

Time to get it right:

A report on the provision of health and social care services for people with neurological conditions in England



palliative,
neurological
and bereavement
support

Foreword

In England, people living with neurological conditions — such as motor neurone disease, Parkinson's disease, multiple sclerosis, Huntington's disease and acquired brain injury — are being sold short. As well as having to deal with a devastating condition that will ultimately affect every area of their lives, the health and care systems that are supposed to be supporting them are letting them down in many ways. According to the last available figures, the NHS spent an estimated £3.3bn on neurological services in 2012-12 (3.5% of total NHS spending). Despite the good intentions and efforts of those working within the health and care systems in England, these systems are not consistently delivering for people that need them.

In August 2018, Sue Ryder commissioned a Freedom of Information (FOI) request to all Local Authorities in England asking about their services for people with neurological conditions. This report sets these findings in the context of other recent research and an earlier FOI conducted by Sue Ryder which was targeted at CCGs. The report makes recommendations to policy makers on how to improve care and support for people with neurological conditions.

We would like to thank all of Sue Ryder's staff and service users who contributed to the report, and Jack Alexander for the work on the FOIs. All mistakes remain the author's own.



Catherine, a resident at the Sue Ryder The Chantry Neurological Care Centre

Living with a neurological condition

Neurological conditions are conditions that result from damage to the brain, spinal column or peripheral nerves. This damage can result in problems with mobility/motor skills, speech, cognition, breathing, swallowing and eating. This can have a drastic effect on people's lives, impacting on people's ability to stay in work, to pursue their hobbies, and to connect with their friends and wider community. These conditions can have a serious effect on people's social and emotional wellbeing

and there is also a wider impact on the family and friends of the person with the condition and the community more broadly. Neurological conditions typically require specialist support due to the intensity and complexity of these symptoms. This specialist support can range from physiotherapy - which can help someone to walk again, manage pain, maintain function or compensate for loss of function - to assistive technology that can help someone with speech difficulties communicate.

Key messages

1. The evidence is conclusive: people with neurological conditions in England are being let down.

Recent research from a variety of sources paint a stark picture of how people with neurological conditions are faring, which our new FOI research supports. Whereas overall mortality rates are improving, those for people with neurological conditions are getting worse.¹ People with neurological conditions have the lowest health-related quality of life of any long-term condition.² In the recent NHS inpatients survey, people with neurological conditions "reported poorer experiences for confidence and trust, respect and dignity, respect for patient-centred values and overall experience of care."³ These alarming statistics are symptomatic of the lack of visibility of people with neurological conditions within the health system and the lack of prioritisation given to them.

When investigating this area, the Public Accounts Committee concluded that "[s]ervices for people with these conditions are not consistently good enough, and there remains wide variation across the country in access, outcomes and patient experience."⁴ Our new research suggests that 15,143 people with neurological conditions have been placed in generalist older people's nursing or care homes across England. These settings lack the specialist expertise needed to address the needs of individuals with neurological conditions, e.g. management of complex symptoms or challenging behaviours.

For people with rarer conditions such as Huntington's disease for example, this can be essential. The changes to behaviour that people with this condition can experience can be challenging and distressing.

Treatment and management is often complex in nature and needs to be carefully monitored and delivered by staff who have the knowledge and experience to do so safely and effectively. For younger people with neurological conditions, generalist older people's nursing or care homes are also socially inappropriate.

Our research also found 515 people in 'out of area' placements in non-neighbouring local authorities – the true figure is likely to be much higher as not all local authorities responded. This means that many people with neurological conditions have to live away from their homes, family and friends. This can contribute to social isolation and can introduce additional strain on family and friends having to travel to visit. The fact that people have to receive care so far away from home is indicative of the highly inconsistent state of provision across the country, and from a commissioning point of view, means a loss of direct oversight of services.

These findings match up with our earlier research which found that people with neurological conditions were receiving different levels of services depending on where they live, with vital services not being provided across large swathes of the country. For instance, specialist nurses were only commissioned in 78% of CCGs, which is very troubling given the important role their ongoing support and advice plays. Specialist day respite care also has an extremely important role to play in promoting carer wellbeing and resilience, yet it is only provided in 19% of CCGs. These figures are indicative of the wider picture across neurological services. At best, they suggest that people have to travel to receive care or a diagnosis, and at worst they suggest worrying levels of unmet need.

1 Public Health England (2018), Deaths associated with neurological conditions in England 2001 to 2014: Data analysis report. https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/683860/Deaths_associated_with_neurological_conditions_data_analysis_report.pdf (Last accessed 18 December 2018).

2 NHS England Website. <https://www.england.nhs.uk/ourwork/clinical-policy/lrc/our-work-on-long-term-conditions/neurological/> (Last accessed 12 November 18).

3 NHS Patient Survey Programme (2018), 2017 Adult Inpatient Survey: Statistical release. https://www.cqc.org.uk/sites/default/files/20180613_ip17_statisticalrelease.pdf (Last accessed 18 December 2018).

4 Public Accounts Committee, (2016) Services to people with neurological conditions: Services to people with neurological conditions: progress review inquiry. <https://publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/502.pdf> (Last accessed 18 December 2018).

2. People with neurological conditions are often 'invisible' to the health and care systems.

The FOI that Sue Ryder commissioned found that a clear majority of local authorities do not routinely record whether someone they are providing services for has a neurological condition, and other research paints a similarly troubling picture when it comes to the health system. An earlier FOI commissioned by Sue Ryder found that only 25% of CCGs were able to provide any data on the number of individuals with a neurological condition in their area, and of these, under half could provide the full data requested.

3. This lack of visibility is mirrored in the lack of prioritisation given to neurological services in the health system and the lack of national leadership.

In 2016, neurology lost its National Clinical Director post, despite the Public Accounts Committee warning that this would lead to a "loss of clinical leadership and accountability".⁵ Although the creation of the NNAG (National Neuro Advisory Group) is welcome and has the promise to drive forwards real improvements, its efforts must be supported and sustained and there is still a substantial lack of prioritisation of neurological services at the highest levels of the NHS. There is also a lack of prioritisation at a regional level, with Sustainability and Transformation Plans – key vehicles for change in the NHS in recent years – largely neglecting this area. About 40% of STPs included no substantive plans for neurological services, and under 20% of STPs contained plans that were rated as 'medium' or 'high' in terms of substantiveness.⁶

4. The new NHS long-term plan represents a missed opportunity to address neurological services.

In January 2019, the long-term plan for the NHS was published. While the document has some content pertaining to a couple of larger neurological conditions that the health system has historically given attention to, it did not set out any plans for neurological care more widely, and does nothing to change the historic neglect of other neurological conditions. This is a critically important missed opportunity. There are a number of broad agendas in the plan that are extremely relevant for neurological conditions, and it is crucial that these are pursued with neurological services in mind.

STPs have been told to work up new plans in the first half of 2019. This represents a crucial opportunity to drive forward meaningful improvements for people with neurological conditions. Given the failure of the NHS long-term plan to engage with neurological services, it is vital that STPs play their part in driving improvements for people with neurological conditions.

This lack of prioritisation in England compares unfavourably to the situation in Scotland, which is currently consulting on a national action plan for neurological conditions,⁷ and Wales, which has had a plan for neurological services since 2017.⁸ It is now time for England to follow suit to make sure the neurological population is no longer left behind.

Right: JJ, a resident in supported living at Fourways (provided by Sue Ryder The Chantry Neurological Care Centre) in a physiotherapy session.

5 Public Accounts Committee (2016), Services to people with neurological conditions: progress review. <https://publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/502.pdf> (Last accessed 18 December 2018).
 6 Neurological Alliance and Sue Ryder (2017), Going the Distance 2: National calls to action to improve neurology services in England. <https://www.neural.org.uk/assets/pdfs/2017-06-going-the-distance-2.pdf> (Last accessed 18 December 2018).
 7 A consultation on the draft National Action Plan on Neurological Conditions (2019-2024). <https://consult.gov.scot/healthcare-quality-and-improvement/neurological-conditions/> (Last accessed 18 December 2018).
 8 Welsh Government (2017) Neurological Conditions Delivery Plan. <https://gov.wales/topics/health/nhswales/plans/neurological/?lang=en> (Last accessed 18 December 2018).

What needs to be done to make things better?

- England needs a **national plan** for neurological health and care services to provide direction and coordination and to work to improve things for people with neurological conditions.
- Individuals with neurological conditions need to be properly monitored and recognised by the health and care systems, and their experiences and outcomes properly captured. This **data** needs to be used to ensure services meet the needs of people with neurological conditions.
- The **Public Accounts Committee** should once again shine a light onto services for people with neurological conditions to see what progress has been made since their last inquiry.
- There needs to be a commitment to **end the practice of people with neurological conditions being placed in generic nursing homes** that do not meet their needs, and being placed in homes that are far away from their families and social networks.
- The forthcoming renewed **Sustainability and Transformation Partnership plans** should set out how improvements will be driven for people with neurological conditions, and NHSE should ensure that proper support is in place to enable them to do this.
- Clear **commissioning guidance** is needed for CCGs so that they are able to commission effectively for people with neurological conditions.
- NHSE should ensure that there is clarity about what neurological services people need and that there is clarity on organisational responsibility regarding who provides services, e.g. in the upcoming review of specialised services, to **ensure no-one falls through the gaps**.
- NHSE should promote a **pathway redesign pathfinder** initiative in an STP area to innovate new ways to deliver services for individuals with neurological conditions.



Results of Local Authority FOI

Background

In August 2018, Sue Ryder commissioned a researcher to conduct a series of FOI requests to 151 Local Authorities in England with social care responsibility (i.e. not lower tier local authorities).⁹ 146 responses were received, which was a 97% response rate. Full responses were received from 69 local authorities, 61 provided partial information, 13 responded claiming that they did not hold the relevant information, 3 refused to respond due to the time/resource that would be involved in responding, 5 failed to respond outright. Final responses were handed over in October 2018.

1. Placements in older people's nursing or care homes

How many residents with one of the neurological conditions in your local authority area are in an older people's nursing or care home?

There were 7,822 individuals across the country with a neurological condition reported in responses to this FOI. If we extrapolate up to account for local authorities that didn't respond, we would expect to see **15,143 people** with neurological conditions in older people's nursing or care homes across England. These settings can lack the specialist expertise needed to address the needs of individuals with neurological conditions, e.g. management of complex symptoms or challenging behaviours. For people with rarer conditions such as Huntington's disease for example, this can be essential. The changes to behaviour that people with this condition can experience can be challenging and distressing. Treatment and management is often complex in nature and needs to be carefully monitored and delivered by staff who have the knowledge and experience to do so safely and effectively. For younger people with neurological conditions, generalist older people's nursing or care homes are also socially inappropriate

There were 1,684 individuals below 65 in these settings reported across the country. Performing a similar extrapolation would lead us to expect that there are 3,260 people aged below 65 with neurological conditions in older people's nursing or care homes across England.¹⁰ As well as the problems with specialist knowledge noted above, these settings can be socially inappropriate for younger individuals.

The fact that this is widespread commissioning practice is extremely troubling, and suggests that person-centred care for people with neurological conditions is not being properly delivered. This is despite the fact that proactive neurological care can save commissioners money, as evidenced in our recent report.¹¹

The respondents not providing data for this question justified this on the basis that they do not hold it in an easily retrievable format or on the basis that they do not hold condition since it is not a legal requirement for them to do so.

⁹ Wandsworth and Richmond are run by the same FOI team so are counted as one entity here.

¹⁰ 78/151 areas responded to this question with a figure (52%). If we assume that the other local authorities responded in the same way, we would expect to see 15,143 people with neurological conditions in older people's nursing or care homes across England.

¹¹ Sue Ryder (2018), Proactive Care for People With Neurological Conditions. <https://www.sueryder.org/sites/default/files/2018-09/Sue-Ryder-The-Case-for-Proactive-Care.pdf> (Last accessed 18 December 2018)

Case study

"From the hospital, he was moved to a nursing home, but they didn't have the right rehabilitation facilities that Dad needed, so he still didn't make much progress in that area."

At Sue Ryder Cuerden Hall Neurological Care Centre we make sure people receive the specialist care they need to optimise their health and wellbeing, maximise their independence and support their emotional and social needs. Danny Gallagher has lived at the centre since January 2018. Here, his daughters Daniella and Gemma describe how he came to be at Cuerden Hall and the positive impact it has had on all their lives.

"It was February 2016 when Dad had the accident. He was only 57 when he fell at work and suffered a compressed skull fracture. It was a catastrophic brain injury and they didn't think he would even survive the air lift to the hospital.

"Dad then spent fifteen months in hospital, but wasn't making any progress with his rehabilitation. He is quite a private man and being on a large and noisy ward made him uncomfortable. From the hospital, he was moved to a nursing home, but they didn't have the right rehabilitation facilities that Dad needed, so he still didn't make much progress in that area.

"We'd known about Sue Ryder Cuerden Hall because our Mum used to be a cleaner there, but at first we didn't know that it would be an option for Dad. Nicola, the Head of Care, helped us navigate everything, which was a big deal for us because up until that point we'd had to work out a lot for ourselves. We wanted to get the right type of care for Dad, to find something in the right setting, somewhere he was comfortable – and that place is definitely here. The first time we came to have a look around, it immediately felt like home. The general aura of the place is comfortable and comforting, especially compared to the hospital and nursing home where they could only do the bare minimum and weren't rehabilitation-focussed. "Every time we see Dad now he is able to do something new, speak more clearly, able to move in a way he wasn't before.

When he first came here the movement on his right side was very limited and one of the biggest things they've done here is to help him to remember half of his body. Generally it is great for us to know that the staff are all rooting for him. The whole environment is so positive. By involving him in general discussions about the centre and actually listening to him, they are allowing Dad some autonomy over his circumstances, which is key when you've had so much of that removed as he has.

"There are activities that Dad can get involved in if he wants to, and because he loves being outside, staff take him out into the park where he has made friends with all of the dog walkers. In his old place they would just park him at the window and that was as close as he'd get to the outside world.

"We both have 3 young children and living here has meant that Dad can be a Grandad again. What's nice about this place is that the little ones are allowed to play as they would if this was Grandad's flat, and that just wasn't an option where he was living before. When we come here, it's like coming to his 'home' and when we have to go we always feel comfortable leaving him here. We never had that feeling with his nursing home.

"Dad is 100% happier living here than where he was before. It is everything that we had hoped for and more. It's just so nice to know that he is now living somewhere residential where he feels that he has a future."



Danny at Sue Ryder Cuerden Hall Neurological Care Centre

2. Local authority service provision

Which of the following does your local authority provide or commission for individuals with neurological conditions?

Service	Total number of LAs reporting providing this for people with neurological conditions
Specialist maintenance or short term rehabilitation for people with neurological conditions	31
Specialist slow stream rehabilitation for people with neurological conditions ('step-up step-down')	22
Post-acute rehabilitation.	26
Community rehab team	32
Assistive technology – daily living	83
Assistive technology – communication	59
Early point of diagnosis wellbeing advice and information	44

Local authorities gave a wide range of answers when asked about the services they provide for individuals with neurological conditions. A substantial number claimed that services would always be provided on the basis of individual need, and therefore that they couldn't answer in general regarding their services for people with neurological conditions. Of those that did specify particular services, the most common were assistive technology for daily living (83) and assistive technology for communication (59), followed by early point of diagnosis wellbeing advice and information (44). Whilst not as common, a variety of rehabilitation services were next most widely reported, and five local authorities reported "supported living" under "Other – please specify".

3. Out of area placements

As of 31/07/18, how many people with one of the neurological conditions specified in this FOI request from your local authority were you paying for to be placed in a residential setting in an "out of area placement" in a non-neighbouring local authority?

Respondents reported 515 people in 'out of area' placements in non-neighbouring local authorities.¹² As under half (68/151=45%) of Local Authorities reported totals for this figure, the true figure is likely to be much higher.

This means that a large number of individuals with neurological conditions are not just travelling far from home to receive a one-off appointment, but they are also having to live far away from friends, family and the area they were familiar with. This can contribute to social isolation, introduce additional strain on family and friends having to travel to visit, and speaks to a lack of appropriate provision across the country for individuals with neurological conditions. From a commissioning point of view, this type of placement also means a loss of direct oversight of services.



Simon, a resident at Sue Ryder
The Chantry Neurological Care Centre.

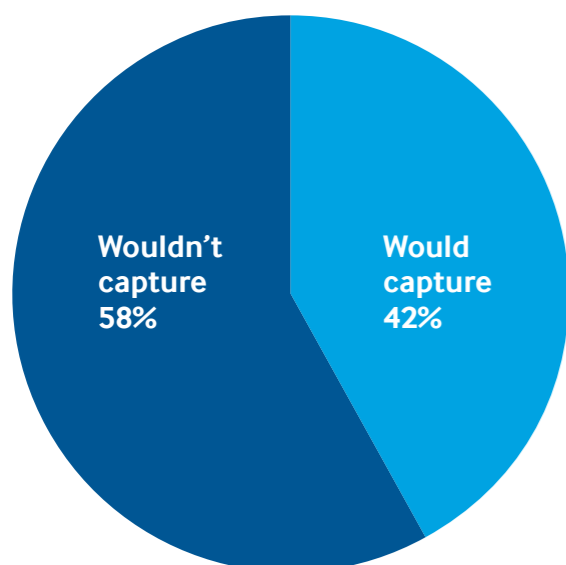
¹² 68 respondents reported 'grand totals'.

4. Data categorisation

What is the primary data category that your local authority would use to categorise/record an individual with a neurological condition (e.g. when administering services)? (Please select one)

Large numbers of individuals with neurological conditions are left effectively 'invisible' to local authorities. This is because they often don't get recorded as someone with a neurological condition by the local authority, but are instead 'counted' under a more general label – for instance being recorded as someone who has a disability.

Just under half of respondents (49/116=42%) reported that they would capture someone either under a specific category for their neurological condition or under a generic neurological condition data category. Of these, some reported that they would record some conditions specifically, but for other neurological conditions they would record someone under a generic neurological conditions label. A number of areas reported specific neurological conditions for each of the conditions listed in the FOI other than Huntington's disease, which often got picked up under a generic neurological conditions label.



The other respondents said that they recorded people with neurological condition/s according to the primary support need (many specified that they felt this would be 'disability' for people with a neurological condition). The Equalities and Classifications Framework (EQCL) was the standard here. Some areas reported that sometimes it might be captured in someone's patient record that they had a neurological condition, but that this could not be guaranteed as it was not a statutory requirement.

A person with a neurological condition has distinct needs that are not captured in a generic functional category. For example, in many cases categorising them simply as part of 'the population of physically disabled people' is not adequate. If individuals with neurological conditions only appear in the minds of commissioners as part of these wider populations, it amounts to them 'getting lost' – and their specific needs along with them.

While it may seem acceptable in terms of the day-to-day running of services for Local Authorities to not know how many individuals in their area have a neurological condition, it is not acceptable for them to lack this data when it comes to making more strategic commissioning decisions for this population or to reflecting on how well services are meeting their needs. Without prevalence data, Local Authorities are either 'flying blind' when it comes to looking at these issues, or failing to look at them altogether. It is hard to imagine how this approach to commissioning could provide services that meet people's needs or achieve good value for money for taxpayers. Unfortunately, as we will see below, a similar story holds for CCGs.

Results of CCG FOI

Background

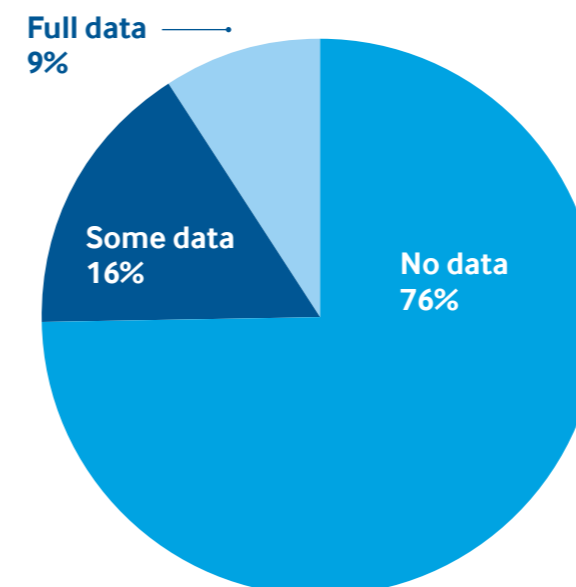
In February 2017, Request Initiative conducted a series of Freedom of Information requests to all CCGs in England. The overall response rate was 208/209 (99.5%) Final results were handed over to Sue Ryder in May 2017. This FOI asked questions about how CCGs were approaching the commissioning and provision of services for people with neurological conditions. Although the data are older, it helps triangulate the FOI of Local Authorities.

1. CCGs data on prevalence of neurological conditions

How many residents in your CCG area have one of the following neurological conditions?

No data	74% (152)
Some data	16% (33)
Full data	9% (19)

204 Responses

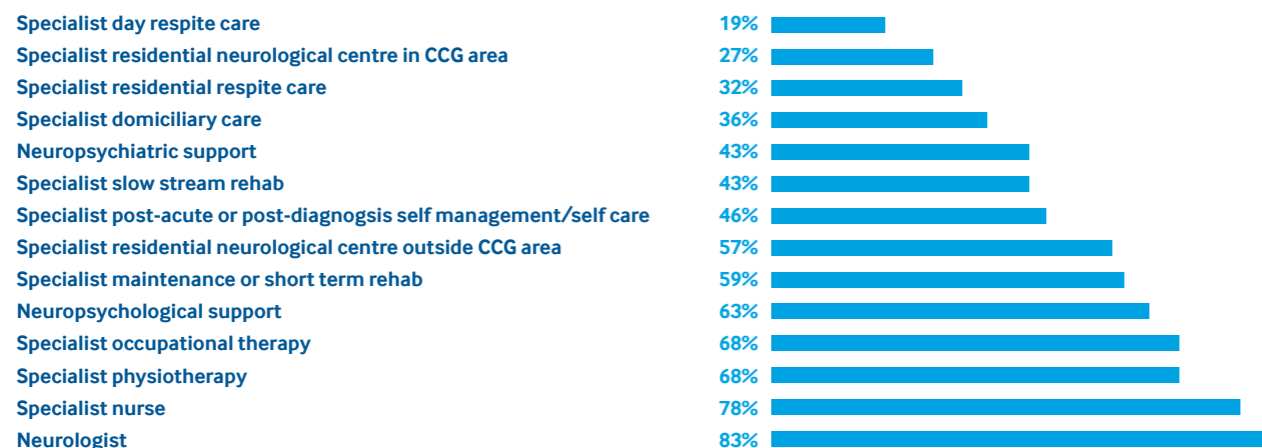


Most commissioners did not know how many people in their area have a neurological condition. This was a clear finding from the research, with only 25% of CCGs answering our FOI request being able to provide any data on the number of individuals with a neurological condition in their area. Of these, fewer than half could provide the full data requested. This means that most CCGs did not have the most basic information they need to understand what local neurological needs are or how to address them. This leads to a similar set of problems to those set out in the section above on local authorities lacking data on individuals with neurological conditions. CCGs that did not provide data either said that they were unable to do so because this data was held by another organisation (such as a GP, trust or providers), or they reported that they held data in a format that would be too cumbersome to analyse in a timely manner, or they stated that they used block contracts to run their services and would therefore not have specific data on individuals. As discussed above, lacking a picture of the prevalence of neurological conditions in their area means they are unable to think more strategically about the services they are providing for this group of people, and are in danger of overlooking them altogether.

2. Service provision by CCGs

What services are provided/commissioned by the CCG?

% of responding CCGs commissioning each service



157 responses. Percentages given are % of CCGs responding. (It should be borne in mind that the FOI results only tell us whether a CCG is commissioning a service, it does not give any insight into the level of service provision or quality.)

Vital services for people with neurological conditions are simply not provided across large swathes of the country. Neurologists were only commissioned in 83% of CCGs, which is especially concerning given their essential role for individuals with neurological conditions.¹³ Similarly, specialist nurses were only commissioned in 78% of CCGs, which is extremely troubling given the important role their ongoing support and advice plays. Specialist day respite care also has an extremely important role to play in promoting carer wellbeing and resilience, yet it is only provided in 19% of CCGs.

This picture is replicated across the gamut of services that individuals with neurological conditions need – many CCGs simply aren't paying for these services at all, despite national clinical guidelines making very clear the importance of a range of

specialist support.¹⁴ At best, this suggests that people have to travel to receive care or a diagnosis, and at worst it suggests worrying levels of unmet need across the country. Taken as a whole, these FOI results show significant variation in provision of some of the core services that individuals with neurological conditions need to be able to access routinely to maintain their quality of life.

Other recent reports echo these findings. The Association of British Neurologists found that the likelihood of a patient with a neurological condition being seen by a neurologist varies significantly across the country, and noted that there was a "wide variation of access to specialist services for patients presenting with acute neurological disorders."¹⁵ That report noted that differing approaches to service commissioning and provision in different areas of the country have led to "significant inequity of service provision."

13 For instance, the involvement of a neurologist leads to a change in diagnosis and management in up to 79% of patients. See Ali, E., Chaila, E., Hutchinson, M. and Tubridy, N. (2010), The hidden work of a hospital neurologist: 1000 consults later. *European Journal of Neurology*.

14 See, for instance, National Institute for Health and Care Excellence (2016) Motor neurone disease: assessment and management. NICE guideline (NG42) (<https://www.nice.org.uk/guidance/ng42>, last accessed 18 December 2018), particularly section 1.5, and National Institute for Health and Care Excellence (2014) Multiple sclerosis in adults: management, Clinical guideline (CG186) (www.nice.org.uk/guidance/cg186, last accessed 18 December 2018), particularly section 1.3.

15 Association of British Neurologists, (2017), Acute Neurology services survey 2017. <https://www.theabn.org/media/Documents/Acute%20Neurology/ABN%20acute%20neurology%20survey%20final%2013%20March%202017.pdf> (Last accessed 18 December 2018).

Specialised commissioning

As well as the services commissioned by CCGs, services for individuals with neurological conditions are also sometimes commissioned centrally by the NHS via a process known as specialised commissioning. This process is intended to "support people with a range of rare and complex conditions",¹⁶ and the services are provided in a relatively limited number of areas.¹⁷ For most conditions, "specialised services only form a part of a patient's care and treatment pathway."¹⁸

Clear, publicly available data is not available on the provision of specialised services for people with neurological conditions. A partial picture can be obtained by looking at the distribution of neuroscience centres (of which there are 28 across the country) and neurology centres (of which there are 21 across the country).¹⁹

These centres are largely concentrated in London and in a number of other urban areas.²⁰ According to figures from the National Audit Office (NAO), 4 per cent of the total specialised commissioning spend is spent on neuroscience and 3.8 per cent on adult neurosurgery.²¹

As the Public Accounts Committee have noted, the division of responsibilities between the CCGs and NHSE has not been clear for some neurological services. In their recent investigation, they warned that "for neurology, what constitutes specialised services has not been clear and this has caused confusion over who should be commissioning which services. CCGs have tended not to engage effectively with neurological services as they believe responsibility for these services rests with NHS England."²² They concluded that "[f]or some patients this division has impacted on the continuity of care, and in some cases access to services."²³ There is work currently beginning at NHSE to look at specialised commissioning in this area, which is an extremely important opportunity to tackle some of these issues.

16 <https://www.england.nhs.uk/commissioning/spec-services/> (Last accessed 18 December 2018).

17 House of Commons Library (2017), NHS Commissioning of Specialised Services. <http://researchbriefings.parliament.uk/ResearchBriefing/Summary/CBP-7970> (Last accessed 18 December 2018).

18 Public Accounts Committee (2016), NHS specialised services. <https://publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/387/387.pdf> (Last accessed 18 December 2018).

19 Association of British Neurologists, Acute Neurology services survey (2017). <https://www.theabn.org/media/Documents/Acute%20Neurology/ABN%20acute%20neurology%20survey%20final%2013%20March%202017.pdf> (Last accessed 18 December 2018).

20 These are mapped online by the Brain and Spine Foundation. <https://www.brainandspine.org.uk/neurological-centres-in-the-uk> (Last accessed 18 December 2018).

21 National Audit Office (2016), The commissioning of specialised services in the NHS. <https://www.nao.org.uk/wp-content/uploads/2016/04/The-commissioning-of-specialised-services-in-the-NHS.pdf> (Last accessed 18 December 2018).

22 Public Accounts Committee, (2016), Services to people with neurological conditions. <https://publications.parliament.uk/pa/cm201516/cmselect/cmpubacc/502/502.pdf> (Last accessed 18 December 2018).

23 Public Accounts Committee (2016), NHS specialised services. <https://publications.parliament.uk/pa/cm201617/cmselect/cmpubacc/387/387.pdf> (Last accessed 18 December 2018).

Conclusion

Despite the best intentions and efforts of those working within the health and care systems in England, these systems are not delivering for people with neurological conditions. There is a lack of national prioritisation on neurological care, a lack of clarity over the division of responsibility for services and an absence of even the most fundamental data that would shine a light on the needs of this population. The result is that people with neurological conditions are being let down, receiving patchy access to services, missing out on the overall trend of improving mortality rates and having the lowest health-related quality of life of any long-term condition.

Our research has highlighted a number of worrying commissioning practices, such as people with neurological conditions being placed in generic older people's homes, and has also painted a picture of high levels of variation in service provision across the country.

Commissioners need additional support and encouragement to engage with neurological services and there is an urgent need for vigorous national leadership. Scotland and Wales have shown what is possible here – it is now time for England to follow their example with a national plan for improving neurological services. We cannot expect a step change in outcomes in this area without a step change in emphasis. If people with neurological conditions are finally going to get the support they deserve, the system needs to step up and commit to making this happen.

Pip, a resident at Sue Ryder The Chantry Neurological Care Centre in an art session.



Sue Ryder supports people through the most difficult times of their lives. For over 65 years our doctors, nurses and carers have given people the compassion and expert care they need to help them live the best life they possibly can.

We take the time to understand what's important to people and give them choice and control over their care. This might be providing care for someone at the end of their life, in our hospices or at home. Or helping someone manage their grief when they've lost a loved one. Or providing specialist care, rehabilitation or support to someone with a neurological condition.

We want to provide more care for more people when it really matters. We see a future where our palliative and neurological care reaches more communities; where we can help more people begin to cope with bereavement; and where everyone can access the quality of care they deserve.

For more information about Sue Ryder

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