Sue Ryder

The forgotten millions
Social care for people living with neurological conditions

A blueprint for reform

Foreword

Sue Ryder has provided services for people with neurological conditions for nearly 60 years. The people you will see in our centres live with extremely complex and challenging conditions and needs. They will often need support for many years.

By the time our service users reach us they have often grown tired of fighting the system for the care they deserve. We see individuals flourish when given the opportunity to receive services that help them to manage their condition and its progression, not just their needs on any given day. This approach helps us to plan for the future and to help the people who use our services achieve what they want to. This is why we believe services tailored specifically to people with neurological conditions are so important.

One size doesn't fit all when it comes to service delivery. Residential care for a 23 year old with a brain injury shouldn't look the same as residential care for an 85 year old who is frail and needs support. And yet we do not see enough provision of services specifically for people with neurological conditions, who may be from younger generations than others with care needs.

The government's focus on dementia in recent years is to be commended. However, dementia is not the only neurological condition; often those such as multiple sclerosis, Huntington's and motor neurone disease get overlooked. We would like to encourage a more holistic approach to services for people living with neurological conditions.

This starts with something so basic: knowing that they exist. The findings of this report – that only 5% of local authorities are able to tell us about all of those living with neurological conditions in their area – are stark. The past year has seen the publication of a critical report from the National Audit Office and the Public Accounts Committee has stated that health and social care services are 'failing to provide an integrated range of services for people with neurological conditions'. Now is not the time to just examine the record. It is time to change it.

We hope that some of the problems and solutions set out in this report will have resonance with local authorities. They must seize this opportunity to work with charities such as Sue Ryder to ensure that people living with neurological conditions are not forgotten.

Paul Woodward
CEO Sue Ryder

Executive summary

Sue Ryder, the UK's leading provider of health and social care services for people living with incurable illnesses, has undertaken in-depth research into the strengths and weaknesses of local authority care provision for people living with neurological conditions in England today. Sue Ryder issued Freedom of Information (FOI) requests to local authorities, asking five questions:

1. Does the local authority have an agreed local commissioning strategy for people with neurological conditions?

2. How many individuals with neurological conditions do you provide social care services for? What proportion of your population does this represent?

3. Do you collect detailed data which categorises the specific neurological conditions?

4. Do you have an agreed strategy for assessing and commissioning the range of services required by an individual with a neurological condition and complex needs?

5. What services are available within your local authority to a person with a neurological condition and complex physical needs?

The results are alarming. Only 10% of responding authorities (131 in total) have an agreed strategy. A significant proportion of these are generic long term conditions strategies rather than neurology specific. Just 5% know exactly how many individuals with any neurological condition they care for, while only 6% categorise specific conditions.

This report is calling for specific actions to be undertaken to support improved care for people living with dramatically life-changing neurological conditions such as motor neurone disease or multiple sclerosis.

Strong leadership

- There should be greater leadership for neurology at a national level. In addition, the NHS Commissioning Board should develop an integrated strategy for people with neurological conditions.
- Health and Wellbeing Boards should ensure that a section of their Joint Health and Wellbeing Strategy is devoted to scoping services specifically for people with neurological conditions.

Robust data collection

- Local authorities should collect and record information about an individual's condition when they are conducting assessments.
- Local authorities should amalgamate this data to produce detailed condition-specific data about the number of people with neurological conditions for whom they provide services in their area. This should be collated with information collected by the local health services and made available in the Joint Strategic Needs Assessment.
- This data, alongside other information about local demographics, should be used to develop the Health and Wellbeing Boards' Joint Health and Wellbeing Strategy, local authority's Market Position Statement and Clinical Commissioning Groups' commissioning plans.

End the postcode lottery

- The government must ensure that the draft Care and Support Bill enshrines not only consistency in assessment for those in need of social care, but also consistency in approach to allocating resources and services.
- We would like to work with the government to devise a care calculator for people living with neurological conditions.

Recognised standards

- There must be improved choice for those living with neurological conditions over the services they receive. These should cater for their diagnosis and needs in order to help people to create a personalised care plan.
- Local authorities should be expected to provide transparent, accessible information and advice, and should be held to account by a 'kitemark' scheme in addition to, or as an extension of the Information Standard.
- Information services should be provided in an integrated way, by working with health services, and where possible including the broadest range of information.

Who cares? The neurological health and care landscape

What are neurological conditions?

Neurological conditions are caused by the physical deterioration of the nervous system that affects movement and brain function. Some can be life-threatening, while many others cause lifelong disability. The term can apply to congenital diseases as well as acquired conditions resulting from damage to the brain, spinal column or peripheral nerves. These conditions fit broadly into the following four groups:

- **Sudden-onset: for example, an acquired brain injury or spinal cord injury resulting from an accident**
- **Intermittent and unpredictable: for example, epilepsy, types of headache or early multiple sclerosis (MS)**
- **Progressive: for example, motor neurone disease (MND), Parkinson's disease or later stage MS and dementia**
- **Stable: for example, post-polio syndrome or cerebral palsy in adults.[1]**

A complex picture

The onset of a neurological condition can happen to anyone at any time. The last extensive audit of people living with neurological conditions in the UK was carried out in 2003[2] and since then numbers have grown across neurological conditions, in particular dementia. The number of people living with neurological conditions is set to increase over time. The complexity of the neurological conditions we see will also increase as people live for longer, sometimes with more than one long term condition.

We know that 6 out of 10 people living with dementia have not been diagnosed.[3] We know that the numbers of people living with this condition alone are set to rise enormously – by 2021 there will be one million people living in the UK with dementia.[4]

Though dated, the 2003 audit showed that there were 10 million people in the UK living with a neurological condition that had an impact on their lives. Of this 10 million, more than one million were disabled by their neurological condition.[5]

People with neurological conditions have complex care requirements. Many of them need a truly integrated approach to their care provision and will utilise services from health, social care, housing, transport and welfare. In many circumstances, family members will be acting as carers and also require support. In addition, with a hereditary condition like Huntington's disease, the strain on the family should not be underestimated.

The scale of services or 'web of care' required by an individual living with a neurological condition such as MND can be seen in the diagram on the opposite page. It is confusing to look at, and even more complicated to live through.

Those living with neurological conditions will often require complex state support for many years, as some conditions, such as brain injury, can strike at any time without affecting life expectancy. Others, such as MS, tend to first affect people in their 30s, while dementia is far more common amongst those who are 65 or over.

Access to the right services at the right time is critical. Future planning is therefore extremely important. A condition such as MND tends to be rapid in progression, meaning that there is more need for an individual to plan for the future and be aware of the services they might need. MS can be fluctuating which means services need to be scaled up and down according to an individual's needs.

As a result of the very specific issues facing those with neurological conditions, their care is predictably expensive.

Testament to this is the fact that, between 2006 and 2010, health spending on people with neurological conditions increased by 38%, compared to the 20% increase in spending seen across the NHS as a whole.[6]
The National Audit Office report demonstrated that there are no national figures for social services spending as it is defined by disability and need rather than condition. Social services spending on adults with a physical disability (where neurological conditions are most likely to be classified) remained flat since 2005–06.[7] The report also revealed that £2.4 billion is the estimate of adult social services spending on people with neurological conditions in 2009–10 based on an estimate (25%) of the proportion of adults with a physical disability that have a neurological condition.[8]

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[1] National Audit Office, *Services for People with Neurological Conditions*, December 2011, p. 5.

[2] The Neurological Alliance, *Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition*, April 2003.

[3] Department of Health, November 2011.

[4] The Alzheimer's Society via: http://alzheimers.org.uk/site/scripts/documents_info.php?documentID=341.

[5] The Neurological Alliance, *Neuro Numbers: a brief review of the numbers of people in the UK with a neurological condition*, April 2003.

[6] National Audit Office, *Services for People with Neurological Conditions*, December 2011, p6.

[7] National Audit Office, *Services for People with Neurological Conditions*, December 2011, p.18.

[8] National Audit Office, *Services for People with Neurological Conditions*, December 2011, p. 4.

Motor neurone disease
What services will I need?

Recreational therapy

Motor Neurone Disease Association regional care adviser

Neurological specific care agencies

Specialist residential care

Specialist respite

Complementary therapy

Counselling

Care services

Day hospice

Hospice care

Respite care

Information, advice and advocacy support

Wheelchair service

Voluntary sector services

Care agencies

Home adaptations and equipment

Family carer

MND co-ordinator

Social worker

Housing advice

Day opportunities

Specialist day opportunities

MND Connect

Paid carer

Welfare rights adviser

Hospice at home

Disability employment adviser

Residential care

Motor Neurone Disease Association care centre

Fall prevention service

Personal budget

Family carer support

Social services occupational therapist

Speech and language therapist

Community matron

Neurologist

Community and outpatient dietician

Neurological rehabilitation physiotherapist

Respiratory physiotherapist

GP

MND specialist nurse

Orthotics

District nurses

General hospital inpatient and outpatient

Continence adviser

Palliative care consultant

Continuing healthcare service

Clinical psychologist

Neurological rehabilitation occupational therapist

Health services

MND specific consultant

Who cares? The present neurological health and care landscape

Sue Ryder provides a range of services for people with neurological care needs; from residential and nursing care for those living with any long-term neurological condition, to day services that are condition-specific. A neurology-specific approach is the best way to meet their needs and provide them with a service likely to improve their quality of life. Consistent availability and provision of services such as those offered by Sue Ryder is therefore critical to providing the right care.

What are neurological specific services?

Sue Ryder, Dee View Court

Dee View Court is a purpose-built residential care centre designed to meet the needs of adults between 22 and 70 years old, living with long term and progressive neurological conditions, including Huntington's disease, MS and acquired brain injury. Onsite care services include a permanent physiotherapist, hydrotherapy pool, recreational therapist and complementary therapists. Residents are enabled to maintain their independence whilst being offered high quality, personalised care that improves patient health and wellbeing in a safe and secure environment.

The centre is designed around the needs of individuals who live in self-contained apartments with individual bedrooms, living room and kitchen. Residents are enabled to live their lives, and where they can to maintain independence and do things for themselves. At the same time they are supported with physiotherapy, hydrotherapy and recreational therapy.

Having a physiotherapist permanently on site ensures people can access support when they want. Often in a nursing home whether or not a patient receives physiotherapy is decided by the staff, according to what they think the resident needs and benefits from, often conflicting with the wishes of the resident. At Dee View Court it is believed that if you benefit from having physiotherapy and you want it then you should be entitled to receive it when you want it.

The specially designed hydrotherapy pool helps people with relaxation, pain relief and exercise. The weightlessness in the pool means wheelchair dependent residents can move more easily, exercise and relax.

Recreational therapists take residents out on trips of their choosing, to the pub and shopping in the city and supporting people to continue their hobbies. Carers help residents to continue everyday activities. It is important for residents to feel they are not limited in pursing everyday social and leisure activities because they are now living in a residential home. This is part of supporting people to maintain their independence for as long as possible.

Sue Ryder, Thorpe Hall – Neurological day service group

Thorpe Hall's neurological day service group runs five days a week and is designed to support, offer advice and promote an active life for people with degenerative neurological conditions. The service supports people living with complex care and support needs such as MS, Parkinson's disease, stroke, acquired brain injury and MND.

The day service helps to reduce the risk of social isolation and supports people to maintain their independence. Staying active and feeling part of the local community is vital to maintaining quality of life and helps to increase confidence and self-esteem.

Thorpe Hall offers at least two community activity days a month which may be swimming, the gym, visits to places of interest combined with centre based activities which include complementary therapies like reflexology, gardening, games and cooking. The day service focuses on removing barriers and enabling disabled adults to do more for themselves. Each attendee has an induction and is supported to design a person-centred programme of activities. A tailored programme like this enables individuals to take part in activities of their choosing and achieve their goals.

The service is managed by a registered nurse who has links to other health and care professionals including community physiotherapists, nurses specialised in conditions such as MS and Parkinson's, local GPs and social workers. More general day services tend not to have registered nurses and therefore don't understand or consider the difficulties that people face with particular neurological conditions.

Sue Ryder, The Chantry – Synergy café and dementia day service

The Sue Ryder Synergy Café in Ipswich is run in partnership with the Alzheimer's Society. It provides a supportive environment for people with dementia and their carers to socialise and access information, including talks from external health and social care professionals.

The Chantry also runs a dementia day service. On joining the service everyone has a personal assessment and a care plan is developed with them, alongside input from family carers. This includes ensuring that basic needs, such as safety, eating and drinking, mobilising, personal care and maintaining independence are met. The care plan identifies what individuals wish to achieve and identifies how they will need to be supported. They will take part in activities designed to stimulate, motivate, relax and reassure.
The service seeks to support people living with dementia and family carers to enable the attendees to remain independent at home for as long as possible.

What can specialist neurological services achieve?

Romana Ali

Mother of two, Romana Ali, suffered a brain haemorrhage four months into her second pregnancy in 2004 which left her paralysed and unable to speak. After spending time in hospital and in a nursing home, professionals felt that Romana's condition would not improve, she was referred to one of Sue Ryder's neurological care centres.

At the time Romana was wheelchair dependent, couldn't speak or do any daily activities unaided. With the rehabilitative support from the centre she is now able to talk, feed herself and walk with the support of a frame. Romana explains, "When I first came here I couldn't get out of my chair. Now I can walk. I wasn't able to use the toilet or shower. Now I can do both, with no help. I have gone through a big, big change since coming here. Before I couldn't make my breakfast or my bed. Now I can."

It has been from her own determination and the availability of physiotherapy treatments, the use of the hydrotherapy swimming pool and the various activities that Romana has developed a renewed sense of purpose and been able to regain her confidence.

Paul Scotney

Four years ago Paul fell and suffered a serious head trauma which affected his ability to walk and his dexterity and speech. He attends a Sue Ryder neurological day service where he particularly enjoys learning how to cook.

Rehabilitation is a big part of enabling Paul to live his life, and the activities that the day service provide enable him to regain some of the skills that may have been affected by his brain injury.

Paul explains, "I like coming to Sue Ryder as I feel safe here. I want to keep busy and I know that when I come to the day service I have a chance to choose from so many different activities. I like outdoor activities and when I am attending the day service, I can go swimming, sailing, gardening and once a month we go shopping, to a pub or a restaurant."

The future neurological health and care landscape

Because of the complexity of neurological conditions and the age at which they can affect people, those who live with them often require a broad range of services that cross the boundaries of health, social care, housing, welfare and transport. If people with neurological conditions are to receive the support they require and deserve, appropriate commissioning is essential to ensure quality care is delivered alongside value for money.

Unfortunately, a body of research shows that, despite increased spending, services continue to lack integration and inpatient admissions for this group have risen by 31%, – 10% higher than the NHS service-wide figure.[9]
Studies by the National Audit Office (NAO) and the Public Accounts Committee (PAC) have recently highlighted these shortfalls in provision, as well as the failure of integration between these services.

Commenting on the findings of the NAO report, Amyas Morse, NAO Controller and Auditor General, summarised that, 'services for people with long-term neurological conditions are not as good as they ought to be, despite a large increase in spending'.[10]

The Health and Social Care Act 2012 introduced significant changes to the commissioning landscape, passing extensive powers to Clinical Commissioning Groups (CCGs) that will become statutory bodies by April 2013. Another key element of the government's wider reform agenda has been to modernise, simplify and consolidate adult social care, as outlined in the care and support white paper, *Caring for our Future*, and the draft Care and Support Bill.[11]

In line with this agenda, the new CCGs will play a pivotal role in local commissioning decisions that affect neurological care, specifically within the field of health. Local authorities, on the other hand, will be expected to develop a Market Position Statement for their area in order to promote diversity and quality, as they will be carrying out fewer commissioning functions with the continued roll-out of personal budgets.

Health and Wellbeing Boards will drive integration between the two services. Recent reports that the government may legislate for CCGs and local authorities to pool a certain proportion of their budgets are a positive step for those living with complex neurological conditions.[12]

These boards will be responsible for the delivery of the local Joint Strategic Needs Assessment (JSNA) and the associated Joint Health and Wellbeing Strategy (JHWS). The JSNA, JHWS, CCG commissioning and the local authorities' Market Position Statement will only be successful if they collect adequate data on the needs of their local population. Without this, it will be impossible to stimulate or deliver locally driven service provision.

The new landscape created by the Health and Social Care Act creates a very real opportunity to get service provision and delivery right for people living with neurological conditions. In order to understand the scale of the task ahead of us, Sue Ryder decided to undertake an audit of current local authority data collection, resource allocation and strategies provided by local authorities for this group.

We used Freedom of Information requests to gain an accurate picture within a set time frame. Now that we have completed this audit, we can clearly see where the biggest challenges lie, and hope to work with local authorities and Health and Wellbeing Boards to seize the opportunity to improve the system.

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[9] *National Audit Office, Services for People with Neurological Conditions, December 2011, p.4.*

[10] Amyas Morse, head of the National Audit Office, 16 December 2011 via: http://www.nao.org.uk/publications/1012/neurological_conditions.aspx.

[11] Department of Health, *Caring for our future: reforming care and support*, July 2012; the Draft Care and Support Bill, July 2012.

[12] Health Service Journal, *NHS commissioners could be made to pool budgets with councils*, via: http://www.hsj.co.uk/news/finance/nhs-commissioners-could-be-made-to-share-budgets-with-councils/5050431.article, October 2012.

The problem: neurological conditions and care

Using Freedom of Information (FOI) requests in the form of a questionnaire, this research sought feedback from local authorities in answer to the following five questions:

1. Does the local authority have an agreed local commissioning strategy for people with neurological conditions with complex needs? If so, does that strategy include working with charity providers? If not, does your authority have plans to draw up a specific commissioning strategy for services to meet the needs of people with neurological conditions?

2. How many individuals with neurological conditions (ie, people with MS, Huntington's, Parkinson's, MND, stroke, brain injury, dementia) do you provide social care services for? What proportion of your population does this represent?

3. Do you collect detailed data that categorises the specific neurological conditions (such as those listed above) those individuals have, and if so, which conditions are included and how many people have each one?

4. Do you have an agreed methodology (eg, care fund calculator) for assessing and commissioning the range of services required by an individual with a neurological condition and complex needs? If yes, what is it?

5. What services under the following categories (advice; supported living; community support; and registered residential services) are available within your local authority to a person with a neurological condition and complex physical needs?

These questions were chosen to gain insight into four areas of neurological care commissioning at the local authority level, specifically:

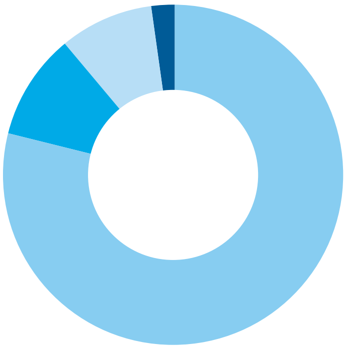
- the quality and quantity of data concerning neurological conditions collected and available at the local level;
- the agreed assessment methodologies used to commission services;
- the services across a care pathway available for those living with a neurological condition in the area;
- the commissioning tools and strategies available to assist in the provision of services.

Results

Strategies and leadership

Question 1

Does the local authority have an agreed local commissioning strategy for people with neurological conditions with complex needs?



●	No	79%
●	Yes	10%
●	Working on one	9%
●	Too expensive to respond	2%

The first question sought to understand whether neurological services were commissioned using local strategies across different local authority areas in England. National leadership has consistently failed to focus on a commissioning strategy for neurological conditions. While the creation of a Strategic Clinical Network for neurology, mental health and dementia was a positive step, more could be done at the national level to facilitate a better understanding of neurological conditions.

The government is due to publish a long term conditions strategy later this year which we welcome. However, we are disappointed by reports that this generic strategy will be accompanied by 'companion' documents on specific conditions that do not include neurology. We believe that if the government is taking a condition-specific approach to some areas, neurology should be included.

Probing these issues at the local level has revealed that only 10 % of the local authorities questioned are working with an agreed commissioning strategy. A significant proportion of these strategies are generic long term conditions strategies or dementia strategies and do not focus on neurological conditions either specifically or as a whole. However, we do welcome the fact that neurological conditions have clearly been considered by the local authorities that make up this 10 per cent – Birmingham, Bradford, Buckinghamshire, Dudley, Enfield, Lambeth, Newham, Oldham, Somerset, Staffordshire, Surrey, Windsor and Maidenhead, and Wirral – all should be seen as examples of best practice. However, it is clear that on the whole local authorities are spending money on people living with neurological conditions without having a strategy for how best to meet their needs.

As identified previously, neurological conditions are expensive to care for, and the current funding envelope used is set to grow as a result of an ageing population and medical advances. In order to ensure that money is spent in the most targeted way, a strategy is required.

It is possible that the lack of prominence given to neurological conditions as a whole from central government has influenced this. At a time when government strategies focus on cancer, dementia, stroke and autism to name a few, it is understandable that local authorities do not have the resource to devise strategies for all conditions. However, we believe this should be prioritised because of the factors that set neurology apart as different. For this reason, we would suggest that both central and local government look at neurological conditions as a whole. We know this group is extremely complex in needs and service requirements. If the system were to work in a way that was responsive to their range of needs and provided them with a person-centred pathway, it is likely that the same would be true for other conditions. If we get it right for the most complex, we will have built a system that can respond to all. In addition, in order to ensure money is spent as wisely and effectively as possible it is important to ensure a strategic rather than scattergun approach is taken to service design and delivery.

Our recommendations:

Strong leadership

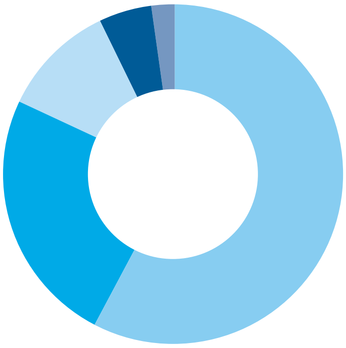
- **There should be greater leadership for neurology at a national level. In addition, the HNS Commissioning Board should develop an integrated strategy for people with neurological conditions**

- **Health and Wellbeing Boards should ensure that a section of their Joint Health and Wellbeing Strategy is devoted to scoping health and social care services specifically for people with neurological conditions.**

Data collection

Question 2

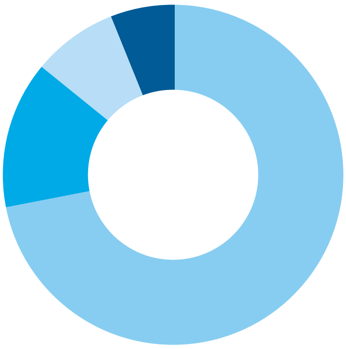
For how many individuals with neurological conditions (ie, people with MS, Huntington's, Parkinson's, MND, stroke, brain injury, dementia) do you provide social care services for? What proportion of your population does this represent?



● Data not collected	58%
● Partial data	24%
● Too expensive to respond	11%
● Detailed data	5%
● Info unclear	2%

Question 3

Do you collect detailed data that categorises the specific neurological conditions (such as those listed above) those individuals have, and if so, which conditions are included and how many people have each one?



● Data not collected	72%
● Partial data	14%
● Too expensive to respond	8%
● Detailed data	6%

There is very little reliable data that can quantify the number of people with neurological conditions in England who are in receipt of state funded local authority care services. Questions 2 and 3 sought to collate this data from local authorities and to identify the methods used locally to collect the figures. We were therefore extremely concerned to find that the majority of local authorities do not collect this data about the people they provide services for. The fact that only 5% of local authorities were able to tell us how many individuals with any neurological condition they provide care for is not positive, nor is it sustainable.

Those collecting partial data (24%) tended to focus on conditions that are seen as national priorities such as dementia or stroke.

This situation must change.

An accurate picture of the number of people with neurological conditions requiring social care and other support services would inform local spending decisions and provide an overall figure for the cost of neurological social care services. Financial efficiency could then be tested nationally to determine the best approach. Without this data it is impossible for local authorities to commission or stimulate the provision of services as effectively as they should. There is a human cost to this, as illustrated by some of the case studies we have detailed. If data is categorised by condition, it will assist local authorities to successfully take on their new role of shaping the care market. Only in this way will neurology-specific social care services be guaranteed – something that we have seen improve both health and social care outcomes of individuals as seen overleaf.

If the overarching figure of people living with neurological conditions and receiving health and care services in each area was collected by Health and Wellbeing Boards during the construction of Joint Strategic Needs Assessments, it would go on to inform the Joint Health and Wellbeing Strategy. These figures should be collated with the numbers of those receiving local health services. Collection of these figures would greatly assist in integrated future financial and service development or market stimulation planning. In order to ensure these top line figures are available, diagnosis should be collected as part of the assessment if it is the reason that the person requires care.

Our recommendations:

Robust data collection

- **Local authorities should collect and record information about an individual's condition when they are conducting assessments.**

- **Local authorities should amalgamate this data to produce detailed condition-specific data about the number of people with neurological conditions for whom they provide services. This should be placed in the JSNA alongside information about those receiving health services and used to facilitate integrated planning.**

- **This data, alongside other information about local demographics, should be used to develop the Health and Wellbeing Boards' Joint Health and Wellbeing strategy, local authority's Market Position Statement and CCGs commissioning plans.**

Karen Morgan

In 2003 Karen had a stroke and was left barely able to speak and dependent on her wheelchair. After spending two years in rehabilitation, professionals believed that it would not be possible to improve Karen's condition and she was referred to a Sue Ryder neurological care centre.

When she came to Sue Ryder, Karen couldn't bear her own weight, and had very limited speech. Through slowly understanding how Karen communicated, the care team at Sue Ryder were able to establish exactly what she needed. Karen was given an electric wheelchair which gave her some much-needed freedom, started to see a speech therapist and began physiotherapy, as well as being supported by the local Stroke Club. As a result of this intensive and tailored support Karen can now participate in conversations and is learning to walk again.

Karen is very proud of her achievements: "I had to complete exercises and practice every day. It was very, very hard. There were some days I didn't want to do it, but my own determination and the persuasion of the team at Sue Ryder kept me going."

One of Karen's carers explains, "Going through something like a stroke can be soul destroying. You can lose pride; you can lose the person that you were; you can lose your self belief. Just looking at Karen now you can see how far she's come. Just a few years ago you wouldn't recognise her, now she's getting back to that person again. As a member of staff here it is so rewarding to see. With Karen we've got someone who came here totally reliant on another person or mechanical device to move, someone who had been completely written off, to someone who's about to go out back into the community to live in her own bungalow."

Karen adds, "Back in 2003 my family and I were told that was it. I was written off but look at me now. I can't wait to be living in my own space again, being able to do my own things".

Becki Cook

Diagnosed with MS, Becki is dependent on her wheelchair to get around. With little support, advice or guidance about what it meant to live with MS, Becki struggled with low self esteem and confidence.

She was referred to the Sue Ryder 5Rs (relax, rebuild, reenergise, reintegrate and regenerate) MS day service. "It was great getting to know everyone. At the end of the first day I was like, wow, what was that that just happened? I had spent so long trying to keep away from MS and here I was confronted by it in a positive way. I thought that it would be silly but I came home feeling great, I didn't realise I was able to feel like this. It was incredible, I realised that there were people out there with MS that have had similar experiences and I wasn't on my own.

"The 5Rs was brilliant. There were so many different activities I could take part in, including reiki, aromatherapy, Indian head massage, shiatsu, Buddhist meditation, acupuncture, art therapy, music therapy and pilates. As well as the therapies it was the first time in a long time that I had the opportunity to have a joke, laugh and relax with new friends. The programme has helped me to build my confidence. Before the 5Rs there was no other external help or support and I didn't want to be involved with anything associated with MS.

"My self esteem and confidence have definitely improved since I started coming here. Attending a day service is like taking away everything else I struggle with in myself. Now I do the best I can to get on with my life, attending the 5Rs and a day service has allowed me to do just that. It's a question of dealing with what will come along."

The postcode lottery

Question 4

Does the local authority have an agreed methodology for assessing and commissioning services?
This research also sought to identify the ways in which local authorities assess the needs of clients with neurological conditions, how this informs commissioning and the extent to which any methodologies dedicated to doing so are standardised.

We know that the assessment and commissioning picture across the country is fragmented. Much coverage is given to the assessment procedure with local authorities tightening eligibility criteria for services and interpreting national guidance in different ways. This has prompted the government to propose new assessments in the draft Care and Support Bill. We welcome this, but believe that the government needs to go further if it is to eradicate the negative impact of the postcode lottery.

We are concerned that the methodologies used to determine a care package or service provision vary widely across the country. We have residents in Sue Ryder centres in different parts of the country with the same needs and yet significantly different funding packages and resulting care plans.
We believe any reform to assessments would benefit hugely from a holistic approach that also examined resource allocation.

When undertaking this research, it was hoped that the results would reveal a degree of uniformity in the approach taken by local authorities to allocate resources and calculate care packages for individuals. However, the results received (illustrated overleaf) show the different methods used across the country.

Of the 131 local authority responses, 60% indicated that they used some variety of agreed assessment methodology to inform the commissioning of services for individuals. While 19% of replying authorities based commissioning decisions upon individual assessments, 20% did not use either approach.

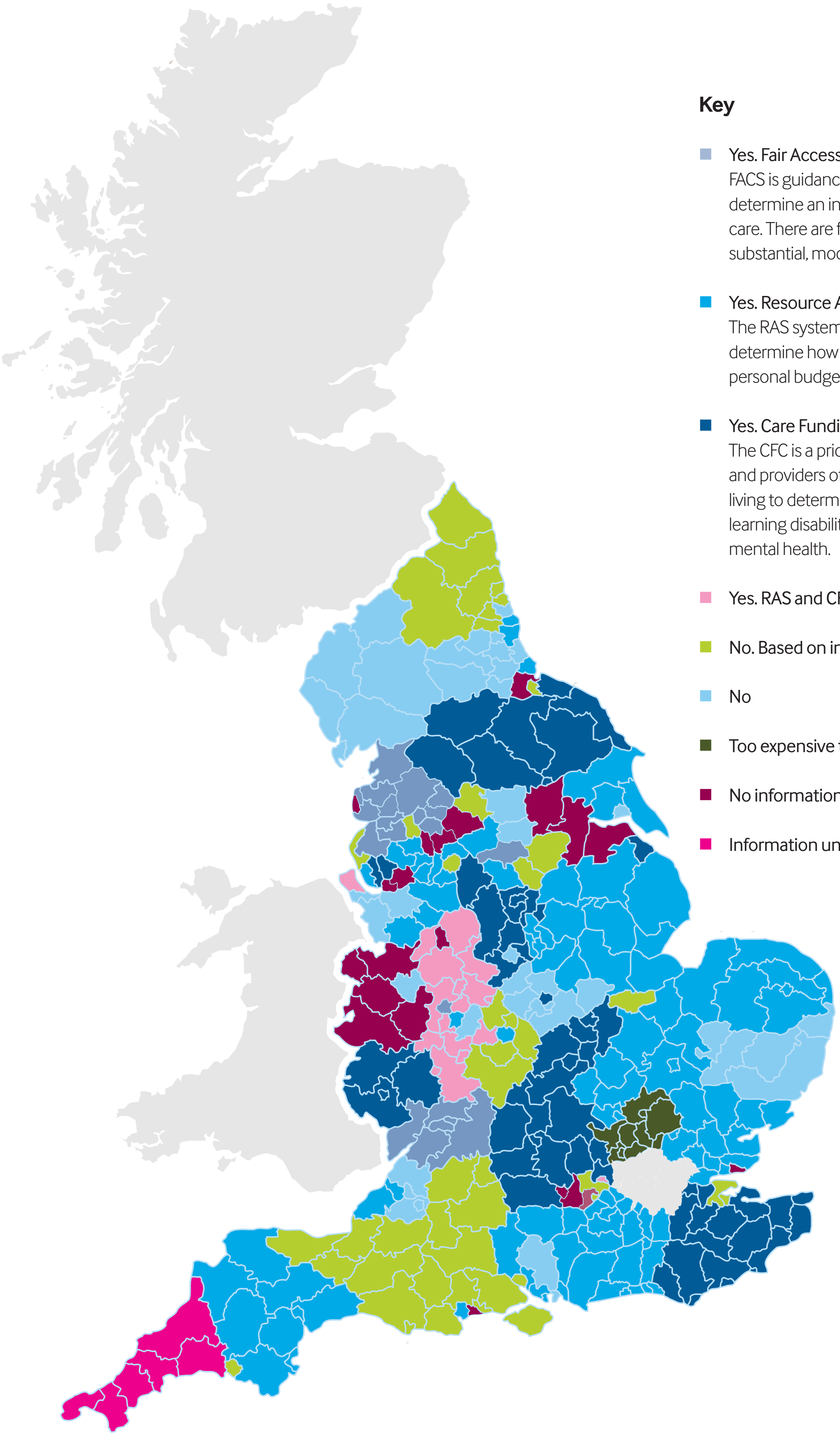
Allocation of resources and funding packages also need to be standardised alongside social care assessments if we are to truly banish the postcode lottery for care services.
To this end, we would like to work with central and local government to establish a common method of calculating care costs for people living with neurological conditions.

Our recommendations:

End the postcode lottery
- **The government must ensure that the draft Care and Support Bill enshrines not only consistency in assessment, but also consistency in approach to allocating resources and funding.**

- **We would like to work with the government to devise a care calculator for people living with neurological conditions.**

Does the local authority have an agreed methodology for assessing and commissioning services?



Key

■ Yes. Fair Access to Care Services (FACS)
FACS is guidance issued to local authorities to determine an individual's eligibility for adult social care. There are four eligibility levels; critical, substantial, moderate and low.

■ Yes. Resource Allocation System (RAS)
The RAS system is used by local authorities to determine how much money a person with a personal budget needs to meet their care needs.

■ Yes. Care Funding Calculator (CFC)
The CFC is a pricing tool used by commissioners and providers of residential care and supported living to determine the costs of individuals with learning disabilities, physical disabilities and mental health.

■ Yes. RAS and CFC

■ No. Based on individual assessment

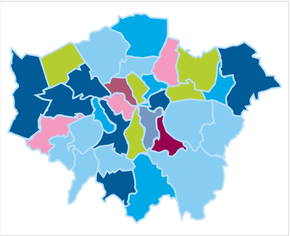
■ No

■ Too expensive to respond

■ No information held by Sue Ryder

■ Information unclear

Greater London



National standards and service provision

Question 5

What services under the following categories (advice; supported living; community support; and registered residential services) are available within your local authority to a person with a neurological condition and complex physical needs?

Sue Ryder's approach to the delivery of care services is called Supporting Me. We believe that every individual with a neurological condition is likely to want to explore and in some cases utilise social care services from four broad categories.

These categories are:
- Information, advice and guidance
- Community services
- Supported living or extra care services
- Residential service or care home

We therefore decided that we would try to build a picture of what the national offering across these four service models was and whether there was uniformity across the country with neurological specific services available in each area.

The 131 responses received from local authorities varied enormously in their content. In order to retain as much fairness as possible in the analysis, we limited ourselves to information specifically provided in the FOI response. Some local authorities provided more information than others, whilst many provided very little information. Many responses provided links to online lists of services that were sometimes difficult to navigate and gave little indication of whether the service is local authority provided or commissioned by the local authority and delivered by an outside provider. Some local authorities provided lists of services, but did not indicate which category they would come under.

In the future, the majority of individuals will use personal budgets to select the social care services that best suit their specific needs. However, their ability to do so will be hampered if information about these services is not readily available. There will always be a role for local authorities in commissioning, particularly in the provision of larger scale services for specific group needs, such as residential care. A menu of local services should be available for those who wish to source their own services.

The returns revealed enormous disparities in the types of service offered in different local authority areas. Whilst this can be seen as evidence of a diversity of services which is to be welcomed in terms of personalisation, the way in which the information was presented typically made navigation extremely difficult. Given the sheer complexity and opacity of service information we uncovered, it is unlikely service users or their families will be able to navigate the local service offer effectively in every case and identify the best service to meet their needs. It is also clear from these results that in many cases there are categorisation issues – where services are not properly identified with conditions – as well as a general lack of neurological specific services in some areas.

Though there is undoubtedly a place for some generic social care services, where possible it is important to provide services that meet diagnosis in addition to needs. This allows for some generalisations to be made which is crucial when providing services on a large scale. For example, MS can be a fluctuating condition which makes the design of services, which may need to be frequently scaled up or down to suit needs, extremely important.

Many local authorities concentrated on the first part of the question (advice services) and gave an indication of their central advice services which provide advice and care/service pathways for clients. In order to analyse this information in a way which is useful, it has been broken down using the following labels.

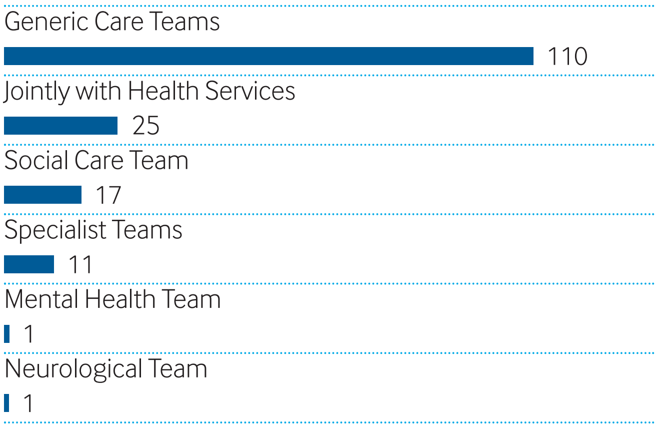
Advice services:
- Offered jointly with health services
- From a mental health team
- From a social care team
- From a neurological team
- From specialist teams
- From generic care teams

Accessibility of information is vital if the right services are to be made available to those that really need them. A kitemark standard – similar to the Information Standard – should be required of local authorities to ensure that information regarding services is easily understandable and accessible to service users. [13]

We welcome the additional monies being allocated to local authorities under the care and support reforms to improve their online information and advice.

However, the information we have collected shows just how far there is to go. The production of a kitemark or the extension of the Information Standard would ensure that information is accessible, clearly laid out, categorised and user-friendly. As a result of the inconsistencies in the returns, this analysis was reduced to advice services – the only area that could be appropriately compared. Here it was found that very few local authorities were providing advice jointly with healthcare teams, and only one local authority – Surrey County Council – provided a dedicated neurological care team to deliver its advice services.

Advice services provided by local authorities (by number)



A Demos report published by Sue Ryder in 2011, 'Tailor Made', suggested that people with the most complex needs do not see their lives in 'service silos', but instead in terms of broad outcomes that they hope to achieve.[14] To help make this a possibility, these individuals must receive integrated services where possible. Information and advice is a good place to start and, by working jointly with health services, local authorities will be able to provide a more integrated information offering.

Our recommendations:

National standards

- **There must be improved choice for those living with neurological conditions over the services they receive. These should cater for diagnosis and needs in order to help people to create a personalised care plan.**

- **Local authorities should be expected to provide transparent, accessible information and advice, and should be held to account by a kitemark scheme.**

- **Local information services should be provided in an integrated way, by working with health services, and where possible including a broader range of information.**

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[13] www.theinformationstandard.org

[14] Demos, *Tailor Made: personalisation must work for those who need in most*, October 2011.

Conclusion

The results that we have outlined show that local authorities are providing social care services with an emphasis on need rather than diagnosis. This approach is widespread but we believe that if we are to build a system that is fit for purpose and ready to withstand the demographic and financial pressures sure to face it, it should be challenged.

April 2013 and the introduction of new commissioning structures in healthcare and a new force for integration in the shape of Health and Wellbeing Boards presents a vital opportunity. We have shown that those living with neurological conditions are some of the most complex service users in today's system. Getting it right for this group requires integrated service provision and planning is at the heart of commissioning strategies. This will benefit all of those in need of social care services.

It is imperative that local authorities work to increase their awareness of those living with neurological conditions in their areas, and that they see this group as having unique requirements. This will ensure that the standard of social care for neurological conditions is consistent across the country and of the highest possible standard.

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Living through life's challenges

Sue Ryder is a charity registered in England and Wales (1052076) and in Scotland (SC039578).
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