About Sue Ryder

As a provider of specialist care, we are uniquely placed to understand the issues and challenges for people who are approaching the end of their lives and those who are living with a neurological condition. Our Policy and Public Affairs team works with and for the people we support, and other people affected, to influence policy and to ensure their voices are heard and that they have access to the care and support that they want and need.

About neurological conditions

A neurological condition is one that affects someone’s brain or nervous system. They can affect movement, communication, behaviour and mental health. Anyone can get a neurological condition at any time. Some, like cerebral palsy, are present from birth. Others, such as multiple sclerosis, motor neurone disease and Parkinson’s disease, can develop at any stage in life. Some can be caused by injury, like a head injury or stroke, or illness, for example tumours of the brain and spine. Many neurological conditions are life-changing because they cause long-term disability and can severely affect people’s ability to live independently. Some conditions improve over time with the right care and rehabilitation, and others may get worse until the person dies.

Response to call for evidence

Sue Ryder is delighted to have been invited to give evidence to the Scottish Parliament’s Health and Sport Committee as part of its inquiry into preventative spend. Our responses to the questions posed are set out below.

1. To what extent do you believe the Scottish Government’s approach and the approach by Integration Authorities and NHS Boards towards neurological conditions are preventative?

Despite the devastating effect that neurological conditions have on individuals affected and their families, to date there has been little to no element of preventative spend in the approach taken to neurological conditions, either at a national or local level. At a local level, there are sometimes limited services or projects for people living with neurological conditions – such as support groups or self-management programmes – but little is being done to develop any kind of care pathway designed to proactively support people and prevent later problems and costs, such as hospital admissions.

Until recently, the only framework available for the provision of specialist neurological services is provided by the National Clinical Standards for Neurological Health Services which were published in 2009. These include standards for all neurological conditions and further
standards for a small number of specific conditions, and only cover NHS services. The first Sue Ryder Rewrite the Future report, published in 2016, showed that the standards were not being properly implemented, with not one health board implementing all of the small selection of standards that were the subject of our Freedom of Information (FOI) request. One of the most fundamental standards is that health boards should have a three year neurological service delivery plan. Our FOI request in 2016 revealed five had a current plan, and our follow up FOI request in 2017 for our second Rewrite the Future report showed that four had a plan with all of these due to expire that year.

After our first report, Healthcare Improvement Scotland launched a review of the standards. A decision has now been taken to rewrite those standards which apply to all neurological conditions (i.e., excluding the condition-specific standards), due for publication in early 2019. Sue Ryder has successfully argued for these to include health and social care services – as people with neurological conditions tend to rely heavily on a range of services in the community. Most importantly, given past experience of the 2009 standards, we would like a clear commitment for an adequately resourced system to be put in place to monitor performance against the standards and drive improvements. While it may be because of the review that health boards have not developed or renewed their neurological service plans, this serves to underline a lack of impetus to drive forward improvements in neurological care, thus impacting on local ability to take a preventative spend approach.

Health and Social Care Partnerships (HSCPs) are under no compulsion to specifically include neurological services within their remit – unlike other service areas such as palliative care – and there is little or no mention of care and support for people with neurological conditions in any HSCP strategic plans. There is no doubt that people with neurological conditions will use some community services that are provided by HSCPs but the chances of them accessing the specialist support they need as a result of the complexity of their condition is very limited. In 2017 we asked health boards and local authorities if they had a specialist neurological rehabilitation team. Such a team would include specialist occupational therapy, physiotherapy, speech and language therapy and others, and is designed to prevent less of function or reduce the rate of loss of compensate for loss. Only a third of health boards had such a team and of our 32 local authorities, only five had such a team. Many local authorities and health boards believed a service or partial service was available locally but did not necessarily provide it themselves. This paints a picture of a complex and piecemeal system, not designed around the needs of people with neurological conditions. It also indicates a further missed opportunity to invest in any kind of preventative spend approach, with people not accessing this kind of support and then presumably requiring more intensive and possibly more expensive care, such as in hospital, or possibly suffering greater consequences of their condition, impacting their mental health and wellbeing.

At Sue Ryder we have seen for ourselves the consequences of inadequate care and support for people with neurological conditions before entering our services. For instance an individual who was being poorly supported at home by a generalist homecare provider moved to Dee View Court in Aberdeen after a rapid deterioration in his physical health and wellbeing. If a bed had not been available in our centre he would have been admitted to A&E for a costly indefinite stay in a hospital not equipped for his needs. In our view, he could have lived at
home for much longer if the care team supporting him had been equipped with the right level of expertise in managing a neurological condition.

However, despite this bleak picture there is now a growing recognition of the need to improve neurological care. This in turn should lead to improved preventative spend. The Scottish Government recently funded the Scottish Huntington’s Association (SHA) to develop a Huntington’s Care Framework designed to support people affected by this condition in a holistic and consistent way. This is now being rolled out, with support from the SHA in a number of local areas.

After the publication of our second report last September, the Scottish Government committed to developing a national action plan on neurological conditions for consultation by the end of summer 2018. The voice of people living with neurological conditions is being used to shape this via a group being coordinated by the Health and Social Care Alliance. To support the development of the action plan, the Scottish Government’s National Advisory Group on Neurological Conditions (NACNC) is carrying out a review of the current provision of neurological care and support by the NHS, local authorities and HSCPs. Not only that, the Scottish Care Home Census carried out by the Care Inspectorate and NHS ISD is for the first time aiming to establish how many people with neurological conditions (excluding dementia which is already known) are placed in residential care. The results of this are due towards the end of 2018. Combined with the new standards for neurological conditions which HIS are developing, there is a real chance that with the right level of leadership and scrutiny neurological care will be greatly improved over the coming years.

2. Is the approach adequate or is more action needed?

There are a number of initiatives, projects and programmes carried out at a local level to support people with neurological conditions that contribute towards the preventative spend agenda. For instance, Sue Ryder provides the 5Rs programme, a ten-week course for people with multiple sclerosis designed to give people practical support, peer-to-peer support and help people self-manage their condition and improve their wellbeing. This is a very popular programme run in Aberdeen which delivers results. For instance, at the end of one programme, a participant said:

“I feel in a better frame of mind then I did 10 weeks ago. I have found myself trying to draw which I haven’t tried in years! I think I will follow up some of the therapies ... I saw my GP last week. She couldn’t believe how much better I seemed. I am now coming off my antidepressants. I have been on them for 4 years.”

We receive similar feedback from people we’ve supported via our Self-Management Programme for people with all neurological conditions in Aberdeen, which is funded by the Transforming Self-Management in Scotland Fund. In this programme, we provide specialist input with support from a community of volunteers who help participants achieve personal outcomes, such as getting out of the house for the first time in years, or being able to pick up a child from school.

While programmes such as these make a huge impact on the lives of people and contribute towards preventative spend, they are often piecemeal and exist on short-term funding. There
is no strategic approach to ensure that everyone with a neurological condition is given the chance to benefit from this type of intervention.

The actions that are now being taken forward by the Scottish Government at a national level have the potential to make a significant difference to the provision of neurological care and to help develop a preventative spend approach.

However, efforts have been previously made – for instance with the 2009 neurological standards – but have not been sustained. This time there must be leadership by the Scottish Government to drive forward changes on the ground, coupled with robust measurement against the new standards and appropriate support for HSCPs. We would like to see:

- The new standards for neurological care must be backed up by an inspection regime that can easily identify where care falls short and how care can be improved at a local level, and this must be acted upon.
- Strategic commissioning guidance on neurological services should be provided to HSCPs, given their lack of experience in this area. This would help deliver person-centred care that meets people’s needs in a timely fashion, rather than relying on generic services to meet need and risking a higher level of unplanned hospital admissions as a result.
- The NACNC should be given the resources and authority to drive forward the action plan – with the Scottish Government’s backing – and regularly report on progress. It should contribute to continuous improvement as new approaches and services emerge that can support people with neurological conditions and contribute to the prevention agenda, ensuring that while local solutions are delivered, no-one misses out.

3. Are the services for neurological conditions being measured and evaluated in terms of cost and benefit?

As far as Sue Ryder is aware, there is no overarching or consistent approach to the measurement and evaluation of neurological services. As a neurological service provider we measure and evaluate our own services as and when required by organisations who are commissioning or funding them. For instance we are currently evaluating our 5Rs programme and self-management programme.

So that we can be assured that we are improving the quality of the lives of the people who use our residential care, we have recently embarked on a programme of outcomes-focused work:

- **Personal Outcomes** - all Sue Ryder neurological centre staff have had training in having person-centred conversations so that service user wishes and interests can be captured informally. This allows us to work together to identify what outcomes are important to them. A set of ‘I’ statements have been developed to be used during service user reviews to measure whether outcomes are being achieved and to capture personal stories.
- **Clinical Outcomes** - all centres will be implementing processes and tools to measure the benefit to people in terms of improvement in function and daily tasks, for those people whose condition it is possible to recover from, at least to some extent. Using the Northwick Park Dependency tool we will be able to demonstrate changes in
peoples' abilities as a result of our services. The intention is that this will allow us to demonstrate a cost benefit as dependency reduces.

In addition to this, we are currently working with New Economics Foundation – Consulting to develop an economic model of neurological care to demonstrate its positive impact on both the public purse and on the individuals concerned. We hope to bring an initial analysis to the meeting of the Health and Sport Committee on 27 March.

As part of the national action plan for neurological conditions we would like to see the development of a coordinated approach to the measurement and evaluation of the services people with neurological conditions use or should be able to use. Such an approach, together with strategic commissioning guidance to HSCPs would allow much better-informed commissioning of people-centred care and support for people with neurological conditions.

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