

Living Matters: Dying Matters

A Palliative and End of Life Care Strategy for Adults in Northern Ireland

The *Palliative and End of Life Care Strategy* has been developed in response to what people expect and value most from palliative and end of life care recognising that living matters and dying matters to all.

The Strategy's vision is that *any person with an advanced non-curative condition, lives well and dies well irrespective of their condition or care setting. This requires a philosophy of care that is person-centred and which takes a holistic approach to planning, co-ordinating and delivering high quality, equitable and reliable care that enables people to retain control, dignity and, crucially, choice in how and where their care is delivered to the end of their life*¹.

Making this vision a reality requires an understanding of the complexity of palliative and end of life care across all conditions, as well as ownership and leadership at all levels of policy, planning, commissioning, education and delivery of care. This will involve commitment to change culture and practice in the following 5 key areas:

Understanding palliative and end of life care

- Palliative and end of life care should be applicable across all conditions and all care settings.
- Palliative and end of life care should enhance quality of life, improve function and ensure comfort.
- Palliative and end of life care should present people with options for choice in by whom, how and where their care can be delivered.

Developing skills and knowledge

- Those responsible for the planning and delivery of palliative and end of life care will have an appropriate level of knowledge, skills and competence to provide sensitive and compassionate support and care.

- Those responsible for the planning and delivery of palliative and end of life care will have access to guidelines providing clear information on the best standards of practice.

Identifying needs and talking about what matters

- The effects of illness on the patient, family, carers and staff will be acknowledged.
- Patients will have a holistic assessment that identifies the social, spiritual, financial, physical and psychological needs they face as a result of their illness.
- Every effort will be made to address patients' symptoms e.g. pain, nausea, shortness of breath, agitation, psychological and spiritual distress.

Planning care - timely information and choice

- Individuals' priorities, options and choices will be at the centre of all palliative and end of life care planning.
- Patients, their families, carers and staff will feel informed and know what to expect as the condition progresses.
- A recorded plan of care will be made so that personal priorities are known to all care service providers and are accessible at all times.
- As far as possible, patients will be supported to die at home if that preference is expressed.
- Patients will have access to specialist palliative care services based on assessed need.
- The concerns and needs of caregivers (including respite), will be assessed, addressed and recorded.

Delivering and co-ordinating care, support and continuity

- Patients, families, carers and staff can count on having access to appropriate professionals to rely upon at all times.
- Movement between services, settings, and personnel should only happen when necessary and to improve quality of care and life for the patient, their family and carers.
- Proactive planning and effective communication must underpin the smooth delivery of care on a 24 hour basis.

Adapted from NICE, 2004, Regional Model 2008, & Improving Care for the End of Life. Joanne Lynn, Janice Lynch Schuster and Anne Wilkinson, Lin Noyes Simon (2008) Improving Care for the End of Life. A Source for Health Care Managers and Clinicians (2nd Ed) Oxford University Press
