoms suggest a primarily psychiatric disorder or a neurological condition. They also provide input into neuro-rehabilitation and psychiatry services for both inpatients and outpatients, for example, to assess and support the behavioural complications that can arise from brain injury.

### 3.3.3 Targeting interventions to individual needs

A range of psychological therapies should be available to address the different psychological and practical needs of different individuals. Some types of therapies might not be appropriate for some individuals, depending upon any neuropsychological difficulties. It is therefore important that individuals receive the right treatment at the right time, which means effective triage and matched care (as recommended in the 2016 National Clinical Guideline for Stroke, for

example). Stepped care is a useful model for offering psychological interventions if it allows open access to all individuals and incorporates an assessment component to identify different therapeutic requirements (although this is arguably matched care, in essence). Clinical neuropsychologists and psychologists will normally tailor and blend therapeutic approaches to meet specific psychological needs of the individual. Group interventions are another option for some individuals.



#### Case study: Royal London Hospital

The Royal London Hospital has developed evidence based group interventions for those with neurological conditions run by clinical neuropsychologists. These cover areas including memory strategies, support for carers, emotional wellbeing, brain injury education, and cognitive strategies. Their aim was to offer families and carers ongoing follow up and intervention, in a service where there were limited staffing resources. The key benefits were to target several patients simultaneously, whilst providing an environment where patients with similar problems are able to seek support from one another.

The groups have been well received by service users who have consistently given positive feedback about the content of the groups, and have welcomed the opportunity to meet other people with similar problems, and benefit from the social and emotional support. Service managers have welcomed the groups as a cost effective means of offering treatment, which has enhanced the service without the need for additional resources.

### 3.4 Information and self-management are important tools in both prevention and management of emotional, cognitive and mental needs of neurology patients

With the right information on the condition and problems people might experience (e.g. cognition, adjustment, managing symptoms), and education and advice on how to manage such issues, depression and anxiety are less likely to emerge.

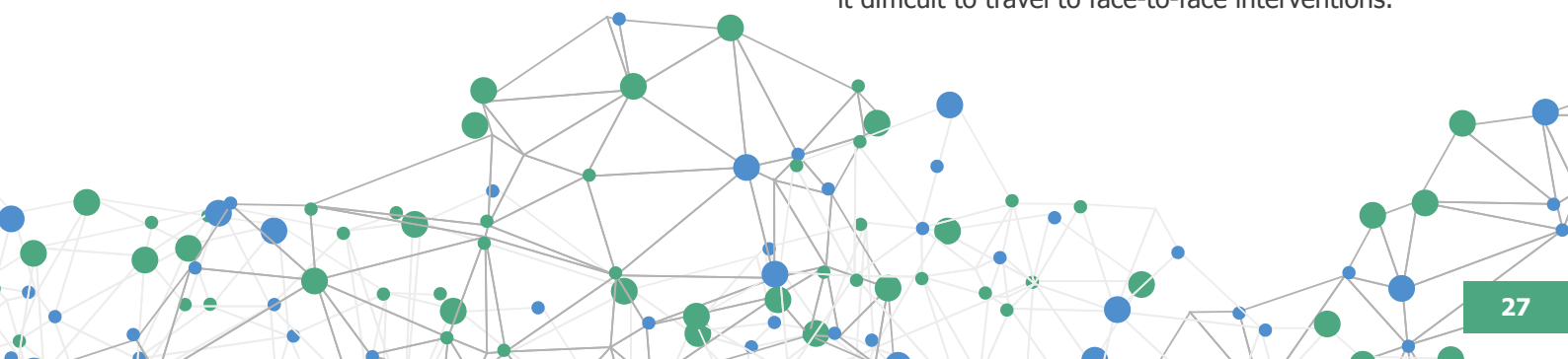
Third sector organisations provide a wealth of information on neurological conditions, including cognitive, emotional and mental health aspects of conditions. It is essential such information is provided at the time of diagnosis but also at later stages to help individuals to adapt to changes. For people with progressive conditions, hospices may also play a role in providing information and advice.

Patient and carer testimony along with reviews by the Health Foundation and National Voices have found that alongside provision of information and screening, both peer support and supported self-management programmes can contribute to improved wellbeing and enhance confidence in self-care, self-efficacy, and levels of activation.<sup>77</sup>

Peer support can be delivered in groups instilling hope and providing informal education about the condition,<sup>78</sup> although a minority described the intervention as not being right for them because 'listening to other people's problems made them feel worse'. Group 'meetings can be open ended or time limited and generally follow a structure provided by a professional or patient support organisation'.<sup>79</sup> Peer support is less costly compared to a professionally led prevention and promotion activity and the voluntary sector is well placed to provide and contribute to the cost of trained volunteer facilitators.

Supported self-management schemes have been commissioned from NHS and third sector providers and the evidence base for what works is increasing. Poor mental health can reduce the motivation and energy needed for self-management, leads to poorer adherence to treatment plans and is associated with unhealthy behaviours such as smoking and alcohol consumption.<sup>80</sup> Harrison et al (2011) found that people with a co-morbid mental health condition can gain particularly large benefits from inclusion in self-management support programmes, suggesting that there should be set targets for referral.<sup>81</sup> Research at Stanford University in the 1990s demonstrated that educating people to manage their own health condition improved outcomes, reduced dependence on services, increased wellbeing and empowered individuals.<sup>82</sup>

The voluntary sector is well placed to facilitate the involvement of people with epilepsy, multiple sclerosis and Parkinson's and other conditions in self-management programmes drawing on both community capacity and clinical expertise. Programmes may include teaching problem-solving, self-management skills, relaxation and physical activities. They are usually backed by self-help materials and tailored to the needs of the condition. Increasingly, supported self-management is becoming a digital offer, which is important as it caters to the needs of people living with mobility issues and other symptoms (e.g. fatigue, pain), which may make it difficult to travel to face-to-face interventions.



## WHAT DOES 'GOOD' LOOK LIKE?



### Epilepsy and You run by Epilepsy Action

**EPILEPSY AND YOU IS AN ONLINE, STRUCTURED SELF-MANAGEMENT PROGRAMME** for adults with epilepsy in the UK. It can be accessed from a computer, tablet or smartphone and takes around two hours a week, over eight weeks, at any time to suit the learner.

The course is full of information, tools, personal stories and activities. These include goal-setting, action-planning, keeping a gratitude journal and contacting other people with epilepsy. Learners are supported to:

- Think about the different ways that epilepsy affects them, both physically, mentally and emotionally
- Learn skills for dealing with issues that arise from living with epilepsy, and take action to use them
- Be more involved in managing and making decisions about their own treatment
- Improve confidence and self-efficacy

Independent evaluation of Epilepsy and You by Coventry University showed that the programme provides 'meaningful benefit and value to people with epilepsy'. In particular, participants reported increased knowledge, skills and confidence (activation) to manage their epilepsy, maintained at least three months after completion. Also, participants reported significant value through reducing their level of social isolation. Feedback on Epilepsy and You clearly demonstrate the benefits in relieving anxiety, and meeting other emotional needs of people with epilepsy.

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*“It’s focused me in a positive way regarding the anxiety side... I can be very positive sometimes but then I let it slip but I think this has made me realise that I need to keep on top of my anxiety and depression week in and week out and it’s just as important as taking tablets.”*

.....

*“It cleared my head and put things in perspective.”*

.....

*“I’m not in contact with other people with epilepsy on a regular basis so it was interesting to read other people’s feelings. Often I keep my feelings to myself. It was a bonus for me to read how other people feel.”*



### Health Coaching Bursary Scheme, Transverse Myelitis Society

**THE TRANSVERSE MYELITIS (TM) SOCIETY HAS SET UP** a health coaching bursary scheme which aims to provide high quality cost effective coaching, mainly over the phone or video conferencing (e.g. Skype) to enable TM Society members, including carers, to find ways to live well with the impact of their or their loved one's condition. The coaches are qualified and include credentialed coaches who have had additional training in working with people with long-term health conditions. TM Society members who access the course pay a nominal rate of £5 per session, and the TM Society pays the difference. A typical coaching package is six sessions. Feedback on health coaching clearly highlights the mental health and emotional benefits for participants:

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*“...I became more self-aware. I began accepting more help from my family and stopped seeing this as a failure on my part. It helped me manage my residual symptoms better, the seasonal adjustments, and medication...Coaching encouraged me to consider where I wanted to be and how I could get there, it enabled me to take back control.”*

.....

*“I am calmer as I don't stress about things that are out of my control.”*

.....

*“As a carer for my Mum, who has TM, we were having some issues with inversion of roles. We had reached a point where we needed help...Coaching helped my mum and I create a new balance within our relationship...”*



### 3.5 A specific pathway for children and young people

To design effective interventions for children with co-morbid neurological and mental health conditions requires specialist paediatric neuropsychiatry and paediatric neuropsychology expertise to be available as part of a multidisciplinary framework.

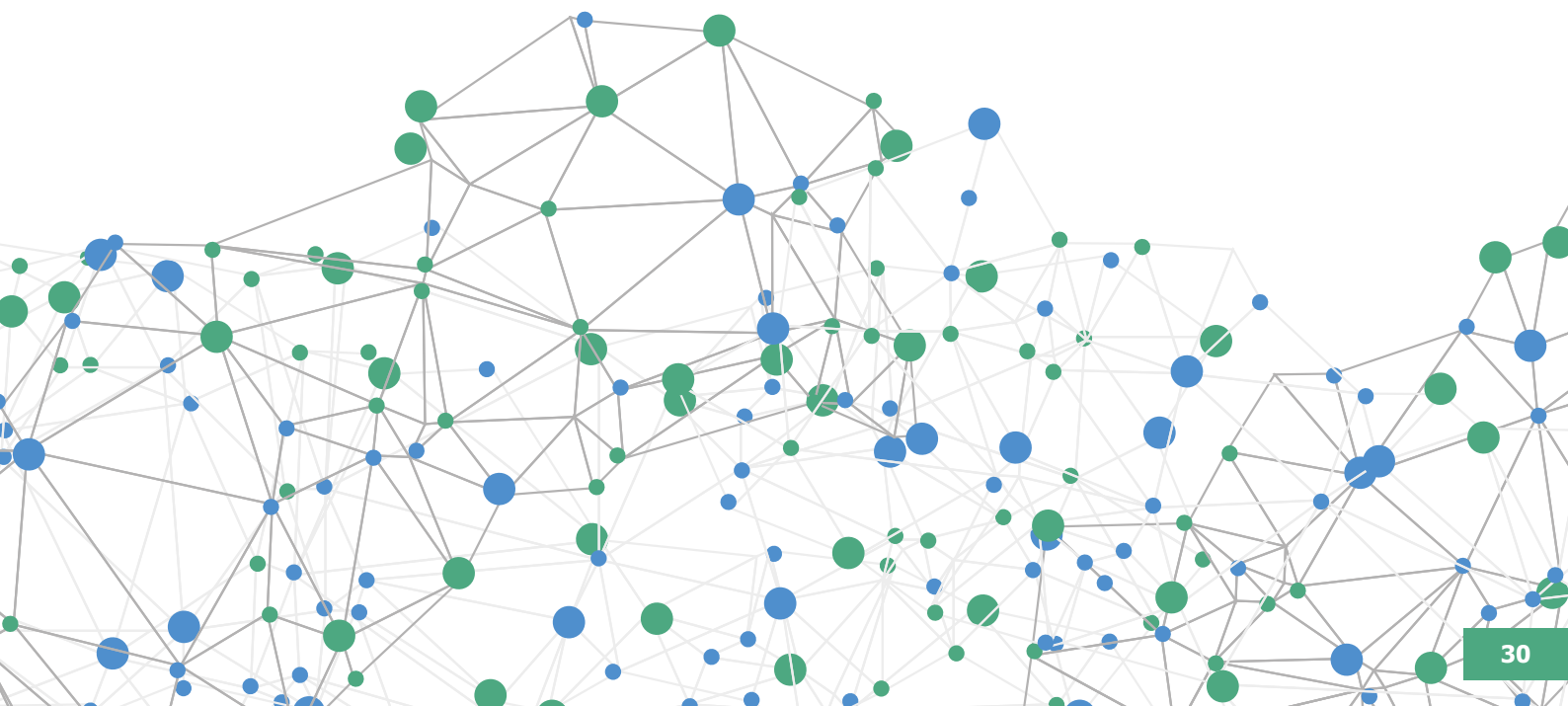
Ideally this expertise should be part of a broader paediatric team to ensure joint working and joint management of patients with psychological, social, neurological, pharmacological, cognitive and emotional challenges. These more specialist services also have a vital role in providing training, expertise and outreach to a wider range of healthcare professionals in regional or local networks across primary and secondary care, as well as to children and families themselves.

Stakeholders and interdependencies may include outreach advice and support to:

- Local secondary care teams especially CAMHS (child and adolescent mental health services)
- Parents/carers in their homes and the CYP themselves at appropriate age
- GPs
- District paediatricians and community paediatricians
- Education services

- Social services – children and young people's teams
- Third sector providers of children's services
- Carer support services
- Therapy services (OT, Physio & SALT), nursing teams in community locally

Therapeutic interventions may be carried out by community teams, who benefit from increased understanding and skill in managing complex children, provided by the specialist team. Equally, when supervised by local services interventions can be provided without the need for burdensome travel for families to regional centres whilst also providing increased skill and support to local teams. Patient organisations also provide invaluable additional information and ongoing support for those caring for children and specialist neuropsychology and neuropsychiatry services support such organisations. Therapeutic inputs may include behavioural support and advice, planning for education and care, and psychopharmacological treatment.



# WHAT DOES 'GOOD' LOOK LIKE?



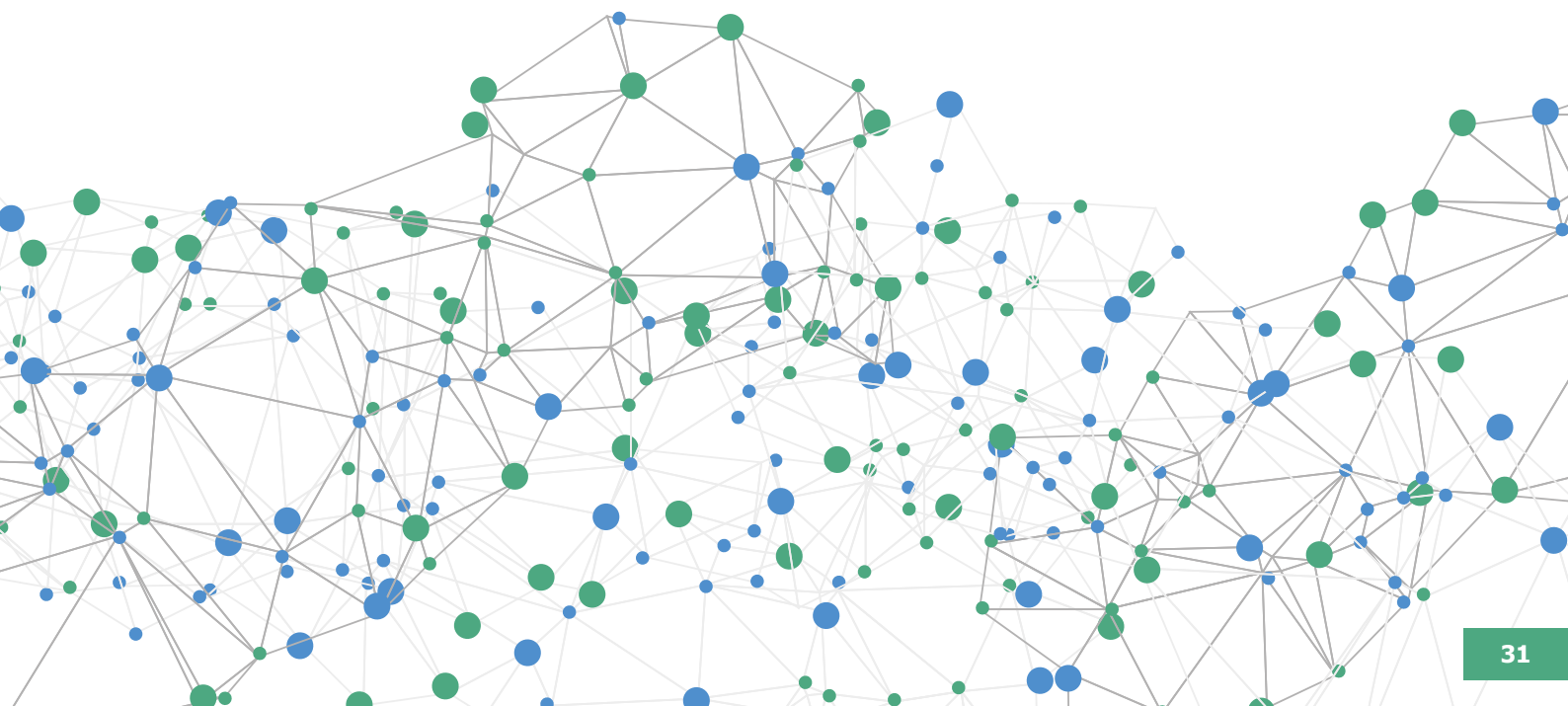
## The Children's Headache Clinic GOSH

**THE CHILDREN'S HEADACHE SERVICE AT GREAT ORMOND STREET HOSPITAL** is run by Dr Prab Parabhakar and his team see over 100 new patients a year.

Referrals, once received from paediatricians and neurologists, are vetted by the Multi Disciplinary Team. Structured questionnaires including headache diaries, RCAD (Revised Childhood Anxiety and Depression Scale), PeDS QL (a measure of quality of life), PedMIDAS (Paediatric Migraine Disability Scale) and Current Concern Questionnaire are sent out. Information on school attendance and social participation is also requested. Information about what to expect in clinic is also given along with pointers to useful resources. It is made clear that a MDT approach involving psychology is offered.

The psychologist offers individual sessions for children with mental health needs. There is a rolling Headache Group for children facilitated by the psychologist which forms part of the Headache Service. The Nurse Specialist and Psychologist also facilitate teleconferences with local teams including paediatrician, psychologist, welfare officers, SENCO, School Teachers to discuss care and way forward. Service audits found that in 3 out of 10 children anxiety/depression co exists with the headache problem. Of these only 1 out of 3 was this picked up and addressed by the referring clinician. In addition, the service has diagnosed young people with High Functioning Autism during the management/screening process – this enabled providing the most appropriate psychological care model.

Following a focus group of parents about the service, the following feedback was reported: 'The team takes a dual pronged approach with both the medical and psychology aspects being equally important. The psychology input was no longer about finding a psychological cause for the headache, but rather recognising the contributing factors and the impact of headache and supporting with dealing with this. This approach allowed young people to be more honest about their feelings, enabling fuller exploration and strategies to help. Having someone to call between appointments was missing from local services. Families expressed feeling isolated and alone between the six month appointments locally, but at GOSH have an easily accessible link for asking questions and accessing support at particularly bad times.'



As [chapters 2](#) and [3](#) highlight, current services are a long way off delivering parity of esteem for neurological conditions. Here we set out a series of recommendations and the practical steps that would support improvement in services and outcomes for neurology patients with emotional, cognitive and mental health needs.

## 4.1 Clarify commissioning responsibilities for neurology and mental health

Meeting the mental health needs of neurology patients requires services and support across the neurosciences pathway – at community, primary, secondary and tertiary care level. This can present challenges and confusion in relation to commissioning of services.

A 2016 study of clinical commissioning groups (CCGs) found widespread disengagement from neurological issues, with some CCGs claiming incorrectly that neurology is exclusively commissioned by NHS England through specialised commissioning. Only 17% of CCGs are able to make an estimate of their spending on neurology services locally, while only 20.5% had made an assessment of the prevalence of neurological conditions in their local area.<sup>83</sup> Commissioner disengagement remains a major obstacle to the delivery of comprehensive and integrated pathways of care for people with neurological conditions. This issue is magnified where emotional, cognitive and mental health needs are concerned.

Often a hub and spoke approach is recommended in NHS strategies for making the link between specialist and local services but in the absence of local services to 'spoke onto' or a lack of time and resource to take on the linking role this can prove difficult. It is clear that different models will be appropriate for different local contexts and CCGs may need to work in clusters to commission for this area effectively. There is no one solution to the issues around where to locate care as these will relate to local services structures and population need. However, we believe there is a need for clearer responsibilities at the different levels in the system to enable effective collaboration on service delivery. It is important that the relationship between specialised commissioning via NHS England and CCG level funding is

clarified, along with the role of STP arrangements and the introduction of co-commissioning.

As well as leading to variation in service provision across the country, a lack of clarity on where services should sit can also affect business cases for service development as cost savings fall across different levels of care complicating the incentives for investing to save. There is little data available on the costs of treating neurology patients with comorbid mental health conditions, compounded by budget lines often being invisible and impact on patient outcomes missing from official data. A related issue is the lack of appropriate tariffs that can be used to cost the assessment and diagnosis, follow up or treatment of the emotional, cognitive and mental health needs of the patient group.

Due to the issues with current structures we have found a need for pump priming to enable testing of services across traditional boundaries to enable patients' needs in this area to be met. One example of where this has been successful is the Dementia Challenge. Another example is the investment made by the MND Society which has seen services developed for people's emotional and mental health needs in partnership with local NHS providers.

We have found that services, where they do exist, tend to have funding which is pieced together from a variety of sources. Many services have developed around individual clinicians who have gradually built them up over time. Often there may be a reliance on



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historic funding arrangements or on pump-priming from third sector sources. In many cases the services and activities in this area will be hidden under broader budget lines such as neurology. There are multiple challenges posed by these arrangements. Where services don't exist it is difficult for them to be developed in the absence of clear commissioning

pathways or a clinician in post who can take an active role in building the case. Conversely, where services do exist they can be vulnerable to changes in staffing as the funding for them may be linked to relationships rather than formal commissioning structures. Overall the current arrangements are not sufficient to ensure parity of esteem for neurology patients.

## What actions are needed to achieve this?

- **NHS England** should allocate some of the funding for mental health and long-term conditions to pump priming new services or demonstrator projects for neurology and mental health.
- **Sustainability and Transformation Partnerships** should consider focussing on neurology and mental health in developing new models of care that integrate across traditional service boundaries, especially in the context of co-commissioning.
- **The National Neuro Advisory Group** should bring together a working group of relevant clinical professionals to develop a guideline on commissioning/service development for emotional, cognitive and mental health needs of neurology patients, including the development of tariff(s).
- **The National Neuro Advisory Group** should champion the integration of the above project into other condition specific pathway design, including linking into mental health commissioning bodies.
- **The Neurosciences Clinical Reference Group** should ensure the redevelopment of the neurosciences specification and neuropsychiatry specification clarifies responsibilities around commissioning for neurological and related mental health services. The new neuropsychiatry specification should be extended to cover neuropsychology and other specialist services to meet the needs of this patient group.
- **Public Health England's Neurology, Mental Health, and Dementia Partnership Board** should commission a joint piece of work between the neurology and mental health intelligence networks to further explore the level of prevalence and costs of providing services to people with comorbid mental health and neurological conditions in order to support commissioners.

## 4.2 Standardise NICE guidance relating to neurological conditions to address emotional, cognitive and mental health needs

Parity of esteem for patients with neurological conditions and their families cuts across traditional service boundaries in the NHS.

Reflecting the complexity of the 'neurological' patient group, providing for their needs does not lie within one service or commissioning area. Patients should all have:

- Access to specialist assessment from a neuro-psychologist or neuropsychiatrist where required.
- Regular screening for emotional, cognitive and mental health needs.
- Good quality information and support tailored to their condition which can enable people to manage their conditions and prevent deterioration.
- Access to therapeutic interventions or treatments which take account of the underlying neurological condition including self-management programmes along with follow-up.

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## What actions are needed to achieve this?

- **National Institute for Health and Care Excellence** should include the above four components of effective care in condition specific NICE guidelines for neurological conditions
- **NIHR and other research funders** should

undertake more research into effective interventions for people with co-morbid neurological conditions and mental health conditions in order to provide a more robust evidence base for inclusion in NICE guidelines.

## 4.3 Invest in specialists and specialist training

Many patients with a neurological condition will not be able to access the specialist support of a neuropsychologist or neuropsychiatrist due to the shortages of these professionals and also inequitable spread across England.

Through initial investment in specialist training to a broader range of professionals, (nurses, charity workers, social care teams and GPs), it is possible to increase the availability and reach of therapeutic interventions beyond specialist provision. There are excellent examples of this model of working (see case studies below from [South Tees Stoke Services and Down to Earth Wales](#)). What is required is investment to release specialist staff to carry out training and provide supervision. There is a dual benefit to this approach. Not only do patients have physical and mental health needs considered in parallel, but training often goes hand in hand with supervision and a clear referral route so that complex cases can be recommended for more specialist support if this is needed. Conversely, services designed

without specialist input or training can risk being inappropriate to patient needs.

Investment is also needed to grow the number of specialist neuropsychologists and neuropsychiatrists across England, in order to address the current variation. In particular, neuropsychologists suffer from a lack of protected status with the Health Care Professionals Council (HCPC). Having protected status means patients can be sure that a professional calling themselves a neuropsychologist is appropriately trained and up to date in order to ensure the highest standards of quality. A lack of recognised training route for neuropsychiatrists is also something that should be addressed in order to increase the numbers going into the profession.

## What actions are needed to achieve this?

- **NHS England** should consider ring fencing a portion of the money promised to provide for mental health in long-term conditions to support an extension to specialist training for professionals working with neurology patients.

- **The Department of Health** should work with the HCPC to review the lack of protected status for neuropsychologists.



# IMPROVING SERVICES AND OUTCOMES FOR PEOPLE AFFECTED BY NEUROLOGICAL CONDITIONS

## Case study: South Tees Stroke Services

**THE STROKE** Neuropsychology Service of the South Tees Hospitals NHS Foundation Trust worked in partnership with the Stroke Association to help the organisation to develop an 'in house' training programme in psychological therapies. The intention was not to train staff to become psychological therapists, but to develop staff knowledge and skills, to allow them to incorporate some basic elements of a range of contemporary and evidence based psychological therapies into their daily work. The two day training workshop was provided to the regional service managers and care coordinators of the Stroke Association. The workshop encompassed Cognitive Behaviour Therapy, Motivational Interviewing, Acceptance and Commitment Therapy (ACT) and Mindfulness. The delegates found ACT and Mindfulness approaches of particular interest as these approaches are relatively 'new generation' cognitive therapies. The Stroke Association adapted the workshop format and content to meet their specific training needs and developed a one day 'in-house' training workshop which is now delivered to all new Stroke Association staff as part of their organisational training. We also encouraged the Stroke Association staff to make contact with their local neuropsychology departments (or psychology services which work into local stroke services) to explore the prospect of supervision, to further enhance the Support Officers' therapeutic skills.

## Case study: Down to Earth Wales

**IN WALES** a unique partnership has been created between neuropsychologists within a Community Brain Injury Department and a local community enterprise 'Down to Earth' who specialise in outdoor and sustainability activities. Together they have co-created 10 week vocational neurorehabilitation projects for people affected by traumatic brain injuries. The courses are run by Down to Earth who specialise in bush craft and sustainable building but staff are trained and supervised in how to work with those affected by brain injury including how to incorporate therapeutic support to the course. A key benefit of the courses is that issues around organising, emotional regulation and self-mentoring which can be difficult to capture in clinical settings (Sohlberg, 1989), can be seen more clearly in real life group sessions (Tranel, 2007) and therefore people could be better treated. The project helps facilitate community integration and is a stepping stone for patients to access their communities independently.

Data collected for the project indicated that attending Down to Earth Neurorehabilitation Project significantly reduced depression and anxiety in people with an acquired brain injury. Wellbeing and quality of life after brain injury was also significantly improved as a consequence of the intervention. (The data is statistically significant with a 99% confidence level in the effect.)

## 4.4 Improve access to information, care planning and coordination of care for neurology patients

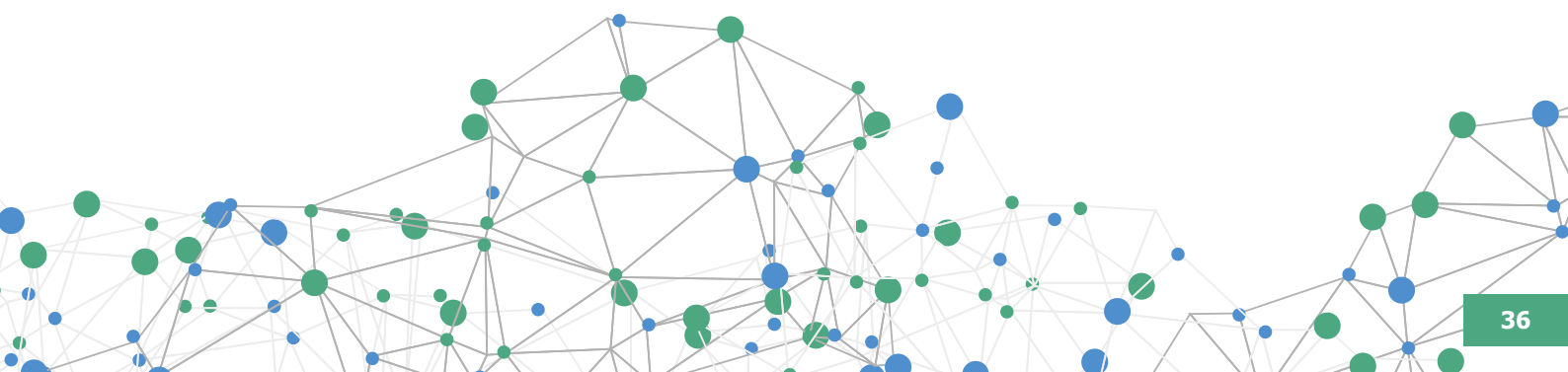
This was a key recommendation in our publication *Falling Short: How has neurology patient experience changed since 2014?* Given the complexity of services for those with neurological conditions and co-morbid emotional, cognitive or mental health needs, care planning and coordination are vital to navigate the complex suite of services that are required.

As we noted in our previous report, the Department of Health no longer includes a commitment to care planning within the NHS Mandate. The Government has noted that support for patients with long-term conditions will instead be measured through indicators such as the NHS Outcomes Framework. It should be noted, however, that neurology is almost entirely unrepresented in such national and local accountability frameworks.

In terms of information and support, patient organisations produce a wealth of information to provide support for specific neurological conditions, but our research suggests that there are barriers to patients accessing such information. Many charities also provide tailored condition specific self-management courses which enable patients to play a more active role in their own health care, including mental health care.

### What actions are needed to achieve this?

- Local NHS trusts and clinicians working in outpatient neurology clinics should work with patient groups to ensure better access to condition specific patient information, particularly at the time of diagnosis.
- The Association of British Neurologists should work with patient organisations to ensure consultant letters regarding diagnosis include signposting to appropriate information and support.
- The National Neuro Advisory Group should play a leading role in championing the use of care planning and coordination for neurology patients.
- Clinicians working in neurology should ensure their patients are fully involved in a process of care and support planning that gives them an annual opportunity to set their goals in dialogue with their named health care professional. This should also include social prescribing which links patients to further information or community support to meet their needs.
- Clinical Commissioning Groups and Sustainability and Transformation Partnerships should consider the value the voluntary sector can add in being commissioned to provide tailored self-management support for people with neurological (and other long-term) conditions.



# IMPROVING SERVICES AND OUTCOMES FOR PEOPLE AFFECTED BY NEUROLOGICAL CONDITIONS

## Conclusion

The right support for the emotional, cognitive and mental health needs of neurology patients can facilitate adjustment to changes resulting from the condition, aid physical rehabilitation and adaptation, restore self-esteem and enable effective condition management. Timely support can also help prevent escalation, avoid critical episodes, maintain wellbeing and support effective self-management. It is therefore critical that appropriate services are available at the right time and in the right place to provide support for mental health needs alongside physical needs of neurology patients.

Currently patients with neurological conditions face a postcode lottery in the services they are able to access with some significant gaps in access to diagnosis, treatment and support for co-morbid mental health conditions. There is often a lack of signposting to appropriate services with patients left to navigate fragmented pathways in order to access the specialist services they need. In terms of local mental health services, we found patients were often denied access to these services due to a mental health condition being considered as part of a physical neurological condition. For patients who are accepted to mental health services, interventions offered are often not appropriate, sometimes with tragic consequences. We also found a lack of preventative services, information and self-management support.

Reflecting the complexity of the neurology patient group, solutions do not lie within one service or commissioning area, rather they require a system wide perspective and approach. The need for this mode of thinking is well recognised with the emergence of Sustainability and Transformation Partnerships which are designed to support integrated commissioning. Parity of esteem for patients with neurological conditions and their

families cuts across traditional service boundaries in the NHS and often needs to be provided in the context of a multi-disciplinary team. Providing an end to end service for people with neurological conditions is not only important for patients, there is a limit to the cost efficiencies that can be unlocked within individual services. Looking to cross cutting areas such as this will be a vital way of releasing funds into the system in the coming years.

The Neurological Alliance will repeat our patient experience survey in 2018 and again ask patients to rate services for their neurological condition and to meet their mental health needs. Between now and when we publish our next survey results, we will work with all parts of the health system to address the issues highlighted in this report and support implementation of the recommendations. For too long mental health has been a hidden area of distinct need within the wider neurology patient group. In turn, neurology patient needs are often lost within the wider long-term conditions agenda. This report has taken the first step in starting a conversation about the mental health, cognitive and emotional needs of neurology patients. In doing so we have taken the first step in making parity of esteem a reality for neurology patients.



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- Professor Adam Zeman, Professor of Cognitive and Behavioural Neurology, University of Exeter
- Chris Naylor, Senior Fellow, King's Fund
- Ben Walters, carer and patient advocate
- Dr Jason Price, Consultant Clinical Neuropsychologist, South Tees Hospitals NHS Foundation Trust (and member of the British Psychological Society's Division of Neuropsychology)
- Anna Mouser, Division of Neuropsychology, British Psychological Association

The insights they shared at the meeting contributed significantly to the development of this report.

## METHODOLOGY AND DATA

The research for this report had three main phases. Firstly, a literature review was undertaken to establish the level of prevalence and need. Members of the steering group shared both data and papers relevant to neurological conditions, which were then reviewed by the Division of Neuropsychology.

The second phase of the work attempted to map the services available to respond to the needs identified. Members of the steering group put out calls to establish the availability of services to their members and both the Division of Neuropsychology and the MND Association carried out more detailed mapping. The Division of Neuropsychology, and its Faculty of Paediatric Neuropsychology, looked in detail at UK neuroscience centres. As this phase did not uncover comprehensive complementary information, members of the steering group were also asked to investigate and document examples of best practice, both in terms of service delivery and effective care.

The report was then drafted, developed and edited by steering group members. The initial findings and proposed structure of the report were discussed at the Neurological Alliance Annual Conference in November 2016 in order to expand and enrich the work of the steering group. A 'call out' was also made across all members of the Neurological Alliance for case studies and patient experiences. Alongside this, the findings from the 2016 Neurological Alliance patient experience survey and other recent research were integrated into the report.



## ABOUT THE NEUROLOGICAL ALLIANCE

We are the collective voice of more than 80 national and regional organisations working together to make life better for the millions of people in England with a neurological condition. We campaign for access to high quality, joined up services and information for every person diagnosed with a neurological condition, from their first symptoms, and throughout their life.

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