We welcome the opportunity to respond to the Health and Sport Committee’s Inquiry into the preventative agenda in Scotland.

Marie Curie provides care and support for people living with a terminal illness and their families and carers. We provide support through our two hospices in Glasgow and Edinburgh, as well as our community nursing services across 31 local authority areas, and our 4 volunteer led Helper services. We also provide nationwide support through our information and support service including our national support line.

Last year we provided care for over 8,000 people living with a terminal illness, as well as their families and carers across Scotland. Our vision is for a better life for people and their families living with a terminal illness. We treat people with all terminal conditions, whether that is terminal cancer, dementia and frailty, MND, or heart failure. Our mission is to help people living with a terminal illness, their families and carers, make the most of the time they have together by delivering expert care, emotional support, research and guidance.

**Prevention when there is no cure**

In health and social care, much of the work on prevention focuses on actions to stop people becoming ill. Policies and frameworks are centred on helping people live longer, healthier lives. While efforts should be focused on interventions in the early years, active lifestyles and encouraging people to make healthy choices, there needs to be a recognition that prevention work doesn’t stop there.

Everyone will die and anyone can be affected by terminal illness. Sometimes this is not preventable. But that doesn’t mean that a preventative approach doesn’t have a role in supporting these people. We can prevent people from dying in environments that they shouldn’t be in, we can prevent unnecessary hospital admissions, we can prevent delayed discharges, we can prevent people dying in pain. By taking this preventative action, we can help to minimise the impact on carers and families and improve bereavement outcomes.

57,500 people died in Scotland in 2015. Around 46,000 of these people would benefit from some form of palliative care. Yet research, carried out by the London School of Economics and
Political Science (LSE) and commissioned by Marie Curie, suggests that nearly 11,000 people who need palliative care in Scotland each year are not accessing it¹. That means that across Scotland about 1 in 4 people are missing out on the palliative care they need.

Palliative care can help people achieve a quality of life that they wouldn’t necessarily otherwise have. Good palliative care can mean the difference between being able to stay at home, get out of hospital, remain connected to families and communities, living the life people want to with some element of independence and control, and dying the way they want to. These are all things that people tell us they want to do.

Investing in palliative care is often not spoken about in the preventative agenda, but we believe it should be. We believe in quality of life and supporting people to live as well as possible until they die. Without the right care and support, even the small things like responding to mail or looking after your cat can become impossible.

Investing in palliative care in the community can prevent unnecessary hospital stays, reduce A&E admissions, reduce pressure on hospital beds and reduce delayed discharges and, vitally, improve people’s quality of life.

A review by the London School of Economics² has estimated that providing palliative care to those that need it could potentially generate net savings of more than £4million in Scotland. Evidence also suggests that investment in community and specialist palliative care services is almost completely offset by savings in the acute setting³. This reduces pressure on hospital beds and has the potential to be a more efficient and effective use of statutory sector resources. The Nuffield Trust estimates that the NHS could be able to realise potential savings of nearly £500 per person by enabling for people at the end of life to be cared for in the community or at home⁴.

Over 50% of people die in Scottish hospitals, but the majority would prefer to die at home or in a homely setting. Investing more resources in community based palliative care outside of the hospital setting also means that costs associated with this can be can be offset by savings associated with fewer people dying avoidably in hospital. Using the Quality Innovation Productivity and Prevention programme (QIPP) estimate of £3,000 per hospital death⁵, around £21 million could be saved in Scotland⁶.

Marie Curie Services

Marie Curie services all contribute to the preventative agenda. These services not only provide health and social care services, but they can also help prevent the social isolation, loneliness

⁵ Hughes-Hallet T, Craft A, Davies C (2011) Palliative care funding review: funding the right care and support for everyone, Department of Health, London.
and ill mental health that can often develop following a terminal diagnosis. This should all be part of the debate and discussion around prevention, and the preventative agenda.

**Marie Curie Nurses** work night and day, in people’s homes across 31 local authority areas in Scotland, providing hands-on care and vital emotional support. This work allows people to stay in their homes, ensures they get the care and support that they need and supports carers and families.

**Marie Curie Hospices** in Edinburgh and Glasgow offer the reassurance of specialist care and support, in a friendly, welcoming environment, for people living with a terminal illness and their loved ones – whether that’s someone staying in the hospice, or just coming in for the day. Our day services not only offer medical outpatient care, but also offer complementary therapies to ensure, occupational therapies such as physiotherapy, emotional support sessions, peer-support and classes such as Tai Chi. This helps people maintain control of their lives, strengthen and provide rehabilitation, keep people active, maintain quality of life and also provide emotional support from professionals and from people who are in a similar situation.

**Marie Curie Helper Services** provide one-to-one emotional support, companionship and information about relevant local services to people living with terminal illnesses, and their families and carers through the use of trained volunteer helpers. We have four Helper services in Scotland, with two more launching in 2017. This service provides companionship and emotional support, practical help to allow people to attend appointments, social events and help with small everyday tasks, provide a break for families and carers and help people find information on further support and services that are available in the local area.

**Marie Curie Fast-track Services** help people living with a terminal illness spend their final weeks at home instead of hospital or a hospice. They ensure care is provided in the community to meet patient and family needs during a very difficult time. They do this by:

- providing care at home to avoid hospital or hospice admission,
- helping people’s safe, timely discharge to their homes, and give a short package of care afterwards, and
- supporting hospital discharge for up to seven days to bridge gap between care in the acute setting and social care services.

**The Marie Curie Fast-track Service in Glasgow** saved 5,807 acute bed days through admission prevention and 31,439 unplanned bed days. 97% of patients died in their preferred place of death and 100% of district nurses told us they would use the service again. Patient and carer feedback also showed that the service improved patient outcomes, made it easier to care for someone end of life and allowed people with terminal illnesses to spend time in their own surroundings in comfort and peace.

**Information and Support Services** are available for everyone affected by a terminal illness, so they can get the information and support they need, whether they have an illness themselves or they’re a family member or friend.

**Consultation priorities**
We believe that the Health and Sport Committee should dedicate time within the preventative agenda to look at preventative actions and spending for those nearing the end of their lives. Early and co-ordinated support is vital. Timely access to care and support services mean that people know what care they need, what is available and know how to navigate support systems. It also means that care providers can personalise care to anticipate when someone is likely to need more support and how that can be co-ordinated across statutory and third sector services.

Palliative care is a good example of integrated health and social care. It is an area, which if properly invested in can mean that people get the care they prefer during the course of their condition and at the end of their lives, but it is also likely to save valuable statutory funds which can be reinvested elsewhere, as well as relieve the pressure on acute services, such as A&E. As palliative care is delegated to Health and Social Care Partnerships, it is well placed to help explore ways that integration can help ease financial pressures and demonstrate effective preventative spend.

Focusing on the preventative aspect of palliative care will also help to reach the Scottish Government’s vision in the Strategic Framework for Action on Palliative and End of Life Care that everyone receives the palliative care they need by 2021, which we fully support.

We would welcome the opportunity to work with the committee to identify how this preventative spend could be identified and tracked more effectively.

**Further Information**

Marie Curie would be delighted to provide further support or insight to help the Health and Sport Committee in its work around the preventative agenda.

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