Sue Ryder

Sue Ryder provides incredible hospice and neurological care for people facing a frightening, life-changing diagnosis. We do whatever we can to be a safety net for our patients and their loved ones at the most difficult time of their lives. We see the person, not the condition.

In Scotland, Sue Ryder provides the following services:

- A purpose-built neurological residential centre, Dee View Court, in Aberdeen. This provides specialist care and support for people living there and includes a supported living unit. A number of self-management programmes for people living in the community are based from Dee View Court.
- Homecare services in Angus, Stirling and Falkirk.
- Palliative care in NHS Tayside to prevent hospital admissions.
- Online community and support for people approaching the end of life and their families.

In addition to our care services, we run a prisoner volunteer programme, supporting people who are due for release to gain skills and experience in our shops.

It is difficult to answer the questions posed by the inquiry comprehensively because we have experience of working with a relatively small number of Scotland’s 31 integration authorities. The level of engagement we’ve had – and continue to have – with those we’ve worked with has varied. In most cases we have contributed to consultations on strategic plans, either in formal consultations or at events. It is difficult to say how much impact this has had on decisions by the authorities themselves.

There is one issue we would like to highlight in the context of consultation with stakeholders by integration authorities, and that is the provision of care for people with neurological conditions, such as motor neurone disease, multiple sclerosis, Parkinson’s disease and Huntington’s disease.

There is clear evidence that people with neurological conditions need specialist care and support. Neurological conditions are complex: they affect someone’s brain or nervous system, which will usually affect movement, communication, behaviour and mental health. They affect every individual differently and cause long-term disability, with many conditions being progressive throughout an individual’s life. This is why Scotland’s clinical standards for neurological health services state: ‘evidence suggests that neurological conditions are most effectively dealt with by specialist clinicians’\(^1\). These services include specialist rehabilitation, physiotherapy, occupational therapy, neuropsychology and self-management support. Yet, the 2016 Sue Ryder Rewrite the Future campaign revealed that provision of these services at that point, by health boards and local authorities, was inconsistent, with some bodies not knowing what services were or were not available locally\(^2\). In response, the Scottish Government has said that there are sufficient arrangements in place to mean that the integration authorities should be able to provide such services for people with neurological conditions going forward. For instance, in response to a PQ on neurological care, Maureen Watt, then Minister for Public

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\(^{1}\) Clinical Standards – October 2009: Neurological Health Services, NHS QIS (October 2009)

\(^{2}\) http://www.sueryder.org/how-we-help/policy-and-campaigns/our-campaigns/dont-write-me-off
Health, said: “the integration of health and social care will tackle the challenge of ensuring a consistent provision of quality, sustainable care services for people who need joined-up, integrated support and care – particularly for those with multiple complex, long term conditions”.

The principles underpinning integration – a focus on person-centred outcomes coupled with local determination of services – are sound and sit very comfortably with the Scottish Government’s vision for health and social care. However, for people with neurological conditions, this approach is not yet working. This is for a number of reasons. Firstly, so far the priority of integration authorities has been to focus on older people’s care, and in particular, building services and capacity to keep older people out of hospital or to provide the right support to get them home from hospital as soon as possible. Secondly, there is no compulsion on integration authorities to provide services specifically to benefit people with neurological conditions. This is because neurological services are not included in regulation or elsewhere as a service that is required to be integrated. Thirdly, there is no national framework or strategy for people with neurological conditions, other than the clinical standards which are supposed to govern health services for people with neurological conditions, and which are currently under review. On top of this, from our analysis, it appears that there is little reliable information on the number of people with neurological conditions locally (or nationally) or their level of need. So while the national health and wellbeing outcomes are a very positive approach, for relatively small groups within the general population, there is a very real risk that their needs go unidentified and unaddressed.

Because of these reasons and despite the Scottish Government’s intentions, people with neurological conditions are currently falling into a gap. Indeed, our latest review of plans by integration authorities carried out in early 2017 shows little or no mention of people with neurological conditions, and no plans to specifically develop integrated specialist services for this group. The only activity in this area is the very welcome work by the Scottish Huntington’s Association to develop the care framework for Huntington’s disease, funded by the Scottish Government. This is to be piloted in two areas later this year, and then may be adapted for other neurological conditions. However, in order for this to happen there needs to be impetus at a national level, otherwise, as a result of the national health and wellbeing outcomes and indicators being so high level that they do not identify people with neurological conditions, there is a risk that there will be little pressure on integration authorities to take this framework forward. This is particularly the case when the authorities have more high profile, and costly, issues to deal with such as providing better care to older people at home to reduce the pressure on acute care. It will be left to local campaigning and relationships combined with the goodwill of integration authorities to turn their attention to the needs of people with neurological conditions.

To answer the question ‘what could be done to ensure greater collaboration and engagement in the decision making process of Integration Authorities’ we would argue that is incredibly difficult for third sector organisations such as ours to engage with each of the 31 authorities, in order to make the case for commissioning integrated services for people with neurological conditions. So for specific groups of people like this who risk being left behind by the integration agenda, a national approach needs to be taken, such as cross-cutting health and

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3 Written question S4W-30496, answered 21 March 2016
4 The National Advisory Committee on Neurological Conditions is currently establishing if it is possible to gain reliable and comprehensive data on the prevalence of neurological conditions across Scotland.
5 http://hdscotland.org/a-national-care-framework-for-huntingtons-disease/
social care standards specifically designed for neurological services, backed up by an adequately resourced inspection and improvement regime. Tools for designing and commissioning neurological services could be provided by the Scottish Government or Healthcare Improvement Scotland, that require involvement of third sector organisations and people who would use the services, in their development. National support is the only way in which there can be consistent and meaningful engagement by people with neurological conditions in the decision-making processes of integration authorities. Otherwise there will continue to be significant gaps in and difficulties accessing appropriate specialist care and support across Scotland.