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Scottish Public Health Network (ScotPHN)

Palliative and end of life care in Scotland: The rationale for a public health approach

Briefing Paper 3: Legislative framework

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This briefing paper, accompanying the report 'Palliative and end of life care in Scotland: the rationale for a public health approach,' outlines international and national legislation pertaining to palliative and end of life care in Scotland.

International legislation

Article 25.1 of the Universal Declaration of Human Rights states that "*Everyone has the right to a standard of living adequate for the health of himself and of his family, including food, clothing, housing and medical care and necessary social services*"¹.

Under Article 12.1 of the International Covenant on Economic, Social and Cultural Rights, everyone has a right to "*the highest attainable standard of physical and mental health*"². The legislation identifies an obligation for States to "*respect the right to health by, inter alia, refraining from denying or limiting equal access for all persons.....to preventive, curative and palliative health services*" and in relation to older people, an obligation to ensure "*attention and care for chronically and terminally ill persons, sparing them avoidable pain and enabling them to die with dignity*"³.

In 2014 the World Health Assembly (WHA) published a resolution which recognised that "*palliative care, when indicated, is fundamental to improving the quality of life, well-being, comfort and human dignity for individuals, being an effective person-centred health service that values patients' need to receive adequate, personally and culturally sensitive information on their health status, and their central role in making decisions about the treatment received*", and identified palliative and end of life care as an "*ethical responsibility of health systems*"³. Member States are required to report their progress against the resolution, including the integration of PELC across the continuum of care, at the 69th World Health Assembly in 2016

National Legislation

There is no dedicated palliative and end of life care legislation in Scotland. In 2010 The Palliative Care (Scotland) Bill was introduced to the Scottish Parliament⁴. The aim of the Bill was to give legislative effect to the key intentions of 'Living and Dying Well: A National Action Plan for Palliative and End of Life Care in Scotland'⁵ by placing a statutory obligation on Scottish Ministers to provide and monitor palliative care for people with life-limiting conditions and their families. The Bill was withdrawn following scrutiny⁶. The Health and Sport Committee noted that progress had been made in achieving the strategic direction outline in 'Living and Dying Well' without primary legislation and that more time was needed to fully evaluate the impact of this strategy. Concern was expressed that primary legislation in this area could reduce the flexibility of service provision and move focus away from delivering the key objectives of 'Living and Dying Well'. A commitment to produce appropriate indicators to monitor progress was sought from Scottish Government.

On 2 July 2015 the Health and Sports Committee announced a Parliamentary Inquiry into the quality and availability of palliative and end of life care in Scotland, 'We need to talk about Palliative Care'⁷. The Inquiry considered access to palliative care, anticipatory care planning, communication with patients and their carers, the patient

and carer experience and training and support for health and social care professionals. The Committee published its findings on 25 November 2015. A number of recommendations were made, many to be taken forward by the Scottish Government in their 'Strategic Framework for Action on Palliative and End of Life Care'⁸. Further legislative change was not recommended. Findings from the Parliamentary Inquiry and the Scottish Government's recently published Strategic Framework for Action are summarised in Briefing Paper 4.

Legislation in a number of other areas is relevant to the provision of palliative and end of life care in Scotland. Under the National Health Service (Scotland) Act 1978 (c29), Ministers have a general duty to promote a comprehensive and integrated health service and the power to institute health boards in order to carry out functions in relation to this duty; although not explicitly stated the provision of palliative and end of life care could be considered within this remit⁹.

Local authorities have a duty to assess the community care needs of anyone who requests it and deliver a package of care in order to meet those needs (sections 12 and 12A) under The Social Work (Scotland) Act 1968¹⁰. Under sections 12AA and 12AB of the same act, carers have a right to request an assessment of their ability to provide, or to continue to provide care; it is incumbent of the local authority 'have regard' for the results of that assessment. The latter legislation may shortly be superseded by The Carers (Scotland) Bill¹¹. Currently under scrutiny the Bill, introduced to The Scottish Parliament 2015, proposes a range of legislative provisions to support and enable carers.

As part of a wider programme of major public sector reform a number of legislative provisions to support the Scottish Governments commitment to deliver high quality patient-centred care in line with the Christie Principles¹², have been made.

The 2011 Patient Rights (Scotland) Act introduced a 'Charter of Patient Rights and Responsibilities' and established a set of health care principles which service providers have a statutory duty to uphold, aimed at improving patients' experiences of using health services and supporting people to become more involved in their health and health care¹³. The Social Care (Self-directed Support) (Scotland) Act 2013 increases autonomy and mutuality by giving people choice over how they receive support¹⁴.

The Community Empowerment (Scotland) Act, passed by Parliament in 2014, supports wider community involvement in the planning and delivery of local services¹⁵. Building on the 2002 Community Care and Health (Scotland) Act¹⁶, The Public Bodies (Joint Working) (Scotland) Act 2014 implemented in Spring 2015 is the legislative framework for integrating health and social care services in Scotland¹⁷.

The 2014 Children and Young Peoples (Scotland) Act¹⁸ will, from 2016, place into statute key elements of from a range of children's services policies including aspects of Getting It Right for Every Child¹⁹.

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