

UN Open Ended Working Group on Ageing United Kingdom policy contribution

Long-term care and palliative care

Long-term care is not defined in legislation in England, Scotland or Wales. An individual's needs for care and support can be met in a number of ways including more traditional 'service' options, such as care homes or homecare, but may also include for instance assistive technology in the home or equipment/adaptations. Legislation in Northern Ireland differs significantly as a result of its fully integrated system of health and social care, with services delivered by Health and Social Care (HSC) Trusts. Everyone has the right to access and receive appropriate levels of advice and support.

In England, the Care Act 2014 introduces a national threshold that defines the care needs that local authorities must meet. All local authorities have statutory duties to look after the vulnerable elderly (and disabled people) in their area. In Scotland, local authorities have a duty under the Social Work (Scotland) Act 1968 to assess a person's community care needs and decide whether to arrange any services.

All four UK nations are working to ensure high quality and sustainable long-term care, described in the following paragraphs. It should be noted that this description does not include the full range of activity, such as support for informal carers.

In England, the Care Act 2014 sets out a legal duty for an adult's 'eligible needs' to be met by the local authority, subject to their financial circumstances. Where a local authority chooses to charge someone for care and support, they must undertake a financial assessment of what the person can afford to pay. The Care Quality Commission regulates, monitors and inspects providers of (health and) social care services to make sure those services provide people with safe, effective, compassionate, high-quality care. The Care Act 2014 provides a legislative focus on personalisation by mandating care and support plans and personal budgets. The adult, their carer and any other person the adult requests, must be involved in the development of the care plan, and agree with the content of the plan. Restrictive physical interventions are risky for all individuals involved, and we know they have a negative impact on patients' dignity and trust in services. Positive and Proactive Care was published in April 2014 to provide guidance for adult health and social care staff in England.

Councils in England have access in total to £9.4 billion more dedicated funding for adult social care over the next three years. The Government has also announced a Green Paper on the care of older people, to be published in 2018, which will consider the fundamental issues facing the care system. Individuals with concerns about the care they have received can request a review right of a care and support plan, raise issues through their NHS Trust or local authority complaints/appeals processes and ask the Local Government or Parliamentary and Health Service Ombudsman to consider their case.

The Department of Health Northern Ireland is currently taking forward a reform of adult care and support to outline the future strategic direction for the provision of adult care and support services. The Regulation and Quality Improvement Authority (RQIA) is the independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services. All individuals in Northern Ireland who are unhappy at any stage of the care management process have the right to make a complaint under the HSC Complaints Procedure. In addition, agencies and establishments regulated

by the RQIA must operate a complaints procedure that meets the requirements of the HSC Complaints Procedure.

In Wales, the Social Services and Well-being (Wales) Act 2014 provides equivalent rights and entitlements for adults and children to high quality and sustainable long-term care. Individually, these rights include a shared approach to assessment across all ages; national eligibility criteria; financial assessment and support planning, including person directed support via the receipt of a direct payment relating to their eligible care and support needs. A prescribed complaints procedure secures redress and remedy, including the role of the Public Service Ombudsman. Strategically, local authorities and local health boards are required to plan and secure population well-being based upon a joint assessment of their local population.

The Welsh Government provides local authorities with funding through the Revenue Support Grant to deliver their statutory responsibility for social services. An additional £55 million of recurrent funding was provided to social services in 2017-18 and an additional £42 million in 2018-19 to support front line service delivery. The Older People's Commissioner for Wales is an independent voice and champion for older people across Wales, standing up and speaking out on their behalf, focussing on the rights of this group.

Free personal care is available for everyone aged 65 and over in Scotland who have been assessed by the local authority as needing it, regardless of income. Free nursing care is available for people of any age who have been assessed as requiring nursing care services. Free personal care is available to people in the last six months of life regardless of age. In April 2019, free personal care will be extended those under 65. The Care Inspectorate regulates and inspects care services to make sure they meet the right standards. Care Services have to provide quality care as set out in legislation the [National Care Standards](#) and, from April 2018, Scotland's new [Health and Social Care Standards](#). The Care Inspectorate will make recommendations, requirements and can even take enforcement action when necessary.

The Public Bodies (Joint Working)(Scotland) Act 2014 legislation brings together NHS and local council care services under one partnership arrangement for each area. In total, 31 local partnerships have been set up and they will manage almost £8 billion in health and social care resources. Integration means a greater emphasis on enabling people to stay in their homes, or another homely setting, where possible. The [Self-directed Support \(Scotland\) Act 2013](#) makes legislative provisions relating to the arranging of care and support, community care services and children's services allows people to choose how support is provided to them by giving them as much on-going control as they want over the individual budget spent on their support.

There is no legal definition of **palliative care** in the UK. The National Institute for Health and Care Excellence (NICE) defines palliative care as '...the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families.' The Department of Health (Northern Ireland)'s 2010 palliative and end of life care strategy for adults, *Living Matters: Dying Matters*, defines palliative care as '...the active holistic care of patients with advanced progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families'. The Scottish Government's *Strategic Framework for Action on Palliative and End of Life Care (SFA)* accepts the World Health Organisation's 2015 definition: 'Palliative care is an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with life-threatening illness. It prevents and relieves suffering through the early identification, correct

assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual.’

With an ageing population, living longer often with health problems such as dementia, the challenge posed to health and social care providers and commissioners is to respond to the increasing numbers of the elderly and extreme elderly in the population and to meet their changing needs for end of life care. In England, there are extensive surveys and collections of data on the provision of palliative care including:

- Data and reports published through the Government’s end of life care intelligence network to support health service providers deliver high quality end of life care.
- The National Survey of Bereaved People (VOICES) survey, which monitors quality of end of life care by collecting the views of bereaved family and friends about the care received by the person they were caring for at the end of life.
- A national audit of end of life care in hospital.

In Northern Ireland, the first phase of a Palliative and End of Life Care needs assessment was completed in 2017 by the Health and Social Care Board and Public Health Agency. The aim was to establish a comprehensive analysis of the number of adults who could benefit from a palliative care approach. A report by the All Ireland Institute of Hospice and Palliative Care ‘*Let’s Talk About*’ (2016), which included the findings and conclusions of a survey of people’s positive or negative experiences of palliative care in both Northern Ireland and the Republic of Ireland, helped inform the needs assessment. Resources used in Scotland to collect information on palliative care include:

- National Health and Wellbeing Outcomes, underpinned by several data points relating to palliative and end of life care.
- Palliative and End of Life Care Research Forum which also regularly undertakes studies to support improvements in palliative and end of life care services and supports.

In all four UK nations, NHS care is free at the point of need and this includes the provision of NHS palliative care. The level of care provided should reflect the level of assessed need. In Northern Ireland, *Living Matters: Dying Matters* sets out the vision that any person with an advanced, non-curative condition lives well and dies well, irrespective of their condition or care setting.

Palliative care in the UK may be provided at home, in a care home, in a hospice or in a hospital. In England, the configuration of services will vary between local areas, reflecting the different geographies and population demographics. It is the responsibility of local NHS decision-makers to arrange services in a way that best meets the needs of their resident populations. In Northern Ireland, palliative care is provided in response to the holistic assessment of the needs of the individual and those important to them. This includes an individual’s physical, psychological, social and spiritual care, from identification of having palliative care needs through to support for those important to them in bereavement. Palliative care is a core service in Wales and all Health Boards have multi-disciplinary Specialist Palliative Care teams, accessible seven days a week with specialist advice available 24/7. Scotland provides palliative care in the same way as in England. However, in 2016 Scotland implemented legislation to bring together health and social care into a single, integrated system, with Integration Authorities now responsible for funding for local services including palliative and end of life care.

Much of what is considered the basis of good practice in palliative care in England was born out the pioneering work of Dr Cicely Saunders in the 1960s. She established the principles that constant pain needs constant control; the importance of relieving the problems of the dying, including bedsores, nausea, depression and constipation; and insisting that dying people needed dignity,

compassion, and respect. Whilst clinical practice and wider health service provision have evolved considerably since, these principles and approaches remain a key feature of the guidance produced by Government, NICE and the professional clinical organisations. NICE has produced a range of guidance for palliative and end of life care to support clinicians and local NHS decision-makers to improve care. In July 2016, the Government set out its commitment to everyone at the end of life in *Our commitment to you for end of life care* which included plans to support delivery of this commitment, including measures to increase personalisation of care, measures to improve care quality and education and training in end of life care, and measures to encourage the spread of innovative models of care and strengthen provision of end of life care support in the community.

In December 2015, The Scottish *Strategic Framework for Action on Palliative and End of Life Care* (SFA) set out an ambition for improving palliative and end of life care. The Scottish Government is currently working with key stakeholders to take forward this programme of work. In Northern Ireland, in 2010, *Living Matters: Dying Matters* included a vision that any person with an advanced, non-curative condition is supported to live well and die well, irrespective of their condition or care setting.

A 2015 review by Regulation and Quality Improvement Authority to assess progress found that there had been very significant progress made in implementing its recommendations, recognising that this was facilitated by strongly committed leadership from both statutory and voluntary sector organisations, with clear evidence of strong partnership working.

A new programme '*Palliative Care in Partnership*' was established in Northern Ireland in 2016 to support the further development of palliative and end of life care. Its remit includes ensuring the delivery of key priorities in palliative and end of life care both regionally and locally.

In Wales, National Clinical Implementation Groups for adult and paediatric palliative care have been established to share good practice and encourage an integrated approach to service improvement were established and they oversee the implementation of the *End of Life Care Delivery Plan 2017-2020*. This plan sets out a vision for palliative care in Wales that emphasises national priorities, including:

- Empowering patients through the understanding that a healthy approach to dying.
- Reducing admissions to Acute Hospitals at the End of Life and supporting patients to remain in their place of residence.
- Improving how we measure success.
- Bereavement care.
- Extending the specialist reach through education programmes for non-specialist teams.
- Improving clinical communication through digital technology.
- Using research and audit to effect change.

The group have produced All Wales guidance on Care Decisions at the End of Life (Adult and Paediatric) and have also secured a dedicated Clinical Lead for transitional care. An All Wales Advance Care Planning Strategic Group has been established to provide clear leadership and strategic direction for all aspects of anticipatory care and advanced care planning across Wales, including Advance Statements, Advance Decisions to Refuse Treatment, Lasting Power of Attorney, Do Not Attempt Cardio Pulmonary Resuscitation, Last Will and Testament, Organ Donation and Mental Capacity.

Autonomy and independence

The Mental Capacity Act

The Mental Capacity Act (2005) empowers people to make decisions for themselves wherever possible and protects those who may be unable to do so. The Act defines a standard of mental capacity that applies to everyone, and states that every effort must be taken to encourage and support the person to make the decision for themselves.

The Act sets out how professionals should support and care for people who may lack capacity and how people can prepare for such a time in their lives. It aims to protect and empower individuals, including older people who may suffer from diseases such as dementia and have a concomitant lack of capacity. It sets out a person-centred approach that seeks to ensure that those who lack capacity are afforded the dignity and respect that everyone would expect.

The Act has five principles:

- You must assume someone has capacity unless it is proved otherwise;
- you must support people to make their own decisions before concluding that they cannot;
- people retain the right to make unwise decisions;
- anything done for people without capacity must be in their best interests; and
- anything done for people without capacity should be the least restrictive possible.

The Act provides for Independent Mental Capacity Advocates whose role is to represent and support persons in the cases of provision of serious medical treatment by the National Health Service or accommodation by the National Health Service or local authorities. Court of Protection Rules, which are made under the Act and govern the procedure in the Court of Protection, have been amended to require judges to determine how best to secure the involvement of the individual in proceedings.

The Act provides for Lasting Powers of Attorney and Advance Decisions, which give an individual the ability to plan. This is seen by many as an important form of support, whereby an individual can state their will and preferences, which should be followed at a time when they may not be in a position to communicate their wishes to others. There are currently 2.3 million registered Lasting Powers of Attorney. There are no details of the numbers of Advance Decisions, as these do not require registration.

Awareness raising

In 2015, the UK Government formed the National Mental Capacity Forum to promote and raise greater awareness of the Mental Capacity Act. In February 2017, the forum held an Action Day – the theme of which was “Supporting decision making”. The Action Day was attended by 140 stakeholders who ranged from health and social care, together with those from other sectors (for example, finance, legal, police, housing). The Forum held another action day in March 2018, again on the theme of “Supported Decision Making”. The Forum continually promotes supported decision-making and through its close association with the Social Care Institute for Excellence now hosts extensive materials on the subject, which can be accessed by both the public and professionals. The National Institute for Health and Care Excellence is also working on guidelines for supporting decision-making.

The UK Government has worked closely with the Social Care Institute for Excellence to produce materials and training on the Mental Capacity Act for social care professionals. This training contributes to the care professionals “Continuing Professional Development” accreditation. In

addition, the Care Quality Commission – the independent regulator of health and adult social care in England - monitors the use and awareness of the Act in care homes.

In England, the UK Government has worked with the Social Care Institute for Excellence to produce training materials on the Deprivation of Liberty Safeguards and the UN Convention on the Rights of Persons with Disabilities. We are aware that there are criticisms of the Deprivation of Liberty Safeguards and in light of criticisms, the UK Government asked the Law Commission to investigate and make recommendations on the process. The report was published in March 2017 and the Government responded to it in March 2018.

Health Services and Social Care

The NHS Constitution sets out a range of patient rights including:

- The right to receive care and treatment that is appropriate to the individual, meets their needs and reflects their preferences.
- The right of the individual to be involved in planning and making decisions about their health and care and to be given information and support to enable them to do this. This includes being given the chance to manage their own care and treatment, if appropriate.

Local authorities must promote wellbeing when carrying out any of their care and support functions in respect of a person. The wellbeing principle applies in all cases where a local authority is carrying out a care and support function, or making a decision, in relation to a person. 'Wellbeing' is a broad concept, and includes:

- personal dignity (including treatment of the individual with respect);
- control by the individual over day-to-day life (including over care and support provided and the way it is provided);
- participation in work, education, training or recreation.

Disabled Facilities Grant

The Disabled Facilities Grant (DFG) is a capital grant paid to local authorities in England. It helps to meet the cost of adapting a property for those on a low income with a disability or a care need, so that they can live safely and independently in their homes for longer – and therefore avoid the need for costly hospital stays.

Adaptations include widening doors, installing ramps, grab rails, stair lifts, level access showers and raised toilets, improving access to gardens and in some instances home extensions. Heating systems, insulation and telecare can also be funded through the DFG.

People of all ages can apply to their local authority for a DFG. Local housing authorities in England are under a statutory duty (through the Housing Renewal Grant Regulations 1996) to provide a means tested grant aid to those people who qualify, which is also subject to an assessment of need usually by an occupational therapist.

The DFG is currently (April 2018) being independently reviewed. It is expected to make evidence-based recommendations on how the Grant could change in the future. The review will report in early summer 2018. The DFG funds around 40,000 adaptations each year in England. Scotland, Wales and Northern Ireland operate separate systems.