Sue Ryder’s policy proposals for Scotland

An introduction

Sue Ryder supports people through the most difficult times of their lives. Whether that’s a terminal illness, the loss of a loved one or a neurological condition – we’re there when it matters.

In Scotland we provide care for people with conditions such as motor neurone disease, Parkinson’s Disease, multiple sclerosis and acquired brain injury at our specialist neurological centre, Dee View Court, in Aberdeen. And we provide care and support for people living at home with conditions such as dementia and stroke in Stirling and Falkirk. In addition to this we provide support for people who are bereaved via our online services including an online community and counselling.

Given our experience in these areas we propose the following policy asks for the next Scottish Parliament:

1. Supporting carers after bereavement

In Scotland, every year there are around 40,000-50,000 family members and friends in caring roles that are bereaved. We suspect that this number will be even higher this year due to the COVID-19 pandemic. National Records of Scotland (NRS) has shown that around 90% of people who died with COVID-19 had an underlying health condition, such as dementia (over 30%) and the vast majority were over 75, suggesting that they are likely to have been supported by a family carer.

For many, when their caring role ends so does the vital support they receive from benefits and tax credits, peer support, and even their identity as a carer, as well as their purpose. This can have a significant detrimental impact on their physical and mental wellbeing, but there is currently limited support for carers once their caring role ends and we believe this needs to change.

As outlined in our Life After Death report, we are calling on your support for the following key actions:

- A Carers (Bereavement Support) (Scotland) Bill early in the next Parliament to provide information and a plan to support carers following the end of their caring role
- A new fund to support training and education for carers returning to work/seeking employment
- A new Post-Caring Support Payment to help carers struggling financially following the end of their caring role
To extend eligibility for the Carer’s Allowance and Carer’s Allowance Supplement for up to 6 months after the person’s caring role comes to an end (from the current 8 weeks)

2. Human rights in end of life care

The World Health Organisation states: “Palliative care is explicitly recognized under the human right to health. It should be provided through person-centred and integrated health services that pay special attention to the specific needs and preferences of individuals.” However, in the UK, this does not always translate into reality, with some people and families experiencing such poor end of life care that cases end up in the courts and in some cases, public inquiries.

The COVID-19 pandemic has highlighted the paramount importance of rights-respecting care at the end of life. With that in mind, it’s incredibly important that as a society we do all that we can to ensure the person at the end of life has the best experience possible, in challenging and often confusing and changing circumstances, and at a time of heightened emotion and sadness.

That is why Sue Ryder, in partnership with others, has undertaken extensive work in the area of human rights in end of life care.

We are calling for your support to:

- Review and rewrite all legislation, policies, protocols and guidelines in relation to end of life care to ensure it is rights-based
- Review of the Strategic Framework for Action on Palliative and End of Life Care to ensure a human rights approach is embedded
- Introduce human rights impact assessments to be mandatory for all new government policies
- Introduce a campaign to empower the public to understand and use their human rights

3. Right to rehab

The Right to Rehab is the next major health reform that needs to take place in Scotland. Rehabilitation helps people do more than just survive their condition – it helps them really live. It is vital to people living with long-term conditions or recovering after an accident, operation or illness, in order they can live as well - and as independently - as possible. We are acutely aware of this through our work with people with neurological conditions who are often overlooked by a system not geared towards their needs before they enter our services.

In most cases people’s rehabilitation will require a period of intervention by health professionals. It will also often extend beyond that treatment and into long-term support within
communities. At that point rehabilitation can take many forms and is determined by people’s needs and their goals.

However, all too often people are denied the rehabilitation that would help them get their lives back or that would help them to live well for longer. And when people are able to access rehabilitation it is often for short periods, or too generic to meet their needs.

Without the rehabilitation they need, people are at risk of readmission to hospital, likely to need repeat visits to GPs, need additional care from their family or providers, and may struggle to return to work or live their lives to the full. This is particularly devastating for people with complex neurological conditions.

We want every political party in Scotland to commit to delivering a Right to Rehab. The strategic shift in recent years towards personalised, community-based services must be matched by change on the ground. We must take action now in order to meet demands on health and social care created by an increasing older population, often with multiple conditions.

We are calling for you to support:

- A Right to Rehab which ensures that everyone has access to rehab when needed, and no-one is excluded by a ‘no rehab potential’
- People’s needs to be met locally by having the right workforce and professional leadership.
- The Right to Rehab to be incorporated in a new national Health and Social Care Strategy, placing it at the heart of integrated health and social care.

For information

Do not hesitate to get in touch for further information or if you would like to explore any of the above issues further.

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To support our campaign on bereavement leave please go to:

www.sueryder.org/bereavementleave

And for bereavement support resources please go to:

www.sueryder.org/support