



## **END OF LIFE CARE IN SCOTLAND**

Health and Care services in Scotland (NHS Scotland) are separate from similar services in England and Wales in that they are controlled and funded by the Scottish Government.

In 2015, the Scottish Government published a framework ***Palliative and End of Life Care: A Framework for Action*** in direct response to the passing of a resolution in 2014 by the World Health Assembly requiring all governments to recognise palliative care and to make provision for it within their national health policies.

The Scottish Government built on actions and policies already in place but expanded on the key areas in palliative and end of life care which needed most improvement.

The Scottish Government recognised that more and more people were living with long term health conditions and many of them would have benefitted from palliative and end of life care but had not been receiving it.

The framework set out an ambitious plan committing the Scottish Government to supporting improvements in health care over a 5-year period, their vision being that high quality palliative and end of life care would be available to all who required it by 2021.

Key areas included:

- Access to palliative and end of life care should be made available to all who could benefit from it, regardless of age, gender, diagnosis, social group or location.
- People, their families and carers would have the opportunity to have timely and focussed conversations with appropriately skilled professionals to plan their care and support towards the end of life, and to ensure this met with their needs and preferences.
- Communities, groups and organisations of many kinds could understand the importance of good palliative and end of life care to the well-being of society.
- People would receive health and social care that supported their wellbeing, irrespective of their diagnosis, age, socio-economic background, care setting or proximity to death.
- People would have opportunities to discuss and plan for future possible decline in health, preferably before a crisis occurred, and were supported to retain independence for as long as possible.

- People would know how to help and support each other at times of increased health need and in bereavement, recognising the importance of families and communities working alongside formal services.
- People could access cultures, resources, systems and processes within health and social care services that empowered staff to exercise their skills and provide high quality person-centred care.

## **So What does This All Mean?**

### **Palliative Care**

Palliative care is offered to those people who have an incurable illness or long term, progressive health condition that cannot be cured by helping them manage their pain and other distressing symptoms. It also involves emotional, social and psychological support for the person, if needed, as well as for their family, friends or carers.

While palliative care includes end-of-life care, the key difference is that palliative care can be introduced at any point from diagnosis. The time spent in palliative care differs from person to person depending on the illness and the type of support they need. While some people may spend years receiving palliative care for a prolonged illness, others may only receive this type of care in the months, weeks or days before they pass away.

Both palliative and end of life care are provided by health and social care professionals to people of all ages who may be living, or dying from, an advanced or progressive health condition.

### **End of Life Care**

End of life care is a form of palliative care which is offered to people who are close to the end of life.

People are considered to be approaching the end of their life if:

- They are suffering from an advanced illness such as cancer, dementia or motor neurone disease
- They have an acute condition caused by a traumatic event such as an accident or stroke
- They are deemed elderly or frail and have co-existing conditions that could bring death in 12 months
- Have an existing condition and are at risk of a sudden decline that could cause death

End of Life Care is particularly geared towards managing the physical symptoms for a person while also providing emotional support for them, their family and their friends.

Every person has the right to express their wishes about where they want to receive end-of-life care and where they want to die. It helps if the individual's wishes are written down as a personalised care plan which can be reviewed regularly as the situation in their health changes.

A person can receive end of life care at home, in a care home, hospice or be cared for in hospital, depending on their needs and preferences. People approaching end of life are entitled to high-quality care, wherever they're being cared for.

If receiving end of life care at home or in a care home, a person's GP would have ultimate responsibility for their care. The likelihood is that community nurses and Hospital at Home Services would deliver tailored care packages at home and a person's friends, or family, may also adopt an active role in caring for them.

### **So, Has Scotland's Vision Been Realised?**

Important research conducted by Marie Curie in the wake of the pandemic shows that people in Scotland are still experiencing inequality when it comes to palliative and end of life care. Their report argues that Covid 19 only served to highlight how devastating death, dying and bereavement is to people and its effects will still be felt for many years to come. The pandemic has also intensified the complexities associated with terminal illness and shows the distinct lack of access to palliative care when it is needed most.

In 2023, many people in Scotland are still experiencing inequality and inequity when engaging with, and accessing, palliative care services, especially among certain demographics, such as those dying with non-cancer conditions, older people and women.

Although the Scottish Government are now moving towards the implementation of a National Care Service, as well as updating their framework on palliative and end of life care, it would seem that despite initially making some progress in realising their vision, this has ultimately not been realised as it currently falls well short of its targets.

***'Scotland's ageing population means more people will be dying in the years to come; by 2040 up to 10,000 more people could be dying every year with palliative care needs in Scotland . More people will also be dying in Scottish communities, with nearly two thirds of all deaths taking place in people's homes, care homes and hospices (Ellie Wagstaff, 2021)'***

<https://www.mariecurie.org.uk/blog/better-end-of-life-report-2021-scotland/293313>

<https://www.gov.scot/publications/strategic-framework-action-palliative-end-life-care/>

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