HEALTH AND SPORT COMMITTEE

WHAT SHOULD PRIMARY CARE LOOK LIKE FOR THE NEXT GENERATION?

SUBMISSION FROM SUE RYDER

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As a healthcare charity, Sue Ryder supports people through the most difficult time of their lives resulting from terminal illness, the loss of someone close or a neurological condition. In Scotland, our nurses and carers provide compassionate and expert care as part of the wider health care system so we have a wealth of knowledge on what works well in primary care and what could be improved in order to help people live the best lives they possibly can.

In Scotland we provide specialist care and support for people with neurological conditions such as multiple sclerosis and acquired brain injury from our purpose-built centre in Aberdeen, Dee View Court, both for residents and increasingly for people living in their own homes. We also provide homecare for people living with a range of life-limiting conditions including neurological conditions in Angus, Stirling, Perth and Falkirk. And we provide bereavement support for people who are dealing with the death of someone close, primarily via our online community www.sueryder.org/support

Sue Ryder wholeheartedly endorses the Scottish Government’s vision for primary care.

Why is primary care important for people with neurological conditions?

While people with neurological conditions will generally need a high level of specialist input to help manage their condition, primary care plays an extremely important role as well, particularly in the earlier stages of progressive neurological conditions. A GP will most often be the first point of contact for a referral to specialist neurological services which is vital in terms of getting a diagnosis and then the right care and support (and treatment if available) being put in place. However the GP and wider primary care team is not simply the gatekeeper to specialist care and support; they have a vital role as part of the holistic team in supporting someone to manage their condition. For instance, someone in the early stages of a progressive condition such as motor neurone disease could benefit from physiotherapy to help strengthen muscles and maintain mobility for as long as possible. Someone with multiple sclerosis may benefit from speech and language therapy to help maintain their ability to communicate and to swallow safely as reflexes change. And occupational therapists have a vital role in supporting people with conditions such as these to live as independently as possible at home for as long as possible. All these types of rehabilitation are vital to help manage loss of function and to support people to live as independently as possible for as long as possible.

Not only is appropriate involvement of primary care services the right thing to do for people with neurological conditions, it benefits the wider health and care system. Our report The
case for proactive neurological care\(^1\), sets out how, combined with a proactive and managed approach to neurological care, better use of and involvement of primary care services particularly in the early stages of progressive conditions will save the system money. This includes the widest definition of primary care including services often provided by the third sector in short term funding arrangements, such as self-management. Economic modelling carried out by NEF Consulting for the report showed that if someone with motor neurone disease followed a proactive care pathway there would be an annual saving to the health and care system of between £20,000 and £30,000 compared to reactive, poorly managed care.

NHS HIS recently published the General Standards for Neurological Care and Support\(^2\) which also emphasise the importance of primary care as part of the holistic care and support that should be put in place around an individual with a neurological condition. For instance, Standard 1: Leadership and governance says that ‘To support people living with neurological conditions, there are well-defined pathways of care and protocols to facilitate:…access to multi-agency input including, but not limited to, primary care, community support, specialist neurological services, mental health and third sector support’. The need to ensure primary care staff are supported to continuously develop their knowledge and skills in order to better support people with neurological conditions is also made explicit, as is the role of the primary care team in collaboration on diagnosis and follow-up with appropriate information, support and advice. These standards represent a huge step forward in the way people with neurological conditions living in Scotland should be supported and cared for. How they are going to be adopted, particularly within primary care, is worthy of the committee’s consideration.

Why is primary care important for people living with a terminal illness?

Unless someone at the end of life is receiving specialist palliative care or is in hospital, palliative care is provided by the primary care team. This is very important as evidence suggests that most people would prefer to die at home. As such the role of the primary care team is vital and we welcome the Scottish Government’s commitment in its Health and Social Care Delivery Plan to ‘doubling the palliative and end of life provision in the community, which will result in fewer people dying in a hospital setting’.\(^3\)

It is our clear view that good, integrated and resourced primary care is vital to good palliative care. As such, along with Marie Curie and Hospice UK we outlined a proposal to the Sir Harry Burns 2017 review of national targets and indicators to replace current indicators on palliative care (one of which is unmeasured) with a new one, centring on the Key Information Summary (KIS). The KIS is a GP-generated note of vital information, wishes and plans that is shared across the multi-disciplinary team to aid shared decision-making. While it is extremely difficult to directly assess whether someone had their needs and desires around their death met, having an up-to-date and recently accessed KIS would

\(^1\) https://www.sueryder.org/sites/default/files/2018-09/Sue-Ryder-The-Case-for-Proactive-Care.pdf
\(^3\) https://www.gov.scot/publications/health-social-care-delivery-plan/
at least act as a proxy in that it showed a plan was made to allow a person’s needs and desires to be met as far as possible.

We were pleased that the review recommended that ‘The Key Information Summary, or its successor, might provide a useful driver for the place of the conversations around ‘what matters to you’, and therefore shared and supported decision making – and their recording in a shareable format.’ However it is disappointing that little action seems to have been taken in light of the review of targets and indicators and we firmly believe that finding a meaningful way of measuring palliative care provision within primary care would potentially make a huge difference and assist the Scottish Government in realising its ambition that by 2021 everyone who needs palliative care receives it.

**Why is primary care important for people dealing with bereavement?**

It is widely accepted that bereavement is linked to a number of adverse outcomes, including poor socio-economic and health outcomes, and that bereavement affects people in different ways at different times following the death of someone close. Therefore it’s welcome that the Carers (Scotland) Act places a duty on local authorities to provide information and advice regarding bereavement support and counselling to carers. However, research in Scotland that Sue Ryder and Hospice UK commissioned last year showed that 31% of respondents said they needed support in addition to that from their friends and family but only 6% accessed such support. People who did access bereavement support most commonly accessed it via their GP or practice nurse and of those who didn’t access support, the primary care team was the group people felt most comfortable approaching for help in signposting to or accessing bereavement support.

Given the unique and trusted position they hold for bereaved people, local primary care teams must be supported with the right tools, training and information to both directly support people and to identify people who could benefit from additional support and enable them to access the right support for them.

While every health board in Scotland has an individual who has responsibility for leading bereavement support, little change has been made to reflect the integrated health and social care structures that are now in place, so it’s unclear how easy or otherwise it is to access bereavement support or how well equipped the primary care team is to help people access the right kind of support. However, our research does suggest there is a significant need to improve this access and support across the country.

**Future of primary care**

The role of the primary care team in helping people approaching the end of life, those who have lost someone close to them and those living with neurological conditions is vital. In summary we believe the committee should consider:

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1. How primary care teams can be better equipped to provide rehabilitation and self-management support for people with neurological conditions

2. How primary care teams (and the wider system) should be supported to adopt the new General Standards for Neurological Care and Support

3. How better information sharing would allow the primary care team to work with others to deliver more holistic, integrated palliative care

4. If an indicator on palliative care would assist the primary care team to improve access to palliative care

5. How the primary care team can be better equipped to provide bereavement support and signpost people to other forms of bereavement support

Elinor Jayne
Head of Influencing
Sue Ryder