Neurology: A handbook for action

An audit of neurological services in Suffolk
**Introduction**

This Quality Neurology report follows an audit of the neurology services in Suffolk during 2013.

Local professionals (staff from both of the Suffolk CCGs, Serco, the main community provider and social services) and the Suffolk Neurology Network asked Neurological Commissioning Support (NCS) to review neurological services across health and social care to help them understand how well they are being delivered.

The auditors consulted with over 200 people: professionals, patients and their carers within the Suffolk County Council area. This included people with the following conditions:

- Acquired brain injury (ABI)
- Ataxia
- Cerebral palsy
- Dystonia
- Epilepsy
- Huntington’s
- Motor neurone disease (MND)
- Multiple sclerosis (MS)
- Narcolepsy
- Parkinson’s disease
- Progressive supranuclear palsy (PSP)
- Stroke

Data were collected through focus groups, questionnaires, and interviews.

Over 50 professionals who commission or provide services for people with neurological conditions were involved in the audit. This included neurology consultants, specialist nurses and therapists. However, no representatives from mental health, pharmacy or housing attended the audit days, and there was minimal input from CCG-level commissioners although their comments were encouraged through different means.

This Quality Neurology audit was measured against the ‘quality requirements’ (QRs) set out in the National Service Framework (NSF) for long-term neurological conditions. The NHS Outcomes Framework was also taken into account. You can read more about both of these frameworks on our website: [www.ncssupport.org.uk](http://www.ncssupport.org.uk)
Executive summary

The Quality Neurology audit was conducted jointly by Suffolk Neurological Network and Neurological Commissioning Support. The audit found that Suffolk did not fully meet the quality requirements of the National Service Framework for Long Term Neurological Conditions (2005).

Equity of access to services across Suffolk needs to be addressed for all people with neurological conditions and their carers. Patients and carers need consistent services, between east and west of Suffolk and within these areas too. The audit indicates that patients and their carers need improved access to some specialist services. Access to equipment also needs to be in an appropriate and timely manner.

During the audit data from service users and carers indicated that local GPs have limited knowledge of neurological conditions, information supply and psychological support following diagnosis was limited and whilst specialist nurses and therapists were excellent, access could be difficult with long waiting times.

Data indicates that Suffolk lags significantly behind other areas in terms of specialist nursing and therapy cover and there are significant inconsistencies across the east and west of the county. This situation not only impoverishes the patient and carer experience, it results in the potential ineffective use of resources such as consultants seeing patients who could be seen by nurses or therapists, resulting in higher costs.

The audit found that people across Suffolk urgently need better communication about what services are available and where to go for help. Information needs to be streamlined and it’s essential that patients are given clear information both at diagnosis and to support self-management throughout the duration of their condition.

It appears that neurology is potentially underfunded in relation to other long-term conditions across Suffolk. The population of over 65s in Suffolk is expected to increase by 49% by 2021 and the proportion of over 85s is expected to grow by 90%. This will have an impact of the number of people living with neurological conditions locally and the demand on local services. For example, given that the incidence of Parkinson’s increases with age, it is likely that the prevalence of Parkinson’s across Suffolk will increase with compound growth in the potential prevalence of admissions putting pressure on the local NHS, social services and other statutory services. In the absence of future investment the situation could possible deteriorate with the expected increase in people living with long-term conditions in the area over the next decade.
Key findings

Services in Suffolk were measured against each Quality Requirement. This was undertaken across the two CCGs consecutively. Overall the score was 65% which equates to a result of ‘part met’.

NHS Gloucester CCG, a Suffolk comparator CCGs, was audited in 2010 and re-audited in 2012. These results are highlighted for comparison alongside a further CCG that has experienced similar issues in neurology service delivery, NHS Kernow CCG.

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<td>QR1 A person centred service</td>
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<td>Not met</td>
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<td>QR2 Early recognition, prompt diagnosis and treatment</td>
<td>Part met</td>
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<td>QR3 Emergency and acute management</td>
<td>Part met</td>
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<td>QR4 Early and specialist rehabilitation</td>
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<td>Part met</td>
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<td>QR5 Community rehabilitation and support</td>
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<td>QR6 Vocational rehabilitation</td>
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<td>QR7 Providing equipment and accommodation</td>
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<td>QR8 Providing personal care and support</td>
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<td>QR9 Palliative care</td>
<td>Part met</td>
<td>Not met</td>
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<td>QR10 Supporting family and carers</td>
<td>Part met</td>
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<td>QR11 Caring for people with neurological conditions in hospital or other health and social care settings</td>
<td>Part met</td>
<td>Not met</td>
<td>Part met</td>
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<td>Part met</td>
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<td>Overall score</td>
<td>265/405</td>
<td>243/405</td>
<td>274/405</td>
<td>303/405</td>
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All the categories were part met in some areas of service provision but there is not uniformity even though many of the individual elements are performing well – this is related in many cases to individual professionals leading services rather than commissioned services. There is scope to learn from positive practice and examine what remains to be addressed to see how the QRs can be met.

There are examples of good and notable practice across the area:

- Dedicated staff across the statutory services and experienced specialist nurses, both in the acute and community setting.
- Effective working relationships between the statutory and voluntary services.
- A whole-system approach to end-of-life care.

However, there is need for improvement, particularly around integration of services where more joined up working practice could improve services considerably.

- Services differ across east and west Suffolk, which could lead to inequalities for people with neurological conditions.
- The capacity of specialist nurses is extremely stretched across the whole of Suffolk.
- There is minimal nursing provision for people with rarer neurological conditions.
- Access to therapists is also inconsistent with provision often being generic opposed to specialist.
- Local mental health services have minimal input into the care of people with neurological conditions.
- There is scope for wider engagement across all partners commissioning and providing services for those with neurological conditions, for example housing.
Principles for neurology

Service users and professionals raised the same priorities during the audit about why some services are falling short and not meeting the needs of those with a neurological condition.

The most urgent agreed concerns are:

- **Information & communication** – people urgently need better communication about what services are available and where to go for help, and professionals need to be consistent in how they communicate this. Information needs to be streamlined so that clearer materials and information sources such as websites are available to both professionals and patients. It is essential that patients are given clear information both at diagnosis and to support self-management throughout the duration of their condition.

- **Prioritise neurology** and define what specialist services look like in collaboration with all stakeholders, with systems in place for less common conditions. There is an opportunity for the newly established Strategic Clinical Network to enhance and support the coordination and development of regional services.

Major priorities are:

- **Equity** – patients need consistent services, between east and west Suffolk, and within these areas too. There should also be equal access regardless of who a person is and where they living, acknowledging how rural Suffolk is and that accessing transport can be a problem. For example, there is anecdotal evidence that some people living in east Suffolk that use the West Suffolk Hospital have no access to a nurse because of their address. The use of public health data would support the planning of consistent services.

- **Coordinated care through keyworkers** – person-centred care with keyworkers across nursing, therapy areas and social care who use condition-specific integrated pathways through the course of the condition. This should include follow-up for patients who are not on therapy and management of long-term needs. Consider re-organising cover for out-of-hours care so that there is 24-hour and weekend cover.

- **Ensure funding is spent more efficiently** so that Suffolk residents to get the neurology care they need. There is a need to review resources and manpower around specialist therapies and keyworkers. There is also a need to use data to identify high spending and redirect funding to gap areas, investing in services to save money. This may include reviewing emergency/non-elective admission costs and reviewing community service provision costs in A&E. Making better use of the voluntary sector may support this approach.
Access to right services at right time – patients need improved access to some specialist services: psychological services, transition services, leisure and wellbeing, pain management, personal budgets, and parenting support. Access to equipment also needs to be in an appropriate and timely manner.

Share best practice – identify good practice and transfer it to other areas. Take the opportunity to share models through integrated care planning.

Proactive management – avoid unnecessary crises and admissions by risk profiling patients and monitoring those at risk ensuring high-risk patients are seen more frequently. In a crisis, patients and carers need a point of contact to call.

Education and training – non-specialist social and health care staff and care home staff need better training, with mandatory competency standards. Gaps in training cause unnecessary admissions and spend. Written care plans would mitigate some of these issues.
What is important to you?

We held a feedback day for patients and professionals to discuss the findings of the audit and to get people’s ideas and opinions on the results. The outcomes and discussion are illustrated below:
Overview of audit findings

What the audit found
Supporting actions for neurology

In addition to our key recommendations, here is a list of four solutions to support neurology locally – our recommendations for delivering improvements to patient care right away:

**Produce a neurology services information booklet for both patients & professionals**
Available through professionals and online, this booklet could give comprehensive details about all the neurology services available and signpost to further support that patients can access.

Getting the right information means patients can access the appropriate services and are supported to self-manage as much as possible. A booklet will also support professionals to manage patients effectively and improve care pathways. NCS has already developed a neurology services information booklet in Cornwall, the template of which could be used for Suffolk.

Professionals across Suffolk should work with the local Suffolk Healthwatch hubs to support the dissemination of information.

**A one stop shop for neurology advice**
Provide a single access number for neurology patients to contact a neuro-advisor. This will mean service users will have easy access to specialist advice and information to support and signpost patients and proactively deal with problems before the onset of a crisis.

**Implement integrated care pathways (ICPs)**
Collaboration is the key to good patient care, and implementing ICPs could promote this. Suffolk’s neighbour Norfolk has already piloted and developed an ICP for Parkinson’s; developing a similar pathway in Suffolk would facilitate better care for this condition and could also influence pathway development for other conditions. Development of a multiple sclerosis pathway has started in Suffolk with a view to launching this in early 2014.

**Care plans**
Use care plans written by key workers, agreed with patients and implemented by all professionals including out-of-hours doctors and consider developing a specific neuro-folder for service users and their carers to carry on their person ensuring information is available when needed.
Data
Now that data performance has been measured and a baseline measure of services obtained, regular monitoring of data could help ensure greater efficiencies are realised.

Work towards developing joint IT systems for health and social care and look at other web-based systems to see how they can be used in Suffolk.

Explore the development of an integrated record system to have a record of professional notes across Suffolk. Further consideration could be given to embedding handheld patient modified records in future plans and service signposting.
QR 1 A person-centred service  Part met 72%

People with long-term neurological conditions are offered integrated assessment and planning of their health and social care needs. They are to have the information they need to make informed decisions about their care and treatment and, where appropriate, to support them to manage their condition themselves.

Information & signposting
People with neurological conditions in Suffolk have access to education and self-management programmes such as ‘Expert Patient’ programmes and ‘Newly Diagnosed Days’. There are ‘getting to grips’ days for people with MS and courses provided by Sue Ryder. Icanho and Headway provide training in understanding the physical, cognitive and psychological consequences of brain injuries. A new trauma pathway is being developed for East Anglia.

Most people we surveyed say that health and social staff understand their condition well enough to support them well and listen and take into account their views and wishes.

Integrated care pathways for people with neurological conditions in Suffolk are lacking. Professional groups have issues sharing service user information. There is no system to share information electronically between health and social care and different IT systems are used, which is challenging for all healthcare professionals.
“Coordinating with social services is a work in progress.” (Service user)

“There is no one-stop shop.” (Service user)

“I would like to have consistency in GP surgery, a key person – I would like a doctor to know me – I’m not able to see a doctor who understands the condition.” (Service user)

“There isn’t any coordinated working. Long waits. A single point of access would be good, like a nurse and/or social worker. Neurology is overlooked in Suffolk; the focus is on other conditions.” (Service user)

There is confusion about information, with the exception of the Disability Resource Centre. Professionals are not sure about:

- What information is available and where to signpost people.
- What training is available in the management of patient/service user-related information.

**Variation**

Care planning systems are variable across Suffolk, although care planning for end-of-life care is generally good. A yellow folder system is used across Suffolk and an electronic register identifies patients in their last year of life, which is linked to advanced care planning.

**Most people we surveyed did not have a written care plan, although of the people who have one, more people say they found it useful than those who do not.**

![Bar chart showing the distribution of written care plans](chart.png)
For most people no care planning is in place, they do not understand how it would help, or if they do it is not being offered (comments from focus group).

People want continuity of care, and find it difficult to get professionals to work in integrated way (comments from focus group).

Integration between various health departments works well, for example between specialist nurses and the district nurses. However, on the east side of the county the role of community matrons’ in providing services for people with neurological conditions needs to be clarified. In Norfolk, Great Yarmouth and Waveney, which was audited in 2012, there are disease-specific multidisciplinary clinics for people with some common conditions – an example of good practice in providing integrated care which could be replicated in Suffolk.

When patients are moved out of the county for specialised services, for example to Addenbrookes Hospital, communication can break down and professionals are concerned that patients have to travel for care when services could be provided closer to home.

“We are considering moving to Colchester as the commissioning provides better services and the Colchester consultant is also apparently better. However, it takes a long time to get an appointment as he is over-subscribed.” (Service user)

Specialist nurses
A review of specialist nurses is of high importance across the area. The level of specialist nurses differ across the County and there is evidence that local caseloads for the specialist nurses do not comply with NICE guidelines. For example, a recent report developed by the community supplier Serco, indicates that Suffolk is in the highest quintile nationally for MS specialist work caseload and the lowest quintile for available nurse time.

People with a neurological condition have a named point of contact where possible. Systems for this vary across Suffolk: the specialist nurses in the west are community based and in the east they are based in the acute hospital. In the west there is an open referral system for specialist nurses who, once accepting referrals, become the named contact for advice and support.

Staff who took part in the audit have no knowledge of any nurses for rarer neurological conditions. Staff audited in Norfolk, Great Yarmouth and Waveney in 2012 said the same.

Service providers across Suffolk find it difficult to deliver a multi-professional range of expertise at all times. The present tariff system can cause difficulties in this area.
“Many people really need nurse support but are having to do okay without this service.” (Service user)

“I don’t see why Great Yarmouth and Waveney has four community neuro nurses but down here there is so little access to an MS nurse for people who need it. 700 patients in a 3-day a week post is madness!” (Service user)

Specialist nurses are highly valued, but there is poor access in Suffolk. Many people who need nurse support have to cope without it (comments from focus group). This differs from the results of an audit in Norfolk, Great Yarmouth and Waveney in 2012, where people who have access to a specialist nurse had mixed views on the benefits of the service.

Most of our survey respondents have a neurology or specialist nurse, who they see every 6 months; however, a quarter of people see their nurse less often than once a year.

The majority of people say that the information and support their nurse gives them helps with managing their condition, and most people find that the nurses help them access services needed:

![Bar chart](image)

The majority of people say they had been reviewed by a neurology/specialist nurse, GP, or consultant in the last 6 months. Most people have never been reviewed by a social worker, although a fifth have had a review in the last 6 months.

Service users we spoke to at focus groups told us that transport is a big problem in Suffolk.
“Transport is an issue to access services. There are limited buses and they sometimes do not have the ability to take people with disabilities.” (Service user)

KEY RECOMMENDATIONS

- A one stop number for accessing neuorology advice and support
- Develop integrated care pathways that increase collaboration on assessment and information sharing
- Review care planning so that there is a consistent approach and all service users have a care plan
- Explore information systems. For example, consider:
  - A patient information booklet for all neurological conditions that signposts to specific services, made available across Suffolk and online
  - An information booklet for staff listing colleagues’ roles and locations
  - Developing a neurology folder
- A review of specialist nurse provision across the whole of Suffolk to ensure capacity issues are addressed and that service users and carers across Suffolk have equitable access to specialist nurses
  - This includes reviewing the need for specialist nurse support for those with rarer neurological conditions.
People suspected of having a neurological condition have prompt access to specialist neurological expertise for an accurate diagnosis and treatment is as close to home as possible.

Diagnosis
Diagnosis is given in different ways depending on which service a person is accessing across the Suffolk area. Respondents to the survey indicated that there are some issues with gaining a diagnosis locally. 29% of respondents to our survey waited over a year for a diagnosis, 3% have never been given a diagnosis. After diagnosis 70% of people were not offered emotional support after diagnosis. Only 18% of respondents could give a positive response to this question.

Service users we spoke to at focus groups told us:

- People are not getting enough information or emotional support at diagnosis.
- The voluntary sector and internet are important sources of information

Training gaps
Training for front-line/A&E staff to recognise neurological symptoms both in the east and west of the county is ad hoc. There is no planned training programme in place. Specialist nurses in the east and west have worked to heighten awareness of the needs of patients with neurological conditions on general wards and in A&E departments. However, this can be difficult due to staff capacity and the surge of staff through the system.

Gaps in training can often cause unnecessary hospital admissions. If respiratory or acute urinary infections are recognised and treated earlier, this could prevent admissions.

“GPs need better education on the condition and services.” (Service user)

- GPs and A&E staff need educating about neuro conditions say service users at our focus groups

Accessing specialists
Shared protocols for referring patients for further specialist assessment mean that people receive appropriate priority. Genetic disorders are managed by the genetic services at Addenbrookes Hospital and referrals for this service are clear. Some professionals are concerned about the lack of a neuro-rehabilitation consultant, meaning that patients have to be seen outside the area – for example for spasticity.

Professionals say that diagnostic services across Suffolk are delivered according to NICE Guidance where available. Services take account of agreed national guidance and protocols.
Half of people surveyed were seen by a specialist within three months of first reporting their symptoms. However, 20% are waiting more than a year.

Half of people got a diagnosis within 6 months of reporting their symptoms; however, a third had to wait over a year. (A few respondents had not yet received a diagnosis.)

Provision of specialist nurses is the lowest across East Anglia and needs to be reviewed to move towards recommended levels and to ensure equity of access across Suffolk. Data indicates that levels are currently below recommendations. Specific consideration needs to be given to managing rarer neurological diseases.

The majority of respondents access a specialist nurse 6 monthly:

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<th>Frequency</th>
<th>Percentage response</th>
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<tr>
<td>less than 3 months</td>
<td>11.50%</td>
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<tr>
<td>3 monthly</td>
<td>10.60%</td>
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<tr>
<td>6 monthly</td>
<td>41.60%</td>
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<tr>
<td>yearly</td>
<td>12.40%</td>
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<tr>
<td>less than once a year</td>
<td>23.90%</td>
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Information
For the main neurological conditions, service users and their carers are given appropriate information before starting medication to enable an informed choice. However, if English is not their first language, professionals struggle to provide information. Links exist between local specialist nurses and pharmacy services, and medication reviews are done at GP level with local GPs doing audits in this area, including polypharmacy, where service users are on more than three medications.
Similar numbers of people were/were not offered information at diagnosis about their condition. Most people, however, did not receive information about support services:

![Pie chart showing percentages of people who received information about support services at diagnosis.](chart1)

At the time of diagnosis, did you receive information about the support services that might be available to you?

- Yes: 54.8%
- No: 32.9%
- Don’t know/can’t remember: 12.3%

Most people got more information about their condition by searching online, or were signposted by a professional.

“Nothing is explained – you have to search out information.” (Service user)

Most people were not offered emotional support after diagnosis or brain injury:

![Pie chart showing percentages of people who received emotional support.](chart2)

Were you offered emotional support/counselling by a professional after diagnosis/brain injury?

- Yes: 70.2%
- No: 17.9%
- Don’t know/can’t remember: 11.9%
KEY RECOMMENDATIONS

- Explore a consistent approach to giving a diagnosis across primary and secondary care
- Review the systems and capacity for providing emotional/psychological support at time of diagnosis
- A patient information booklet for all neurological conditions that signposts to specific services, made available across Suffolk and online
- An information booklet for staff listing colleagues’ roles and locations
- Condition-specific information packs for GPs and consultants to give to patients

- Training for non-specialist staff to understand the needs of people with neurological conditions
People needing emergency admission for a neurosurgical or neurological emergency are to be assessed and treated in a timely manner by teams with the appropriate neurological and resuscitation skills and facilities.

Acute and emergency management of sudden onset neurological conditions are, in the main, effective on both sides of Suffolk, and comply with NICE guidance where available.

**Resources and specialist links**

The two local hospitals accepting people with a neurosurgical or neurological emergency have appropriate resources to treat, manage and review patients presenting with a sudden onset of neurological conditions. Supervision is available from Addenbrookes Hospital if needed.

There are links to the specialist neuroscience centre at Addenbrookes Hospital although transfer waiting times can be long due to capacity. Neuro-rehabilitation is more problematic as it can be difficult to access beds. This can lead to delays in treatment and can have an impact on local resources.

West Suffolk NHS Foundation Trust do not have a neurologist on site at weekends and there is no dedicated ward there, meaning service users may not always get the best care.

A minority of respondents had used emergency medical services in the last 12 months. Most of these used the services 1 to 3 times, and only a small number used the services more than this. One in 10 people had been to A&E because they couldn’t get help quickly enough from health practitioners for their condition.

17% had been admitted to hospital as an emergency because of their condition in the last 12 months. People have mixed feelings about whether staff understand their neurological condition when they are admitted to hospital.

“There needs to be regular contact with someone – with instant availability – who knows the patient and is interested such as nurse or MS specialist.”

(Service user)

**KEY RECOMMENDATIONS**

- Training for non-neurological staff about what to focus on for admissions of neurology patients
- A flagging system when a neurology patient is admitted to a non-neurology ward
• A journey map or disease pathway covering both health and social care roles with:
  o clear pathways for care, and role and responsibilities
  o a secondary to primary care discharge pathway and policy to support sustainable rehabilitation
• Review access to neuro-rehabilitation across Suffolk to ensure that delays to treatment are kept to the minimum
People with long-term neurological conditions who would benefit from rehabilitation are to receive timely, ongoing, high-quality rehabilitation services in hospital or other specialist settings to meet their continuing and changing needs. When ready, they are to receive the help they need to return home for ongoing community rehabilitation and support.

Professionals say the levels of specialist-trained rehabilitation staff are low across Suffolk. We will explore data in this area further during the audit.

Access
Access to early and specialist rehabilitation differs across the two sides of Suffolk.

In the east there is good access in the hospital setting. If urgent, patients are seen within two weeks or when the next appointment is available. Access to the multidisciplinary team could be improved and there is a six to eight week wait for outpatient rehabilitation. In the main there is access to specialist equipment.

In the west access in the hospital to rehabilitation can be patchy and dependent on both condition and level of need. There is not enough rehabilitation available to those who would benefit from it. Service providers and users have issues accessing an occupational therapist splinting service. There is little evidence that staff are following inpatient rehabilitation programmes, on an ongoing basis, in the community for those who need them.

Complex needs
Services to meet the needs of people with very severe and complex disabilities across Suffolk are limited. Where necessary people are referred to specialist centres outside the area such as Stoke Mandeville.

KEY RECOMMENDATIONS
- Review access to early and specialist rehabilitation to ensure that this is equitable across Suffolk.
- A secondary to primary care discharge pathway and policy to support sustainable rehabilitation
- Review services to meet the needs of people with severe and complex disabilities across Suffolk to identify if local services can be improved
QR 5 Community rehabilitation and support Part met 66%

People with long-term neurological conditions living at home are to have ongoing access to a comprehensive range of rehabilitation, advice and support to meet their continuing and changing needs, increase their independence and autonomy and help them to live as they wish.

There is good access to community rehabilitation in Suffolk. There are issues, however, with waiting times although prioritisation methods are in place to ensure that people are seen within 18 weeks. Icanho and Headway provide some specific rehab programmes.

Holistic care
People in Suffolk can access holistic outpatient and day rehabilitation programmes. In contrast, patients audited in Norfolk say that access to holistic care is a problem, and this is exacerbated by poor communication between teams and predominantly a focus on urgent need rather than supporting self-management. In Suffolk there are a number of exercise classes run but these can be poorly planned and depend on geography instead of need. No specialist occupational therapist is trained in vocational rehabilitation.

The community rehabilitation teams do not specialise in neurology and staff do not have to be trained in neurology to be part of the team. If there is a specialised trained member of staff there is no guarantee that a patient can see them. Professionals say this is a postcode lottery.

Self-management
Where possible the local rehabilitation teams support service users to develop knowledge and skills to manage their condition and provide proactive intervention, where relevant, to maintain function and prevent deterioration as the condition progresses.

Integration
Integration across acute and mental health care is problematic. Input from the local mental health services into the care of people with neurological conditions is minimal. There was no representative from the mental health trust at the audit so we will explore this area further later in the audit.
Most people were not offered emotional support after diagnosis or brain injury:

"Medication is okay but support is needed on living with epilepsy outside the seizures." (Service user)

“A neuropsychologist is needed – there is not enough counselling and psychology specific to neurology. It is a postcode lottery – for some people what they want is in east Suffolk but they live in west Suffolk so it is not accessible and vice versa.” (Service user)
There were mixed responses to our survey about access to services. Half of respondents say access is good/excellent, but some say they are unsure about access or that it is difficult.

When asked about funding, about a third of the respondents say they have to pay for these services:

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<th>If you had to pay for services, how are they funded?</th>
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<td>Direct payments: 32%</td>
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<td>Personal budgets: 17%</td>
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<td>Self funded: 30%</td>
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<td>Health continuing care: 11%</td>
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<td>Charity Vol Group: 10%</td>
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KEY RECOMMENDATIONS

- Rehabilitation services are further developed in the community to ensure that these meet the needs of local people with neurological problems.
- Skills of community rehabilitation staff are reviewed and where possible specialist neurological therapists are employed.
- More proactive community management of patients is developed to prevent deterioration in patients condition keeping patients in a maintenance phase for longer.
QR 6 Vocational rehabilitation  Not met 38%

People with long-term neurological conditions are to have access to appropriate vocational assessment, rehabilitation and ongoing support, to enable them to find, regain or remain in work and access other occupational and educational opportunities.

Professionals and service users say vocational rehabilitation is an area of weakness.

**Signposting & support**
Although there are some examples of vocational rehabilitation being addressed, there is no coordinated multi-agency vocational rehabilitation available across Suffolk for people with neurological conditions, and there is no evaluation of vocational rehabilitation. There is some signposting from health services but this is not comprehensive and many professionals are unsure of who to refer to – a problem that was reported by staff in Norfolk too.

**Third sector**
Professionals rely on the voluntary sector to a degree to provide the signposting and support needed for vocational support. There are access-to-work schemes run by voluntary sector organisations such as Icanho (brain injury rehabilitation) and Headway, and some training for employees available about epilepsy.

**Three quarters of people we surveyed are not in work. Just over half said this is because of their condition. Of those who do work, some access support, such as Access to Work.**

“Once you have declared your epilepsy it can affect you returning to work.” [Refers to not being offered interviews] (Service user)

**KEY RECOMMENDATIONS**
- Vocational rehabilitation is addressed and improved through better information for patients and wider training for staff.
QR 7 Providing equipment and accommodation
Part met 62%

People with long-term neurological conditions are to receive timely, appropriate assistive technology / equipment and adaptations to accommodation to support them to live independently, help them with their care, maintain their health and improve their quality of life.

Timeliness
The contract for central equipment services is being transferred to a new provider (Serco). Professionals identified occasions recently, where there have been difficulties in accessing basic equipment which has caused delay in patient treatment and transfer between the acute sector and the community. Wide variation in equipment provision was also reported by service users in our audit of Norfolk, Great Yarmouth and Waveney.

Point of contact
Suffolk Council provides a single point of contact for individuals with equipment problems; however, there is minimal information on equipment waiting times for service users which can lead to a level of distress.

Suffolk Independent Living and the Disabled Advice Bureau provide information on using direct payments/individual budgets for equipment and vouchers for wheelchairs. There are fast track systems to provide equipment to support people who choose to die at home and there is access to equipment from the local hospices if needed (St Elizabeth’s). The council (social care) provide modifications to the home but there is wide variation in timeliness of these, which is pertinent where people with rapidly advancing conditions have made the choice to die at home.

Professionals said that housing services do not always work in a joined up way with other statutory services. There was no representative from housing services during the two day so this will be followed up.
In the last 12 months people have commonly received equipment to help them be as independent as possible, followed by personal care and domestic assistance. Most people do not feel they had to wait an unreasonable length of time for these:

A significant proportion of respondents paid for their equipment/adaptations themselves:

“The branch bought physio equipment they use themselves. The branch bought it with advice from the physio.” (Service user)
“I’ve had adaptations to the house – a bungalow grab rail, ramp, shower seat etc. I paid for the ramp, didn’t ask for funding. My wife has DLA so we used this for the ramp.” (Service user)

“I’m interested in Functional Electrical Stimulation machine as there is proof of it helping but I’m not sure if it comes under equipment. It would be a GP commissioning decision and would come under my personal health budget.” (Person affected by MS)

“The hospital arranged adaptation to my house with my social worker which was quicker than going through my GP.” (Service user)

A large amount of respondents are receiving equipment at the home:
Service users at our focus groups told us:

- Delays in equipment mean it is often too late when it arrives
- There are problems with equipment being out of stock
- Specialist equipment – service users cannot afford it, but recommended by occupational therapist

KEY RECOMMENDATIONS

- Information about what equipment is available and waiting timelines to expect
- Review central equipment store processes to ensure timely provision of equipment to meet patient needs, defined by clinicians involved in their care
- Enhance engagement between health and social care professionals and housing
QR 8 Providing personal care and support  Part met 50%

Health and social care work together to provide care and support to enable people with long-term neurological conditions to achieve maximum choice about living independently at home.

There is scope to improve the information available from health and social care on personal budgets and direct payments.

**Nursing care**
In the west, specialist nurses visit care homes to give support and advice on managing neurological conditions, although in the east they do not have the capacity to visit care homes. Therapists give advice to care homes, with Headway also providing training in other care settings. Staff across Norfolk also say there are gaps in general training in care homes, citing issues with the capacity to provide education in this setting.

**Support in the community**
Assessment for continuing care differs across the social care provided by the County Council. Staff are concerned about inequality – the County Council has the third lowest rate of uptake of continuing care across England councils which may indicate poor access across the area.

The Supporting People Programme (housing) has been reduced due to budget cuts.

**Young people**
Age appropriate residential care options for young people are lacking.
The majority of respondents have a family member of close friend who gives regular support:

“I would like to see services that provide emotional support. Feelings of isolation cannot be discussed anywhere. You need to mix with like-minded people to feel connected and accepting of your mental health situation.”

(Service user)

KEY RECOMMENDATIONS

- Give service users more information about personal budgets and direct payments
- Review continuing care assessment rates across Suffolk to ensure that they are comparable to similar Councils.
- Review availability of age appropriate residential care
- Establish e-learning for nursing and residential home staff to use as part of the induction package for new staff
People in the later stages of long-term neurological conditions are to receive a comprehensive range of palliative care services when they need them to control symptoms, offer pain relief, and meet their needs for personal, social, psychological and spiritual support, in line with the principles of palliative care.

In general professionals say palliative care services across Suffolk for people with neurological conditions are good. There is an appetite to make service pathways more solid across the area and move the model of care to better fit with neurological conditions.

Teams across the west and east promote the use of ‘yellow folders’ and, although joint clinics are not held, there is joint working with the palliative care team and with the local hospices.

Where possible, local people with neurological conditions are given the option and support to die in their own home. Specialist nurses and community rehabilitation services provide support, advice and training to local staff and carers on palliative care for people with a neurological condition. The local hospices run a ‘hospice at home’ network. In Norfolk, however, in contrast, there is no formal advice or training for non-specialist staff delivering palliative care in the community.

Suffolk has some problems with respiratory care in the community and professionals see this as a gap and often a cause for unscheduled admissions.

There is scope for continued training for neurologists and their teams in palliative care. Although training has been received, this can quickly become out of date. Community therapists and rehabilitation teams would also benefit from further training particularly on neurology.

KEY RECOMMENDATIONS

- Follow the Gold Standards Framework for everybody with a neurological condition
- Ensure advanced care planning can be discussed with all neurology patients
- Provide ongoing training to staff, including neurologists and their teams, on managing a person’s end-of-life care needs for a neurological condition
- Review respiratory care in the community to avoid unscheduled admissions due to respiratory conditions
- Encourage GP’s to find their 1% of patients with a neurological condition who are in their last year of life to support meeting End of life care priorities
QR10 Supporting family and carers  Part met 80%

Carers of people with long-term neurological conditions are to have access to appropriate support and services that recognise their needs both in their role as carer and in their own right.

Professionals said that carers could not choose the extent of their caring role and the kinds of care they provide. Carers are frequently given larger care roles than they would wish to have and it is often then difficult to step back. People with a voice, the financial resources or the capacity to do so, can have a choice but this is not true for all carers.

Carers’ support is available and there is a very strong and well-respected Suffolk Carers Network. There are also other initiatives such as the Carers’ Kitchen at Ipswich Hospital that is open every afternoon, which is provided by the Network.

Staff have minimal knowledge of carers being offered a written care plan (of their needs as carers) – the same was reported by staff and carers in Norfolk. Allocation of a single point of contact is variable depending on where you live and the amount of access is different dependent on the services.

Suffolk Carers Network offers a comprehensive moving and handling training programme for carers, and Epilepsy Society and the epilepsy specialist nurses provide training to carers on seizure management.

There is some level of emergency planning for carers but this is not consistent across Suffolk. There is also some level of planned out-of-hours and crisis prevention but it is not clear how much professionals and individuals with neurological conditions know about these. In Norfolk our survey found that a number of people accessed A&E because they did not know where else to go, which suggests that patients here are not aware of emergency needs services.

Respite is available at some level across the county and the old PCT provided one bed for long-term neurological conditions.

“My wife gets support from family, the church and friends on a personal level, but nothing on a professional level.” (Person with MS)

“Counselling services would take the pressure off home carers. Carers are not supported; unpaid carers help out organisations as it doesn’t cost anything.” (Service user)
The majority of respondents have a family member of close friend who gives regular support:

Do you have a family member or close friend who cares / supports you regularly?

- Yes: 116
- No: 21

**KEY RECOMMENDATIONS**

- Improve signposting about carer support services available across Suffolk.
- Map and highlight all respite services in the information booklet mentioned in QR1
- Inform carers of their right to a carer’s assessment
- A consistent approach to emergency planning for carers, particularly regarding planned out-of-hours care and crisis prevention
- Clarify issues around the funding available to support people – to take breaks for example
QR11 Caring for people with a neurological condition in hospital or other health and social care settings
Part met 50%

People with long-term neurological conditions are to have their specific neurological needs met while receiving treatment or care for other reasons in any health or social care setting.

On admission to another care setting staff have an ad hoc approach to liaising with a service user’s usual neurological team. The consultant neurologists and specialist nurses will follow up patients where possible and when informed. There is no evidence that staff are using neurological care plans on an integrated basis (see QR1) or that emergency admission protocols are in place with the service user’s community team.

When compared with Norfolk, our audit found that difficulties mainly seem to arise when patients are admitted to non-neurological wards with problems not associated with their neurological condition. People report an overall lack of understanding among staff of their neurological condition. In Suffolk, there is scope for further training to be rolled out across non-neurological settings. Specialist nurses attempt to provide this but can be hindered by capacity issues and conflicting priorities for non-neurological staff. Headway provides training for non-neurological staff where possible.
Neurology/specialist nurses, neurologists and GPs received the highest numbers of positive responses:

In contrast, responses for therapists are significantly lower which may reflect the fact that, in the main, therapists are generic and not neuro specific.

KEY RECOMMENDATIONS

- An alert system that prompts hospital and care home staff to seek assistance about a person’s neurological condition when they are admitted for a non-neurological reason
- Accessible education for non-neurology staff on how to manage specific neurological conditions
Solutions

The following solutions were identified on the stakeholder day by service users and professionals (recommendations are included in the action plan in Appendix 1):

Prioritise neurology
Baseline neurology data is now available in Suffolk for neurology so consideration needs to be given to maintaining high-level data analysis and highlighting the cost of emergency admissions for neurology patients. Addressing emergency admissions would support money saved being invested into service improvements.

Stakeholders should work in collaboration to raise awareness of and improve neurology care.

CCGs should consider monetary rewards when managing people with neurological conditions, for example CQUINS.

Information and education
Patients need to know what services are available and be able to self-refer when required. People need to be empowered to access personal budgets and there is a need to provide education and training for health professionals to increase their awareness of information and the services available to patients. Information solutions could include:
• A website directory and paper versions with explanation of what services are. There is potential to use Healthwatch Hubs in line with the local Suffolk Health Watch.
• Recorded consultations that are handed to patient/family to take away (and could be maintained in a (Suffolk) neuro-file.
• Use TV and other information technology to support information transfer.
• Laptop tablets to take into people homes to access information and write care plans.
• Clinicians’ appraisals to result in improved practice (CPD). All professional practice should be research and evidence based with more local training.

Promote good practice
Identify good practice and promote what is done well. Emphasise the patients’ perspective.

Key contact (one-stop shop)
Patients need to have access to a 24/7 phone line for peace of mind and reassurance, and a care navigator as a point of contact.

Care plans
Comprehensive written care plan solutions are needed that are part of integrated care planning for long-term conditions, including recording unmet need and scheduling reviews. Consider laptop/tablet solutions. Define the needs of complex patients.

Self-management
Patients need to be enabled to self-manage and need contact with experts who monitor patients proactively to avoid crises. Out of hours services are essential.

Risk profiling should be undertaken to identify high-risk patients so that monitoring can be done at appropriate intervals.

There needs to be follow-up for patients without active disease with self-management resources and respect for service users who are experts in their own condition.

Palliative care
Work on how carers who are providing palliative care to family members are being managed to give better outcomes for people with neurological conditions.
The way forward
A separate action plan has been developed to sit alongside this report which will be shared with the local CCGs and social services. The action plan which includes the minimum recommendations and solutions discussed and agreed at the stakeholder meeting will be distributed to the CCGs and social services in January 2014. Some recommendations will need to be agreed as part of the contract between the commissioners and local service providers.
<table>
<thead>
<tr>
<th>Priority</th>
<th>Recommendation</th>
<th>Responsibility</th>
<th>Timescale</th>
<th>QR</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>High Review specialist nurse provision related to neurology across Suffolk to avoid inequitable access to services and to come in line with NICE requirements.</td>
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<tr>
<td>2</td>
<td>High Review specialist nurse provision for those with rarer neurological disease.</td>
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<tr>
<td>3</td>
<td>High Review specialist therapy provision related to neurology across Suffolk to avoid inequitable access to services.</td>
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<td>4</td>
<td>Medium Develop a one-stop service across Suffolk for accessing neurology advice, information and support. Key contact workers are used.</td>
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<td>5</td>
<td>Medium Review care planning so that there is a consistent approach across Suffolk and all service users have a care plan.</td>
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<tr>
<td>6</td>
<td>High Review the systems and capacity for providing consistent psychological support to newly diagnosed patients across Suffolk.</td>
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<td>7</td>
<td>High Develop training programmes for non-specialist staff to understand the needs of people with neurological conditions.</td>
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<td>8</td>
<td>High Develop integrated care pathways for neurological conditions across health and social care and other partners.</td>
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<td>All</td>
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<td>9</td>
<td>Medium Develop a flagging system to identify when a patient is admitted to a non-neurological ward within an acute hospital setting.</td>
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<tr>
<td>10</td>
<td>High</td>
<td>Review access to neuro-rehabilitation across Suffolk to ensure that delays in treatment are kept to the minimum.</td>
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<tr>
<td>11</td>
<td>Medium</td>
<td>Review access to early and specialist rehabilitation to ensure that this is equitable across Suffolk.</td>
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<tr>
<td>12</td>
<td>Low</td>
<td>A secondary to primary care discharge pathway and policy is developed to support sustainable rehabilitation.</td>
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<tr>
<td>13</td>
<td>High</td>
<td>Rehabilitation services are further developed in the community to ensure that these meet the needs of local people with neurological problems.</td>
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<tr>
<td>14</td>
<td>Medium</td>
<td>Review skills of community rehabilitation staff and where possible employ specialist neurological therapists.</td>
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<tr>
<td>15</td>
<td>Medium</td>
<td>Vocational rehabilitation is addressed and improved through better information for patients and wider training for staff.</td>
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<tr>
<td>16</td>
<td>Medium</td>
<td>Provide information about what equipment is available and the waiting timelines.</td>
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<tr>
<td>17</td>
<td>Medium</td>
<td>Review central equipment store processes to ensure timely provision of equipment.</td>
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<td>18</td>
<td>Medium</td>
<td>Ensure that service users have appropriate access to information on personal budgets and direct payments.</td>
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<td>19</td>
<td>High</td>
<td>Review continuing care assessment rates to ensure that Suffolk’s rates are in line with similar Council areas.</td>
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<tr>
<td>20</td>
<td>Low</td>
<td>Review availability of age-appropriate residential care.</td>
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<td></td>
<td></td>
<td>Consider developing an e-learning package for nursing and residential home staff on neurology.</td>
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<td>22</td>
<td>Medium</td>
<td>Provide ongoing training to staff, including neurologists and their teams, on the management of a person's end-of-life care.</td>
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<tr>
<td>23</td>
<td>High</td>
<td>Review respiratory care in the community for people with neurological conditions to avoid unscheduled admissions due to respiratory conditions.</td>
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<tr>
<td>24</td>
<td>High</td>
<td>Improve signposting about carer support services available across Suffolk.</td>
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<tr>
<td>25</td>
<td>Medium</td>
<td>Develop a consistent approach to emergency planning for carers, in particular out of hours.</td>
<td>10</td>
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<tr>
<td>26</td>
<td>High</td>
<td>Local commissioners and service providers (with the Strategic Clinical Network) access and use local data to understand patient flows across the county.</td>
<td>All</td>
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</tbody>
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1 Suffolk Joint Strategic Needs Assessment
2 Suffolk Neurology Business Case: Suffolk Community Health. October 2013 SERCO