

# End of life care policies and laws in England and Japan

## *from mutual learning to policy transfer*

### Executive summary

- England and Japan face significant end of life care challenges in the contexts of population ageing, heavy demands on health and social care systems and changing expectations about death and dying.
- England could further enhance its well-established end of life care systems by improving inter-disciplinary cooperation and simplifying procedures to more widely and quickly deliver care and support.
- Japan is encountering increasing pressures to optimise and diversify its current end of life care systems, while legislation and government-led national strategies are also urgently needed.

### Background

England and Japan are among the top countries in the world for high-quality end of life care and palliative care (Clark et al., 2019). Both countries face a range of challenges in an era of unprecedented levels of ageing, dying and bereavement (Table 1). Whilst benefiting from affluent societies and highly developed care systems, England and Japan both face increasing gaps between the need for end of life care and the capacity for care. Both countries are encountering significant issues and crises in end of life care provision, including funding, cooperation, the level of workforce education, as well as accessibility and equality of care. Given socio-cultural differences, England and Japan also encounter unique situations, when providing end of life care. This briefing refers to England specifically and excludes the other devolved nations of the United Kingdom.

Table 1: Demographics and healthcare

	England	Japan
Population	56m [2018]	127m [2019]
Population aged 65 and over	18.2% [2018]	28.1% [2018]
People with dementia	885,000 [est. 2019]	6,020,000 [est. 2020]
Number of deaths	541,589 [2018]	1,362,470 [2019]
Leading causes of death [2018]	Cancer Circulatory disease Respiratory disease	Cancer Heart disease Senility
Place of Death [2018]	Hospital: 45.4% Home: 23.8% Care home: 22.5% Hospice: 5.9%	Hospital: 73.7% Home: 13.7% Nursing home: 10.6%

[Sources: Public Health England, Office for National Statistics, Statistics Bureau of Japan, Japan's Ministry of Health, Labour and Welfare (MHLW)]

### England

- National Health Service (NHS) provides healthcare to all residents free at the point of delivery
- Social care supported by public and private funding
- Free hospice care to everyone referred
- Hospices are the main end of life care provider, hospitals also provide specialist palliative care
- Over 150 registered adult hospices, many hospitals have palliative care units
- Hospices funding consists of around 1/3 from government and 2/3 local support/charitable giving
- National strategies, legal provision, regulations and guidelines exist on varied aspects of end of life care

### Japan

- National Healthcare Insurance (NHI) subsidises 70%-90% of costs for all residents
- Universal Long-Term Care Insurance (LTCI) covers small out-of-pocket payments mainly for people aged 65+ who need nursing care services
- NHI and LTCI benefits are designed to cover relevant costs of end of life care, such as palliative care and life-sustaining treatments (LSTs)
- Medical institutions are the main source for end of life care
- Over 400 palliative care units exist
- Limited legislation and government guidelines on specific aspects of end of life care

- This policy brief has been conducted within the Mitori Project, funded by an ERSC-AHRC UK-Japan SSH Connections grant (ES/S013865/1), Principal Investigator David Clark, Co-Investigator Hirobumi Takenouchi.
- The work in Japan has been supported by the Uehiro Foundation on Ethics and Education (Japan).

**Authors:** Dr Chao Fang (University of Bath), Ms Miho Tanaka (Japan Medical Association Research Institute)

**Advisors:** Professor David Clark (University of Glasgow), Professor Hirobumi Takenouchi (Shizuoka University),  
Mr Dominic Carter (Hospice UK), Professor Satoshi Kodama (Kyoto University),  
Mr Joshua Gallagher (University of Cambridge)

**Enquires:** Dr Chao Fang [C.Fang@bath.ac.uk](mailto:C.Fang@bath.ac.uk), Ms Miho Tanaka [mipomipo-tyk@umin.ac.jp](mailto:mipomipo-tyk@umin.ac.jp)

## Our approach

### Why focus on policies and laws?

- England and Japan have both responded to the increasing and changing needs for end of life care with various policies and laws.
- These tend to focus on the general population and large groups, thereby applying a standardised approach to individual care at the end of life care.
- It is important to understand how current policies and laws attempt to bridge the potentially competing priorities of public health interests and individual needs and preferences.
- In light of common challenges and opportunities faced by England and Japan, a comparison of policies and laws can enable mutual understanding to inform and reshape future policy-making and legislation in both countries.

### Our aims and methods

- To conduct an in-depth analysis of the latest national policies, official statistics and laws published (enacted) in England and Japan (**Table 2**), with wider reading of other relevant reports and guidelines.
- To identify and compare characteristics, issues and needs for future improvement around end-of-life care, from the selected documents.
- To provide policy recommendations to both countries based on the mutual learning of useful structural mechanisms and practical knowledge.

**Table 2: Main documents we analysed**

#### England

- (2019) Six Months to Live? Report of the All-Party Parliamentary Group for Terminal Illness inquiry into the legal definition of terminal illness.
- (2015) The House of Commons Health Committee End of Life Care Fifth Report of Session 2014-15.
- (2014) The Care Act.
- (2014) One Chance to Get It Right: Improving people's experience of care in the last few days and hours of life.
- (2010) Policy for Prosecutors in Respect of Cases of Encouraging or Assisting Suicide
- (2009) Living Well with Dementia: A National Dementia Strategy.
- (2008) End of Life Care Strategy.
- (2005) The Mental Capacity Act.

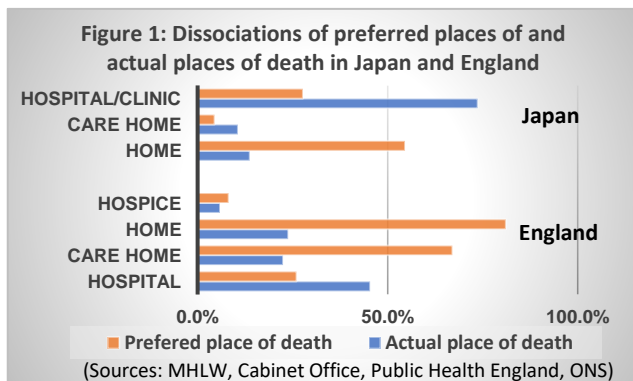
#### Japan

- (2019) The Dementia Policy Promotion Charter.
- (2018) The report on the survey of attitude toward medical and nursing care in the last stage of life.
- (2018) The report on the public awareness of medical and nursing care at the Last Stage of Life.
- (2007, last updated in 2018) The 3rd-term Basic Plan to Promote Cancer Control Programmes.
- (2007, last revised in 2018) The Guideline on the Decision-making Process for Medical and Nursing Care at the Last Stage of Life.
- (2006, last revised in 2016) Cancer Control Act.
- (2000, last revised in 2017) Long-Term Care Insurance Act.
- (1974, last updated 2007) Employment Insurance Act.

## Our findings: challenges and opportunities for end of life care

### Theme 1: Emphasising individualised care and support

The needs and preferences of dying people may not be well recognised or respected at a time when they may lose their capacity to support and make decisions for themselves. For instance, the vast majority of people do not die in their preferred place (**Figure 1**). A range of policy and legal documents in both countries reveals an increasing focus on promoting a person-centred approach, especially in the face of largely unattended individual needs and wishes in health and social care systems.



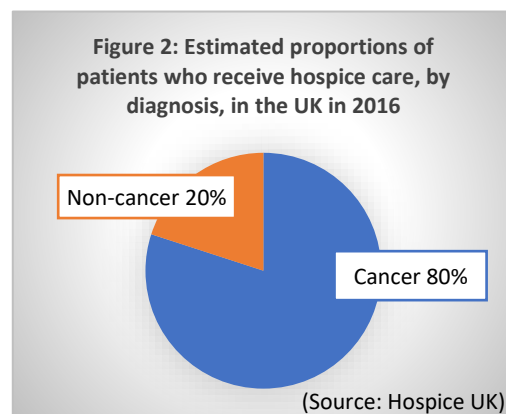
England	Japan
<b>Prioritising individual autonomy</b>	<b>Emphasising individual wishes with family support</b>
<ul style="list-style-type: none"> <li>✓ Advance care planning (ACP) is promoted in both countries to reflect individual needs and wishes.</li> <li>✓ Restricted data-sharing across care settings inhibits the recognition of and support for individual wishes and needs.</li> <li>✓ Neither country has enacted legislation for physician-assisted dying or euthanasia.</li> </ul>	
<ul style="list-style-type: none"> <li>• Patients are widely encouraged to record their wishes for care in consultation with family and practitioners.</li> <li>• There are legal assurances, such as the Mental Capacity Act, to ensure individual wishes and interests are best-respected in end of life care.</li> <li>• Available legal tools include Advance Decisions to Refuse Treatment (ADRT), Lasting Power of Attorney, a court-appointed Deputy and Independent Mental Capacity Advocate.</li> <li>• A number of bills have been brought (unsuccessfully) to Parliament, seeking legal provision for physician-assisted dying.</li> </ul>	<ul style="list-style-type: none"> <li>• The role of the family is often highlighted in the procedures of ACP.</li> <li>• The family is expected to play an active role in caring for a dying patient, such as in the decision-making of starting/forgoing LSTs when the patient is unconscious.</li> <li>• There is little legislation to systematically and explicitly define and regulate how dying patients' needs and preferences can be ensured in different circumstances.</li> <li>• There are few calls for legalisation of euthanasia at the national level, despite some well-known legal cases.</li> </ul>

Sources: End of Life Care Strategy (2008); A National Dementia Strategy (2009); Mental Capacity Act (2014); One Chance to Get It Right (2014), Policy for Prosecutors (2014); The Fifth Report (2015).

Sources: The Guideline on the Decision-making Process (2018); Dementia Policy Promotion Charter (2019); The Report on attitude toward medical and nursing care (2018); The Report on the public awareness of medical and nursing care (2018)

## Theme 2: Improving care access and inclusion

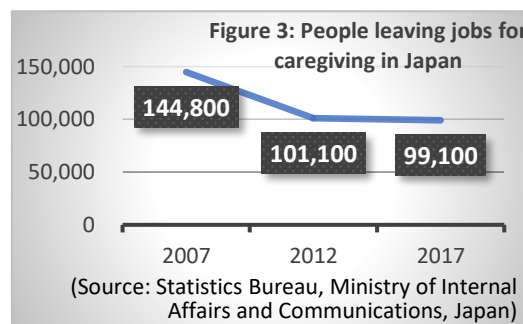
End of life care resources are not equally distributed in either country. For example, in the UK, cancer patients receive about 80% of hospice care, while cancer only causes about one-quarter of total deaths (**Figure 2**). Similarly, according to the Japanese Society for Palliative Medicine in 2018, 95% of Japanese patients whom palliative care teams supported had cancer. In addition, ambiguous definitions of end of life and associated care in official documents can cause barriers when accessing required support and care. As pointed out by the *Six Months to Live* Report, the current legal definition of 'terminally ill' by the UK government is outdated, preventing dying patients with a life expectancy over six months from gaining faster access to social benefits. Meanwhile, in Japan, highly medicalised definitions of end of life care can also be invisible barriers for people who seek end of life care and related support.



England	Japan
<b>Promoting inclusion for everyone</b>	<b>Enhancing inclusion for vulnerable people</b>
<ul style="list-style-type: none"> <li>✓ Both countries face funding shortages due to increasing demands.</li> <li>✓ Non-cancer patients may experience some difficulties in accessing care.</li> <li>✓ Both countries have promoted public awareness of dying to combat people's misconceptions about end of life care.</li> </ul>	
<ul style="list-style-type: none"> <li>• More support is urged for the following people:                             <ul style="list-style-type: none"> <li>- non-cancer patients.</li> <li>- people with socio-economic disadvantages.</li> <li>- minority groups (Black, Asian &amp; Minority Ethnic).</li> <li>- terminally ill people with a prognosis of life expectancy over six months.</li> </ul> </li> <li>• A more inclusive and equal approach is advocated to support dying people in diverse circumstances.</li> <li>• Social care is separate from health care.</li> <li>• Publically-funded social care is only for economically disadvantaged people, resulting in an increase in private paying users.</li> </ul>	<ul style="list-style-type: none"> <li>• Policies and legislation pay most attention to cancer and dementia patients in relation to end of life care.</li> <li>• Although Japan has recently revised its immigration laws and therefore adopted a more open approach to immigrants, no relevant policies focus on end of life care for people and their family from outside Japan.</li> <li>• A separate compulsory social care insurance (LTCI) is introduced in addition to NHI.</li> <li>• The universal LTCI system enables older people with terminal and chronic conditions to access continuous benefits, including expenses for inpatient and home-based end of life care.</li> </ul>
Sources: Six months to Live Report (2019); The Fifth Report (2015); One Chance to Get it Right (2014); Living well with dementia (2009)	Sources: The Process Guideline (2018); Cancer Control Act (2016); Long-Term Care Insurance Act (2017); Dementia Promotion Charter (2019)

## Theme 3: Supporting informal carers and family members

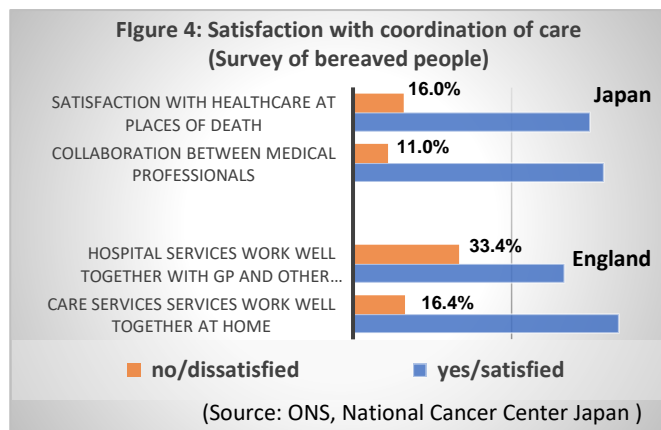
In addition to dying patients in the UK and Japan, informal carers and family members also need to access support. The UK Family Resources Survey suggests that nearly half of adult informal carers are in employment, much like in Japan. If they cannot access adequate support, the informal carer may be forced to quit their job. The national survey for employment structure in Japan shows that nearly 90% of carers do not utilise employee benefits. The estimated number of people who leave their job to care for family members is around 100,000 (females accounted for 80%) (**Figure 3**). Both countries have implemented policies and laws to support informal carers and family members, however, the support provision is different.



England	Japan
<b>Respecting carers' well-being and rights</b>	<b>Focusing on employee benefits for carers</b>
<ul style="list-style-type: none"> <li>✓ Both countries provide benefits and support for informal carers and family members.</li> <li>✓ Both countries face the challenges of government funding shortages and insufficient support for carers.</li> </ul>	
<ul style="list-style-type: none"> <li>• Local councils have legal responsibilities for assessing carers' needs and providing suitable support accordingly.</li> <li>• The UK government provides some with the Carer's Allowance and other benefits, although sufficient paid leave for carers as an employee right is yet to be legislated.</li> <li>• Hospices provide respite care and bereavement care for family members, although such services are often fragmented and insufficient.</li> </ul>	<ul style="list-style-type: none"> <li>• A universal LTCI system has been developed, providing needs-based services for people who care for others.</li> <li>• There are legal assurances, such as the Employment Insurance Act, to entitle employees to paid leave when caring for their family members.</li> <li>• The NHI has not included respite and bereavement care, while the LTCI has provided short-stay services and day services.</li> </ul>
Sources: Care Act (2014); The Fifth Report (2015); One Chance to Get it Right (2014); End of Life Care Strategy (2008)	Source: The Process Guideline (2007, 2018); Long-term Care Insurance Act (2017); Employment Insurance Act (2007).

### Theme 4: Promoting integrated and holistic approaches

An integrated and holistic approach is one of the essential characteristics of high quality end of life care. Care for dying people has complex aspects including physical, emotional, familial, social and spiritual dimensions. Co-ordination of care needs to be improved to ensure integrated and holistic practices in end of life care. A national survey in England captures bereaved people's dissatisfaction with quality and coordination of care for their loved one. In Japan, this is less apparent, but has also been seen (Figure 4). Policy and laws in both countries have called for wider and deeper cooperation and communication across all parties involved in end of life care.



England	Japan
<b><u>Furthering an individualised approach to multi-dimensional care</u></b>	<b><u>Developing a comprehensive community-based approach for individuals and family</u></b>
<ul style="list-style-type: none"> <li>✓ Both countries have shifted their focus from medical care to integrated and holistic care at the end-of-life.</li> <li>✓ The need for further improving training and education for professionals has been highlighted in both countries.</li> <li>✓ An unstable workforce of care professionals has been recognised as a fundamental challenge to care provision.</li> </ul>	
<ul style="list-style-type: none"> <li>• The approach focuses on individuals' multi-dimensional needs and inter-disciplinary cooperation to meet them.</li> <li>• Individualised care and round-the-clock specialist services are urged in palliative care provision.</li> <li>• Integrated spiritual care is promoted, involving patients, family members, health and social care professionals and spiritual care workers.</li> <li>• The UK government seeks to further improve care and support for minority groups and disadvantaged people and to enhance data-sharing of end of life care and ACP.</li> <li>• Bureaucratic barriers to support and cooperation are identified.</li> </ul>	<ul style="list-style-type: none"> <li>• The emphasis is on medical and nursing care for symptom control and pain relief.</li> <li>• Psychological and social support is also offered, although spiritual care is not strongly emphasised.</li> <li>• The importance of prevention is reflected in the LTCI budget, showing increased funding for prevention services, such as exercise classes and community centres.</li> <li>• The MHLW has promoted the Community-based Integrated Care System to ensure comprehensive provision of health care and social support.</li> <li>• There is a lack of systemic regulations and guidance to define and promote this kind of care and support.</li> </ul>
<p>Sources: The Fifth Report (2015); One Chance to Get It Right (2014). End of Life Care Strategy (2008); (2009) Living well with dementia: A National Dementia Strategy.</p>	<p>Sources: The Process Guideline (2018); The Commentary of the Process Guideline (2018); The 3rd-term Basic Plan to Promote Cancer Control Programmes (2018)</p>

### Conclusions and recommendations

England and Japan both face similar issues and challenges associated with changing and diversified needs for end of life care. A range of improvements for care provision and cooperation has been highlighted in the policies and laws of the two countries, although some procedures are yet to be realised. The official documents from Japan focus on establishing regulations and standards for care more generally, while British documents pay attention to more specific issues in various settings.

#### Common issues and challenges

- ✓ Funding pressure, workforce shortfall and education are common issues faced by both countries.
- ✓ Access to end of life care for non-cancer patients with other life-limiting conditions is yet to be improved.
- ✓ At a structural level, further cooperation and communication are needed between care professionals from different disciplines and organisations. This is also needed between care recipients and care providers.
- ✓ More policy and legal provision are needed to instruct and regulate both end of life care and physician-assisted dying.

#### What can England learn from Japan?

- ✓ To further emphasise the role of family carers in end of life care settings.
- ✓ To improvand social care providers, as well as communities to further enhance cooperation and flexibility of care provision
- ✓ To learn from Japan's LTCI to explore a universal, instead of an income/need-based social care system.
- ✓ To further emphasis prevention services to keep the social care system more sustainable.

#### What can Japan learn from England?

- ✓ To introduce national strategies and specific legislation on end of life care.
- ✓ To clarify cost-saving for a sustainable system in future policy strategies.
- ✓ To secure sufficient government funding to improve and promote spiritual care for dying people and bereavement care for their families.
- ✓ To ensure equal and easy access to end of life care for residents from non-Japanese backgrounds.