

Consultation on Palliative Care in Northern Ireland

Submission by the Democratic Unionist Party

Introduction

The Democratic Unionist Party is committed to improving palliative care and support for those diagnosed with serious, complex and often terminal illnesses. Whether the cause of suffering is end-stage chronic illness, cancer, cardiovascular disease, cancer, acute trauma, premature birth, frailty in old age, it is our view that integrated palliative care services should be developed, strengthened and implemented across all levels of health and social care. As a Party we are alarmed by recent Ulster University research shows that current patterns of usage indicate that palliative care is accessed late in the course of illness. That should not be the case. Given that it is estimated that the population need for palliative care in Northern Ireland is predicted to increase by 31% by the year 2040, there also needs to be a step change toward ensuring future service delivery is capable of matching demand for support. With ever-growing pressure for assisted dying to be legislated for, it is now more important than ever that we provide the best possible palliative care.

Palliative Care in Northern Ireland

The DUP recognises the vital and indispensable contribution of our hospices, care units and the medical professionals who specialise in the provision of palliative care in inpatient, primary care and community settings. We also acknowledge that various initiatives demonstrating elements of a public health approach to palliative health have been developed. These include the 'Heart of Living and Dying' initiative developed by a social worker in the Southern Health and Social Care Trust which is being delivered regionally. In the Northern Health and Social Care Trust, 'End of Life Companion' services are being delivered. The 'Compassionate Communities North West' initiative is working towards changing attitudes and behaviour towards life, age, death and loss.

Building on the anticipated inclusion of death, dying and bereavement in the final Executive Programme for Government, the DUP would support a refreshed and strengthened palliative care strategy which affords children and adults who suffer from serious, long-term and debilitating illnesses the opportunity to live well with a care strategy in place. There is an obvious overlap with other headline public health strategies, including the long-term commitments on cancer. However, in our view, this should not be to the detriment of distinct and bespoke approaches to seeking improved outcomes for palliative and end of life care.

People across Northern Ireland must have access to a valued end-of-life experience. Too many people at end of life end up in hospital when they do not want or need to be there and the picture is the same across the UK. Palliative care is of vital importance in supporting people to live well and achieve the best quality of life as their illness progresses.

A commitment was made in New Decade New Approach that the Executive '*will provide increased investment to fully implement service improvements for palliative and end of life*

care including enhancing the contribution of hospices; and to increase support for palliative perinatal care.' Indeed, we want to see palliative care regarded as a core aspect of statutory health provision, rather than dependent on the generosity of the local community. The recent uncertainty around, and loss, of hospice beds, was, and is, unacceptable.

Access to Palliative Care

According to Marie Curie, 90% of the population will need palliative care in their last months, weeks and years of life. Despite this, research commissioned by Marie Curie in 2015 and carried out by the London School of Economics and Political Science suggested that nearly 3,000 people who need palliative care in Northern Ireland each year are not accessing it. This is a pressing issue and there needs to be an ambitious plan from the Department for Health for how additional resources will be allocated to reinforce and enhance access to our palliative care and hospice network. This must be done in co-design with clinicians, care providers and be person centred at its core.

The DUP sees merit in the proposal to integrate palliative care specialists within primary care networks and emergency services. This would enable timely identification of those needing end of life care. Having 24/7 clinical support in this area would enable people impacted to receive care outside of a hospital environment which would also reduce demand on urgent care services. Marie Curie, for example, have argued this would transform people's end of life experience and free up hospital beds for those who need them.

Demographic Changes

The population in Northern Ireland is changing. NISRA statistics have demonstrated that the population aged 85 and over has increased by 25.8% in the decade since 2013 - a rate over five times higher than the population as a whole. This change in demographic will have consequences for health and social care in Northern Ireland. Half of people in Northern Ireland over the age of 65 have a long-term health-related limitation and multimorbidity is set to increase as the population ages meaning that people who are living with a terminal illness will often have a number of conditions to manage at the same time such as chronic heart disease and stroke. The DUP believes there is a need for integrated care across conditions. The responsibility to promote earlier and better palliative and end of life care must be cross-cutting through our health and social care system.

Public Awareness and Knowledge of Palliative Care

A 2010 review of the implementation of the Living Matters Dying Matters Strategy highlighted that whilst many initiatives have been developed to raise awareness of palliative and end of life care, there remained a significant lack of understanding. Regrettably, that gap continues to exist and the DUP stresses the need for a coordinated approach to raising public awareness about palliative and end of life care as a core component of any new strategy, action plan or workstream.

Palliative care can relieve serious health-related suffering for people with many different illnesses including multiple sclerosis, dementia and motor neurone disease. Traditionally, the focus has surrounded care for advanced-stage cancer patients. However, good quality end-of-life care should be an integral part of care provided for individuals living with chronic illnesses. The DUP believes the Department of Health, Trusts and care providers must fully realise the potential to promote anticipatory planning and promote enhanced end-of-life care. This could include embedding this as part of wider public health messaging - in addition to early care guidance directed at the needs of the individual living with the life-limiting condition and their families to ensure their needs are met throughout the illness trajectory.

Such an approach could have significant benefits in the treatment of particular illnesses. For example, research has shown that health care professionals and family carers have difficulty in recognising dementia as a terminal illness, yet integrating a palliative care approach early in dementia care could be beneficial due to the poor ability for an individual living with advanced dementia to communicate their decision making and end-of-life care choices.