End of Life Care

Supplement 2: Policy and Evidence Review

Joint Strategic Needs Assessment (JSNA) Report for

Hammersmith and Fulham   Kensington and Chelsea   Westminster

November 2015

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Contents

About this report

This supplement to the End of Life Care JSNA provides a review of key strategy and policy documents and best available evidence at the time of production of the JSNA. The review includes:

- Recent strategy and policy drivers for end of life care such as the 2015 House of Commons Health Committee review and NHS England's Action for End of Life Care 2014-16.
- Collation of national and local views on end of life, including feedback from an event held by the BME Health Forum in June 2015
- Review of national guidance and published evidence on end of life models of care
- Review of national and local evidence on end of life care for specific communities

1 Strategy context and policy drivers

This section describes some of the key national and local strategies and policy drivers for end of life care in the UK.

1.1 Ambitions for Palliative and End of Life Care 2015-20

This 2015 report from the National Palliative and End of Life Care Partnership builds on the 2008 strategy and improvements that have been made since, and sets out a national framework for local action and delivery. Person centred care is a key theme of the report with the focus very much on improving care for the individual and those around them. The report sets out six positive ambitions to create a new impetus for end of life care and eight foundations required to achieve these ambitions.

Ambitions	Foundations
➢ Each person is seen as an individual ➢ Each person gets fair access to care ➢ Maximising comfort and wellbeing ➢ Care is coordinated ➢ All staff are prepared to care ➢ Each community is prepared to help	➢ Personalised care planning ➢ Shared records ➢ Evidence and information ➢ Involving, supporting and caring for those important to the dying person ➢ Education and training ➢ 24/7 access ➢ Co-design ➢ Leadership

Implementation needs to be locally led and the report is a call for action for collaboration and cooperation by local agencies to deliver improvements in care.

This requires leadership and the Partnership asks specifically for Health and Wellbeing Boards, CCGs, and Local Authorities (or a composite) “to publicly designate an organisation to lead on making these ambitions the reality for the communities you serve”

1.2 Gold Standards Framework

The Gold Standards Framework (GSF) is an evidence based approach to optimising the care for patients nearing the end of life. It is concerned with helping people to live well until the end of life and includes care in the final year of life for people with any end stage illness in the community.

The British Medical Association QOF states that:

“GSF is key to thinking through and implementing high quality patient centred care at the end of life for patients with both cancer and non-cancer diagnoses”.

Previously hosted within the NHS, from 2011 the GSF is managed by a not-for-profit Social Enterprise – The Gold Standards Framework (GSF) Centre CIC. The centre is the national training and coordinating centre for all GSF programmes, enabling generalist frontline staff to provide a gold standard of care for people nearing the end of life

1.3 Dying Matters

The End of Life Care strategy announced the formation of a national coalition known as Dying Matters to support the implementation of the strategy with a focus on raising public awareness and challenging attitudes and behaviours towards death and dying.

1.4 More Care, Less Pathway: A review of the Liverpool Care Pathway

Following concerns raised over the implementation of the Liverpool Care Pathway (LCP) an independent review was commissioned (Neuberger, 2013). The review, More Care, Less Pathway concluded that a 'one size fits all' approach was not recommended and that the LCP should be phased out and replaced by an end of life care plan for each patient, backed up by condition specific good practice guidance

1.5 One chance to get it right

In response to the review of the LCP, a coalition of 21 national organisations formed the Leadership Alliance for the Care of Dying People (LACDP) and set out their recommended approach to care in the last few days and hours of life with the **5 Priorities of Care for the Dying Person**

Table 1: Five Priorities of Care for the Dying Person

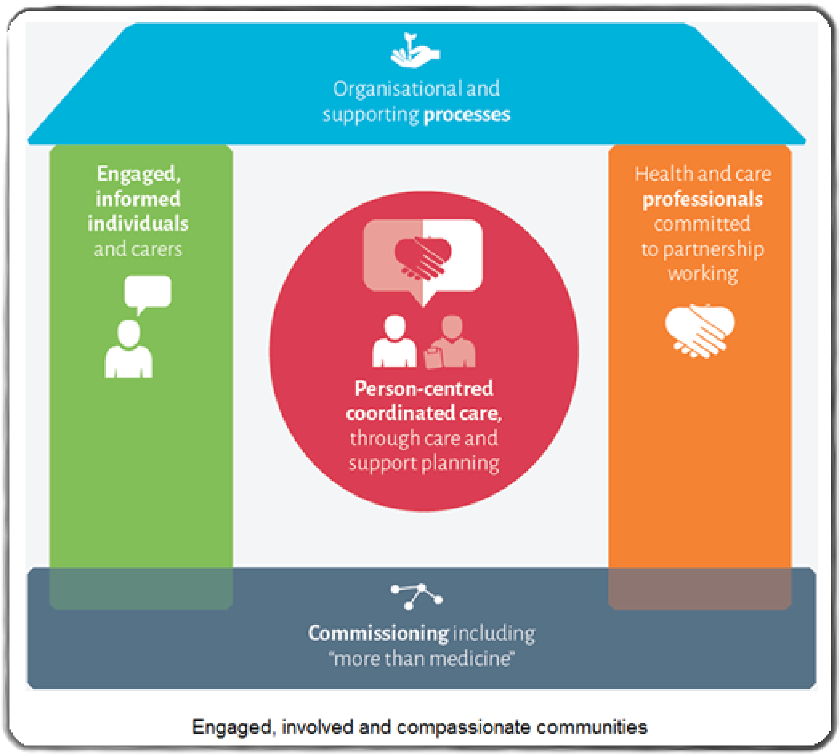
1. This possibility is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

1.6 Actions for End of Life Care: 2014-16

NHS England and the Department of Health have recently acknowledged that the 2008 strategy must be refreshed in order to reflect current needs and changes in the health and social care system. Until this has been developed, NHS England have published their Actions for end of life care 2014-16 which outlines their commitment to end of life care for adults and children.

NHS England have adopted a House of Care model (developed for long term conditions) as a framework for setting out their commitments to end of life care. This is illustrated in the diagram below.

Figure 1: House of Care Model



1.7 House of Commons Health Committee: End of Life Care

Drawing on a range of written and oral evidence from a range of key stakeholders, the House of Commons Health Committee (2015) considered the state of palliative and end of life care.

In line with other recent reviews the Committee identified significant variation in care quality and practice across both acute and community settings. A number of recommendations are made. Some of these are highlighted below.

Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life.

- A senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation
- The Government and NHS England set out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses
- Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care
- All staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning.
- Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. This should involve their plans for the recruitment and training of district nurses
- The Government to provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support
- The Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review
- Bereavement support for families should also be included consistently as part of end of life care
- Further research into measuring the quality of end of life care and the priorities that matter most to people with terminal illnesses, their families and carers.

These recommendations reflect a number of the findings of this JSNA. In October 2015, the Government published their response to the Health Select Committee report.

1.8 National care of the dying audit for hospitals

In 2013/14 the Royal College of Physicians (RCP) and Marie Curie Palliative Care Institute Liverpool (MCPPIL) undertook an audit on the quality of care received by people who died in hospitals in England in May 2013.

Overall, the audit found that there was significant variation in care across hospitals in England. For example, only 21% of hospital sites had access to face to face palliative services 7 days per week. The audit highlights areas for future improvements and the need to ensure better care and support for people who are dying and their families and carers.

A new audit, titled End of Life Care Audit - Dying in Hospital[1], is currently underway and will focus on progressing with the recommendations above and will ensure that the Priorities of Care for the Dying Person (see above) are monitored at a national level.

1.9 Dying without Dignity

In 2015 the Parliamentary and Health Service Ombudsman reported on investigations it had completed into end of life care across the country and across the NHS, including GP practices, hospitals and mental health trusts. The role of the Ombudsman is to investigate complaints that people have been "treated unfairly or received poor service from government departments and other public organisations and the NHS in England[2]."

The themes identified from this report reflect those concerns and findings raised in other reports and include:

- Not recognising that people are dying, and not responding to their needs.
- Poor symptom control.
- Poor communication.
- Inadequate out-of-hours services.
- Poor care planning.
- Delays in diagnosis and referrals for treatment.

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[1] Royal College of Physicians End of Life Care Audit https://www.rcplondon.ac.uk/resources/end-life-care-audit-dying-hospital (accessed 22 July 2015)

[2] Parliamentary and Health Service Ombudsman http://www.ombudsman.org.uk/about-us

2 Views of people at the end of life and their carers

The views of patients and carers are key to improving the quality of service experienced prior to death. There is a lack of research on the views and attitude of local patients and their families or carers on the quality of End of Life Care services, and so this section is drawn largely from national policy, evidence and information captured at a dedicated workshop of the BME Health Forum held in June 2015.

2.1 The national context

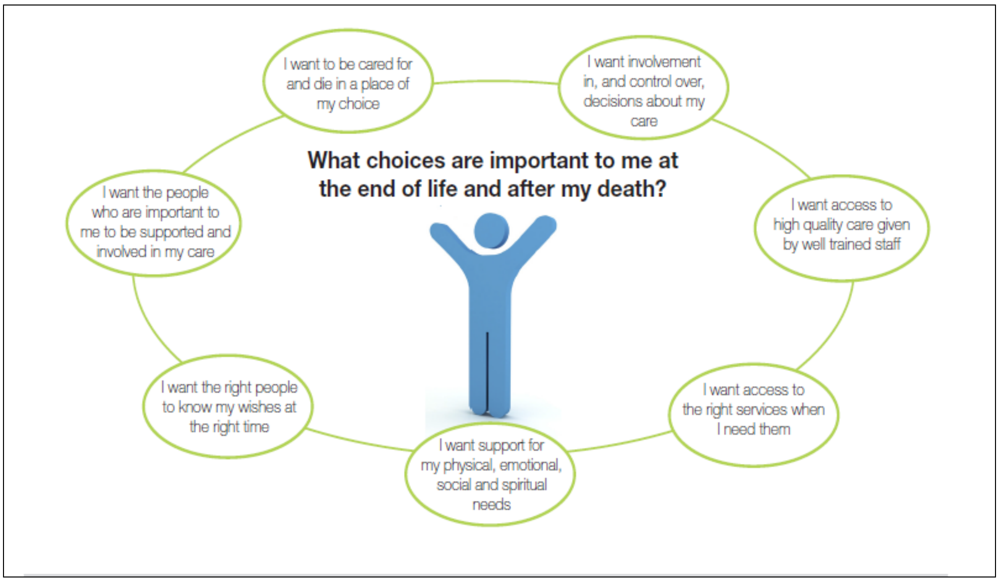
Every Moment Counts is a narrative for person coordinated care produced by National Voices in collaboration with their partners. It outlines five themes that people say are key to coordinated care near the end of life. These are captured in the defining statement:

> *"I can make the last stage of my life as good as possible because everyone works together confidently, honestly and consistently to help me and the people who are important to me, including my carer(s)"*

2.2 What's important to me: a review of choice in end of life care

This 2015 report reviewed how the quality and experience of care for adults at the end of life, their families, carers, and those close to them could be improved by expanding choice. The research identified a number of key themes which were important to people which are illustrated in the diagram below:

Figure 2: What's important to me



A national choice offer for end of life care is recommended:

Each person who may be in need of end of life care is offered choices in their care focused on what is important to them. This offer should be:

- made as soon as is practicable after it is recognised that the person may die in the foreseeable future;
- based on honest conversations with health and care staff, which supports the person to make informed choices; and
- consistently reviewed through conversations with health and care staff.

To enable this national choice offer the report advises on a range of actions that need to be taken to ensure good quality end of life care. This framework is described in more detail in Appendix A

2.3 National Bereavement Survey (VOICES)

The National Bereavement Survey (VOICES) is undertaken by the Office for National Statistics on behalf of the Department of Health. The aim is to "assess the quality of care delivered in the last three months of life for adults who died in England and to assess variations in the quality of care delivered in different parts of the country and to different groups of patients[3]".

National survey results published in 2013 (Office for National Statistics, 2013), reported the following findings:

- Quality of care across all services in the last three months of life was rated by 44% of respondents as outstanding or excellent.
- Respondents of those who died of cancer in their own home rated the quality of care most highly (63%).
- Hospice staff were rated highest for showing dignity and respect while hospital staff were rated lowest
- Among those who expressed a preference, the majority preferred to die at home (81%), although only half of these actually died at home (49%). The most commonly reported place of death was a hospital (52%).
- Two-thirds of respondents (64%) reported that no decisions had been made about care which the patient would not have wanted. However, 17% of respondents said that this had happened

In addition, the first VOICES survey undertaken in 2011/12 analysed results by Primary Care Trust (PCT) cluster. The results did highlight some areas for improvement for North West London as a whole, including:

- Dignity and respect shown by hospital doctors and district and community nurses
- Pain relief at home in the last 3 months

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[3] National Bereavement Survey (VOICES) http://www.ons.gov.uk/ons/rel/subnational-health1/national-bereavement-survey--voices-/index.html

- Emotional support in the final two days
- Involvement of patients and bereaved in decision-making
- Help and support for family at time of death
- Quality of care to be improved across a range of settings

The ONS has taken the decision not to publish analysis from the survey at a CCG level as the small sample size and numbers involved do not allow for representative analysis at this level.

2.4 Experience of patients, their families and carers

Qualitative research undertaken by Marie Curie (Marie Curie Cancer Care, 2014) and involving a mixture of terminally ill people, current carers, and bereaved carers, reported a broad range of experiences both positive and negative. The authors identified a number of themes illustrated below.

Death is a journey, not a moment in time.

Talking is beneficial

Putting people at the centre

There are many unmet needs

The unmet needs highlighted in the research are described below, and reflect the findings of the VOICES survey:

- A ‘road map’ that explains who does what and when at different stages in the journey.
- Better sign-posting and coordination, or an individual to help them navigate the health and social care system.
- Greater consistency in the contact people experience with the system.
- A ‘whole family’ approach, which more actively considers the needs of the wider family and carers.
- Better communication, with more support for terminally ill people and carers to enable conversations and training for health professionals
- Greater access to hospice care and services
- Better access to support for people with non-cancer diagnoses, and a perception that access to support is more difficult for those with degenerative conditions

- A more joined up-system for pain management and administering pain relief at home
- Absence of efficient and empathetic out-of-hours access to medical advice
- Emotional support that helps individuals and carers to adopt a positive, or at least accepting, attitude to diagnosis and prognosis
- Better support for carers, such as respite breaks, and for children of carers
- Bereavement support, available and offered to all families and carers

Research carried out by Demos for Sue Ryder (Wood, Salter, & Demos, 2013) aimed to identify what was most important to people at the end of life. The top four priorities were found to be:

- being pain free
- surrounded by loved ones
- having dignity and privacy
- being in familiar surroundings.

The report highlights that the top priority (being pain free) is recognised as something home care cannot always deliver as well as other locations, but nonetheless, dying at home is the most popular choice. This suggests people are sacrificing the achievement of their top priority for the combined achievement of several of their other priorities. From this the report concludes that people feel that medical and practical support is better in hospitals and care homes, while personal and environmental support are better in the home.

2.5 Cultural perspectives and BAME views on dying and end of life care

It is broadly acknowledged that ethnicity and culture is a key factor in how end of life care and palliative care are perceived by patients, families, carers, and professionals alike (Evans, Meñaca, Koffman, et al., 2012; Kellehear, 2009; Kemp, 2005). As highlighted in Chapter 3 the national and international literature suggests that palliative care and end of life care provision for BAME groups is often inadequate and that they are less likely to die at home or in a care home. Evidence also indicates differing experience of illness, healthcare seeking behavior, lower rates of referrals to services, higher levels of dissatisfaction, and services perceived as culturally inappropriate (Calanzani, Koffman, & Higginson, 2013; Evans, Meñaca, Andrew, et al., 2012).

In contrast, local data showed no significant difference between most countries of birth in the percentage of deaths in usual residence and local data from St Johns hospice suggests there is no inequality by ethnicity in hospice coverage.

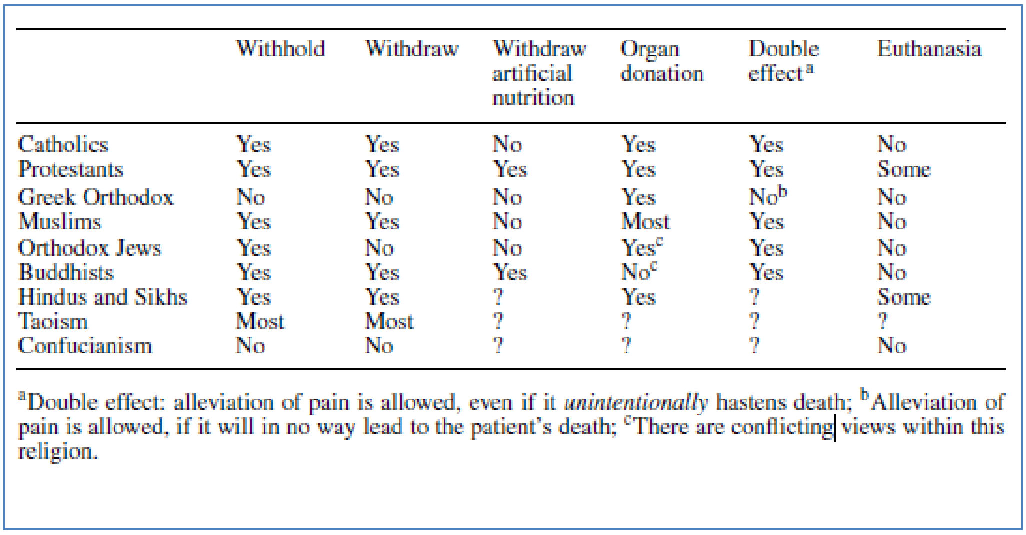
However, cultural perspectives on death and dying are recognised as significant when planning services to ensure that services are culturally competent and provide equitable access (Bulow et al., 2008; Kemp, 2005). For example, religious traditions and family roles are one area highlighted in the research and were reflected in findings from local engagement with the BME Health Forum across the three Boroughs.

Evans et al (Evans, Meñaca, Koffman, et al., 2012) report that while the importance of cultural competence is highlighted in policy and literature, there is a lack of conceptual clarity and definition of cultural competence. Further research to evaluate the impact of culturally competent approaches on patient outcomes are required.

Furthermore, Calanzani et al (2013) conclude that while there may be cultural or religious preferences these will vary considerably according to the individual and cannot be assumed based on ethnic background. They note that the evidence in the literature on whether people from BAME groups do have different preferences is very limited. In addition, preferences based on ethnic background are likely to change over time as new immigrants enter the UK and new generations hold different views to their parents and grandparents.

Research undertaken by Bulow et al (2008)highlighted that healthcare systems need to understand the religious beliefs of patients and practitioners. Their review considered the viewpoints of the major world religions in the context of end of life care decisions in the intensive care unit which they summarized in the following table:

Figure 3: The various religions' views on end of life decisions



	Withhold	Withdraw	Withdraw artificial nutrition	Organ donation	Double effect[a]	Euthanasia
Catholics	Yes	Yes	No	Yes	Yes	No
Protestants	Yes	Yes	Yes	Yes	Yes	Some
Greek Orthodox	No	No	No	Yes	No[b]	No
Muslims	Yes	Yes	No	Most	Yes	No
Orthodox Jews	Yes	No	No	Yes[c]	Yes	No
Buddhists	Yes	Yes	Yes	No[c]	Yes	No
Hindus and Sikhs	Yes	Yes	?	Yes	?	Some
Taoism	Most	Most	?	?	?	?
Confucianism	No	No	?	?	?	No

[a]Double effect: alleviation of pain is allowed, even if it *unintentionally* hastens death; [b]Alleviation of pain is allowed, if it will in no way lead to the patient's death; [c]There are conflicting views within this religion.

One key element highlighted by the authors is the issue of patient autonomy, e.g. the personal freedom to make end of life decisions, which is largely assumed in Western countries but not always so evident in other cultures. For example, the authors cite the Hindu ethos where death is not only a concern for the dying person, but also for those close to him, and it is the healthcare professional's task not to inform the patient of imminent death, but to nurture the will to live. The authors highlight the importance of professional's establishing a patient's religious affiliation early on.

A systematic literature review (de Graaf, Mistiaen, Deville, & Francke, 2012) of the perspectives of Turkish and Moroccan patients, relatives and professionals found that:

Family care is considered a duty, even where it may become a burden for the family (and in particular female family carers)

Hospital care is the preferred choice by many of the patients and their families as it provides a secure environment and they hope for a cure

- Hope for recovery strongly influences the individual's end of life care
- Families are key decision makers in end-of-life care (e.g. withdrawing treatment)
- End-of-life decisions are seldom discussed with the patient, and communication is often limited. This can be exacerbated by language barriers the role of the family.

The authors conclude that the family are key decision-makers in end of life care for Turkish and Moroccan patients and that providers and staff should take these socio-cultural characteristics into account.

Similar themes were reflected by Kemp (Kemp, 2005) reporting on the literature and from his own personal experience. He considers a number of cultural issues in palliative care including:

- People from the same culture or religion having different core beliefs
- Individual experience may differ including experience of war, trauma or torture
- Family involvement in decision making and in providing care may vary across cultures
- Religion and faith and the role of the clergy
- Different cultures may view suffering in different ways
- Meaning of death and dying differs across cultures but the importance of dying with dignity is universal
- Immediate after-care and disposal of the body
- Grief and bereavement

In a review of the qualitative literature, Jones (2005) identified similar themes relating to the importance of family involvement in decision-making and care provision. An overarching theme from the review was that while gender, class and ethnicity were important factors, the literature highlighted that social relationships (particularly family) were vital and supported a relationship-centred approach to end of life care.

The author identified the following key points:

- Qualitative research on palliative care is lacking, with little mention of race, ethnicity or diversity
- As the UK becomes more culturally diverse the risk to minorities of poor end of life care due to cultural misunderstandings is likely to grow
- The rights of families to medical knowledge and their roles in decision-making are just as valid to the cultural belief systems of many ethnic communities, as the patient autonomy model is in Western culture
- Choices relating to end of life care may be more related to ethnicity and culture than age, education, socio-economic status or other variables, but these cannot be denied as contributing factors in a mix of influences in decision making
- Healthcare providers musy recognise that values, principles and assumptions of Western medicine are themselves historically and culturally determined
- Not all members of an ethnic group will adhere to the beliefs of a specific faith

- The hospice approach of facilitating mental and spiritual preparation for death provides a more holistic model on which to expand across spiritual belief systems ,

2.6 Findings from BME Health Forum, 3rd June 2015

Some of the themes that arose from discussions at the BME Health Forum were:

- There can be a reluctance to openly discuss death and end of life care among certain communities
- There is a lack of awareness of all the options available (e.g. hospice care) and consequent need for further information
- Perception of hospices as for 'White British' people only
- In some cultures and instances the patient's family feel responsible for providing care, and not providing that care at home can be perceived as failure and lead to stigma within the community

In response to the question "What does a good death look like?" a number of issues were highlighted as being important by participants, including:

- Not being alone
- A patient-centred approach, where the voice of the patient is heard
- Coordinated care and flexibility from service providers to meet the needs of the individual
- Good symptom control (to meet psychological needs as well as manage physical symptoms)
- Honest and open communication

The forum also identified a number of BME specific issues:

- Care must be spiritually or culturally appropriate
- Recognising the particular needs of different religious faiths is important e.g. swift burial and release of body
- People from BME communities did not feel empowered to ask the right questions from health and care professionals. Patients and their families need to be informed and empowered to be able to ask the right questions.
- Language barriers can be an issue, particularly for people with dementia

Aside from the language barriers, other barriers identified included:

- Perceived lack of respect for cultural/religious/spiritual beliefs
- Lack of information and awareness about services
- Perception that hospices were for old people (and white old people particularly) and were only for those in the dying phase
- Lack of trust in hospices (perhaps arising from not understanding their role) and greater trust placed in hospitals, particularly around pain and symptom management
- Lack of advocates in the community
- Cost. Do people know which services are free and if any cost?

Hospices working with faith and community leaders was seen as pivotal to raising awareness of hospice service provision and better understanding the support that they can provide.

3 Review of evidence and models of care

This section reports on the key guidance and evidence of effectiveness of models of care drawn from the literature. It also considers the literature on end of life care services for specific communities and vulnerable groups.

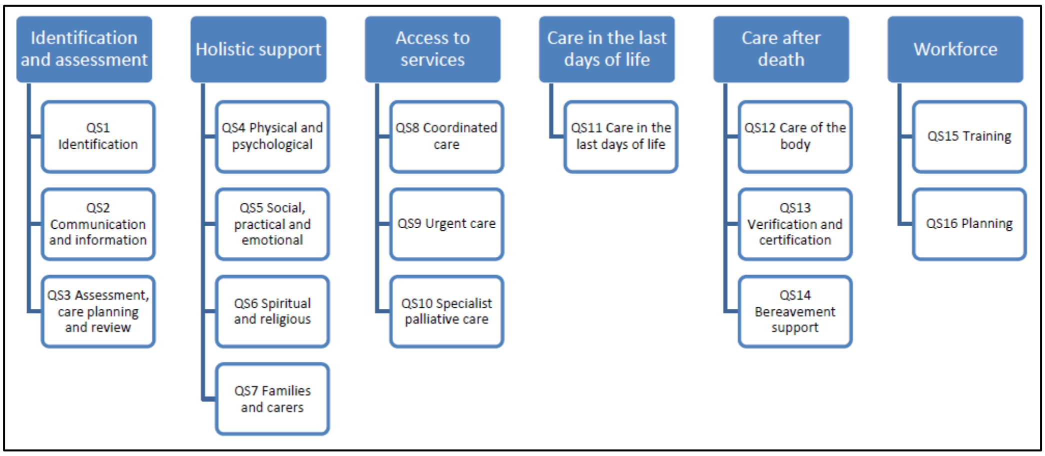
3.1 National guidance

At the time of writing there are no specific end of life care guidelines for adults or children published by NICE. Two guidelines are currently in development:

- Care of the dying adult (publication expected December 2015)
- End of Life Care for Infants, Children and Young People (publication date TBC)

In 2011 NICE published a quality standard for End of Life Care (NICE, 2011) which is described in section the main JSNA report and below

Figure 4: NICE Quality Standards for End of Life Care



The NICE commissioning guide for End of Life Care[4] adopts this framework to specify end of life care services. This is described in detail in the table below.

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[4] NICE Guide for commissioners on end of life care for adults https://www.nice.org.uk/guidance/cmg42/chapter/1-commissioning-services-for-end-of-life-care-for-adults (accessed 22 July 2015)

Table 2: NICE Commissioning Guide for End of Life Care

Identification and assessment	**Successful identification** of people entering end of life is vital and yet a lack of open and honest communication between health and social care staff and individuals about end of life care can hinder this identification. This barrier is related to the taboo around discussing death and dying. Commissioners may wish to consider resourcing local awareness raising activities and the Dying Matters Coalition provide a variety of resources, such as posters and leaflets, which can assist with relatively low cost local promotional activities **Communication** is a core competency for end of life and palliative care and commissioners should specify that providers can demonstrate that all staff involved in end of life care have the required competencies in communication. Commissioners may wish to specify that **information is available in a variety of accessible formats and is culturally appropriate and accessible** to people with additional needs such as physical, sensory or learning disabilities and for people who do not speak or read English. People approaching the end of life and their families and carers, should have access to an **interpreter or advocate** if needed. The local care pathway should provide the opportunity for people who have been identified as approaching the end of life to be offered **comprehensive and regular holistic assessments**, to discuss their preferences and needs and to document these in a care plan. Assessments should be multidisciplinary and coordinated.
Holistic support	**Essential 24/7 services** should include: • generalist medical services (including GPs) • nursing services (defined as visiting, rapid response services and provision of one-to-one care at home, including overnight) • personal care services • access to pharmacy services • access to equipment and adaptations • specialist palliative care advice for generalists on symptom and side-effect management Commissioners may also wish to consider the importance of **specialist palliative care social workers**. Psychological support includes **general emotional support** and empowerment as well as **specialist psychological care** Commissioners of health and social care should work closely to **ensure integration of services**. The local care pathway should incorporate services that meet people's social, practical and emotional needs and clear mechanisms are in place for prompt access and referral. Referrals may be to occupational therapy services, respite and day care services and benefits services There is evidence of a widespread need for t**raining in all aspects of spiritual care**. Some services may be provided through local religious organisations and commissioners may wish to ensure these are reflected in the local care pathway. Spiritual and religious needs may be considered in the assessment and advance care planning process **Support that carers may need** include information, training, emotional support and residential or day respite services and overnight one to one care in the person's home.

	People 'providing a substantial amount of care on a regular basis' are entitled to a **community care assessment** by the local authority Despite the need for comprehensive support for carers, the current evidence suggests gaps in services. When undertaking a joint health and social care needs assessment for end of life care it is important that carers' needs are taken into consideration
Access to Services	The potential partners that commissioners may wish to involve in strategic coordination of services are: • Specialist palliative care providers (NHS, social care and third sector) • Primary care (GPs and practice nurses) • Social care including domiciliary workers • Secondary care providers • Community nursing service • Care homes • Out of hours services (GP and community nursing) • Emergency care services • Ambulance services • Religious leaders and spiritual services • Service user groups and lay people • Mental health teams including those with responsibility for dementia care and psychology services • Condition-specific teams, for example heart failure specialists, respiratory specialists, renal specialists. Electronic palliative care coordination systems (Coordinate My Care) are included as a tool for coordinating care Key workers are one example of how care could be coordinated and promote continuity for the patient and their families/carers . The Marie Curie Delivering Choice Programme is a programme set up to improve the coordination and effectiveness of services **Specialist community palliative care services and hospital palliative care teams** should ensure provision to: • Visit and assess people approaching the end of life face-to-face in any setting 09.00–17.00, seven days a week (provision for bed-side consultations outside these hours is high quality care). • Provide specialist palliative care advice at any time of day or night, which may include telephone advice.'
Care in the last days of life	Commissioners should ensure that care plans are implemented in all end of life care settings. It is important that services have access to a person's care plan, and that policy is coordinated across the care pathway
Care after death	Providers should be able to demonstrate that staff who are involved in **care of the body** and **verification and certification** of death have received the **appropriate training and are competent**.

	Training may need to be tailored locally to accommodate the needs of minority ethnic groups. Standards and guidance on **bereavement care** are available and should be considered when commissioning services. Appropriate education opportunities and assessment of competences should be in place. Local and national third sector providers could play a role in bereavement support.
Workforce	A key element of the high quality end of life care is a **competent workforce** which is resourced appropriately. However, research has demonstrated some considerable **gaps in the knowledge and education of the workforce**, and this is particularly so for people employed in generic roles for whom caring for people at the end of life forms part of their workload The National End of Life Care Programme in collaboration with others outlined **five key competencies** as: • communication skills • assessment and care planning • symptom management, comfort and wellbeing • advance care planning • values and knowledge developments.

3.2 Models of care

Following the concerns raised around the Liverpool Care Pathway (LCP), Chan and Webster (2013) updated their Cochrane systematic review of end of life care pathways. The authors sought to compare the effects of end-of-life care pathways, with usual care (i.e. no pathway) or with care guided by another end-of-life care pathway across all healthcare settings. There was a particular focus on establishing whether there was an effect on symptom severity and quality of life of people who are dying, or their families and carers.

No additional studies were identified which met the review criteria, and so the authors concluded that “recommendations for the use of end-of-life pathways in caring for the dying cannot be made.“ Given the concerns around the LCP the authors do not recommend making decisions based on indirect or low-quality evidence. Furthermore, they recommend that all health services using end of life care pathways have their use of the pathway independently audited and any subsequent use should be carefully audited.

Similarly, Parry et al (Parry, Seymour, Whittaker, Bird, & Cox, 2013) found that no strong evidence on potential benefits or on potential adverse effects and risks of pathways for managing the dying phase in end of life care. There was no research that has produced evidence by robustly comparing these pathways with alternative forms of care.

The authors did identify “moderate, weak, and indirect evidence” (mostly from studies of professionals views and case notes) that suggested pathways for managing the dying phase may improve: symptom management; prescription of medicines appropriate for end of life care; documentation, discussion and referrals relating to bereavement and family members’ support needs; the severity of their bereavement experiences reported by family members; and professionals' ratings of care quality and communication (but *not* family members' ratings; and professionals' confidence). However, as Chan and Webster highlighted, there is a risk to decision making based on such low quality evidence.

Recognising the importance of being able to robustly evaluate and assess the different models of end of life care being developed across the country the recent Health Services Committee report (House of Commons Health Committee, 2015) recommended the development of outcome measures for palliative care in order to improve the quality of care for people at the end of life.

Prior to this, a review of good practice in end of life care by Addicott and Ross (Addicott & Ross, 2010) highlight a number of areas to inform the 6 steps in the end of life care pathway

Table 3: Good practice in end of life care (Addicott and Ross, 2010)

Discussions as the end of life approaches	There is the potential for inequality in access to end-of-life care, depending on both the patient's diagnosis and the process of identifying needs used. These issues could be overcome by a combination of: • training and improvement in the definition of prognoses • multidisciplinary co-ordination of care • interprofessional access to palliative care records However, this potential is exacerbated by an apparent reluctance among some health care professionals to discuss issues relating to death and dying. Specialist and general health care providers should work together to ensure that responsibility for alleviating some of the anxieties about initiating these conversations is shared, and to ensure that all providers are confident and competent in responding to questions from patients and carers
Assessment, care planning and review	Discharge arrangements designed specifically for patients who are nearing the end of their lives can be an effective mechanism for supporting ward staff in assessing the more complex cases and planning the delivery of end-of-life care in patients' preferred location. The development of models of discharge facilitation should take account of, and adapt to, factors within the local health economy to ensure that they work with rather than against existing processes and pressures on other end-of-life care providers. There is no one-size-fits-all approach to design and implementation. Advance care planning (and communication of plans between and among health and social care teams) can help to ensure patients' wishes are respected and accommodated. As an individual's wishes about end-of-life care may change as the disease process progresses, it is important to update the advance care plan regularly on the basis of ongoing discussions.
Co-ordination of individual patient care	Dedicated models of co-ordination can be effective in freeing up district nurses and other community-based health providers, as well as allowing greater oversight with regard to the prioritisation of resources. Such co-ordination models could consider widening their remit to include other functions, such as the booking of equipment and the co-ordination of, or advice on, care home placement.

Delivery of high-quality services in different settings	End-of-life care tools such as the Gold Standards Framework and the Liverpool Care Pathway are important mechanisms for ensuring high-quality, transparent provision of care that is more effectively able to accommodate patient preferences. A whole-systems approach to service improvement is necessary, combining expedition of discharge from the acute setting with increased and/or reconfigured provision of community services to cover patients 24 hours a day seven days a week. Training and education are necessary to ensure the provision of high-quality end-of-life care in different settings. Areas specifically identified by our research include: • identification of patients’ needs • communication skills the physical management of patients nearing the end of their lives
Care in the last days of life	Once a patient has been identified as nearing the end of his or her life, advance care plans should be reviewed continually to confirm that all of the resources are in place to provide the preferred end-of-life care services in the preferred location. Particular consideration should also be given to the needs of carers for information and support, to be included in major decisions, and to participate in the physical care and emotional support of the person who is dying. In the last days of life it is considered important for patients to be: • treated as individuals, with dignity and respect • without pain and other symptoms • in familiar surroundings • in the company of close family and friends
Care after death	Health and social care professionals should be aware of the procedures to follow after the death of a patient to show respect to the deceased and his or her carers. Bereaved carers should have access to good-quality information about the practical steps they need to consider and how to access emotional support if they need it.
Information for carers and relatives	Carers should be seen as key stakeholders involved in the decision-making and planning around end-of-life care needs. Advance care planning and inclusive communication is a valuable process to make care preferences transparent and to ascertain gaps in carers’ ability to deliver care themselves, including their own health care needs (and issues of bereavement). Health care professionals should be honest and transparent with patients and carers about the services and support that are available in the community to ensure that they have a realistic understanding and expectations.

A Cochrane review (Shepperd, Wee, & Straus Sharon, 2011)of home-based end of life care considered 4 trials from developed countries (2 from the US, I from the UK and 1 from Norway, and involving just over 1,000 participants). The authors found that those receiving home based care were more likely to die at home compared to those receiving usual care. There was no significant difference for functional status, psychological well-being or cognitive status. There was some evidence of greater patient satisfaction with home based care, but little evidence was available in relation to the impact on family and carers.

The findings of this review do support the use of home based end of life care programmes although the authors note that the number of patients being admitted to hospital and the time spent at home while receiving end of life care should be monitored. All of the trials in the study highlighted the importance of access to 24 hour care.

A more recent Cochrane review (Gomes, Calanzani, Curiale, McCrone, & Higginson Irene, 2013) – including 23 studies involving 37, 561 participants and 4042 family carers - has provided strong evidence that home palliative care increases the chance of dying at home and reduces symptom burden, in particular for patients with cancer, without impacting on caregiver grief. However, the authors do highlight that further work is required to study cost-effectiveness and to compare different models of palliative care.

A survey undertaken by Help the Hospices and National Association of Hospice at Home identified that patients receiving hospice at home services are likely to die in the place of their preference (88% achieved their preferred place of death)[5].

There is some evidence from Wales (Johnstone, Jones, Fowell, Burton, & Rycroft-Malone, 2012) that an integrated pathway was associated with improved implementation of best practice in end of life care (other than daily review which was high with or without the pathway). The impact was most evident for the implementation of bereavement and spiritual support where the pathway was used. Although there was variation in implementation across sites (hospital, community settings, hospice and specialist inpatient units).

A qualitative study (Hewison, Lord, & Bailey, 2015) - involving 21 interviews with staff in 3 NHS acute trusts - on end of life care in hospitals identified two key criteria for pathways to be adopted by staff:

- leadership and facilitation
- education and training.

Even when these criteria were in place however staff anxieties concerning diagnosing dying and discussing dying and end-of-life care planning with patients and their families could still be barriers to introducing effective care pathways. A number of areas required for improvement in end of life care in hospitals was also identified: difficult conversations; diagnosing dying; and communications across boundaries.

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[5] Heather Richardson (2014) National organisations collaborate to learn more about the impact of hospice at home. www.ehospice.com/uk/Default/tabid/10697/ArticleId/9882

3.3 Advance Care Planning

Advance care planning is a key element of the end of life care pathway and policy which is reflected in the adoption of the Coordinate My Care tool to allow appropriate professionals involved in the care of the patient to access their care plan.

However, there is a lack of evidence on the implementation and effectiveness of care planning in achieving outcomes such as fewer hospital deaths or less use of life-prolonging treatments near the end of life (Houttekier, Cohen, Cools, & Deliens, 2012).

A feasibility study (Boyd et al., 2010) involving interviews and a workshop with GPs and community nurses, identified a number of barriers to early adoption of advance care plans:

- prognostic uncertainty
- limited collaboration with secondary care
- a desire to maintain hope
- resistance to any kind of ‘tick-box’ approach

Following the workshop there was an improvement in knowledge and skills, but there was no clear evidence of more proactive planning. Concerns were raised by GPs over implementing inflexible, policy-driven, care.

A trial (L. Jones et al., 2011) involving 77 patients found that while an advance care planning intervention did demonstrate an increase in discussions about the future between patients and professionals or family, happiness with the communication was the same or worse, and satisfaction with services decreased. In all, 38 of the patients (51%) reported a preference for the intervention.

Qualitative research (Mitchell & Dale, 2015) on the perceptions of pediatric consultants and nurses, identified four major themes:

- recognition of an illness as 'life-limiting';
- Advance Care Planning as a multi-disciplinary, structured process;
- the value of Advance Care Planning
- the adverse consequences of inadequate Advance Care Planning

A number of potential benefits of ACP were recognised including providing the opportunity to make decisions regarding end-of-life care in a timely fashion and in partnership with patients, where possible, and their families.

Barriers to the process include the recognition of the life-limiting nature of an illness and gaining consensus of medical opinion. Organisational improvements towards earlier recognition of life-limiting illness and subsequent Advance Care Planning were recommended, including education and training, as well as the need for wider societal debate.

3.4 Dying Well

Whether a person is able to die in their preferred place of death is commonly viewed as a measure of a ‘good death’. Research suggests that while up to 74% of people say they would prefer to die at home, but currently 58% of people die in hospital (Department of Health, 2009). Critical success factors to enable individuals to die in their preferred place of death include strong commissioning and clinical leadership; use of nationally recognised drivers that attract payment (e.g. CQUINs); flexible budgets and care packages; use of nationally recognised tools or their local equivalent; fast track pathway; shared electronic information systems; clearly defined access to 24hr cover; development of Care Homes; use of facilitator roles and coordination of care across boundaries; and training to support staff delivering EoLC (National End of Life Care Programme, 2012).

Drawing on published research and 33 semi structured interviews with staff involved in the delivery of end of life care in Ireland, Casey et al (2011) identified 3 key factors that influenced the provision of good end of life care for older people:

- *Philosophy , organization and culture of care*. Spending time with those who were dying was considered important. However lack of time, staff shortages, lack of support and the organisational routines and procedures often hindered staffs ability to provide good end of life care.
- *Knowing the person*. While creating a close relationship was considered a key determinant of quality EoL care, few staff openly discussed death/dying with clients and used various techniques to circumvent such conversations
- *Physical environment & resources*. Access to single room accommodation to provide privacy and dignity, and access to good quality palliative care training and education were considered important

The authors found that the potential to ‘die well’ was influenced by these three interrelated factors.

The importance of the physical environment to the experience of end of life care is also highlighted in the strategy (Department of Health, 2009) and the Kings Fund Enhancing Healing Environment programme[6]

Central to this is the importance of providing environments that encourage dignity and respect and recognise the need for:

- Rooms where an individual and their family can go to talk privately
- Informal gathering spaces where families can meet
- Guest rooms where close family and friends can stay overnight, with facilities for catering and communication.

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[6] Kings Fund Enhancing Healing Environments http://www.kingsfund.org.uk/projects/enhancing-healing-environment (accessed 21 July 2015)

In addition, following death particular attention needs to be given to:

- The transfer of the body to the mortuary
- The location of the mortuary and how it is approached by families, friends and carers
- The viewing room
- Rooms where families, friends and carers can sit quietly and receive the deceased person's property and collect the death certificate

The NHS National End of Life Care Programme report has outlined a number of emerging themes in designing environments for end of life care:

- Natural environments can have a profound effect on people and those who are dying, which could include access to gardens, views of nature from windows or doors, artworks depicting nature, natural light and ventilation, and moving water.
- First impressions count and so the entrance space to a building should create a professional impression and sense of warmth, reassurance and friendship. Areas should be uncluttered and information easily accessible
- Comfort. The design should be inclusive for all ages and cultures, and be welcoming. Colour can be used to create a domestic feel rather than institutional.
- Privacy and dignity. Informal spaces and private rooms should be provided, and bedrooms should allow privacy
- Spiritual spaces should be accessible and support all faiths (and people with no faith)
- Spaces for relatives and friends should be provided with drinks and access to toilets/showers and the facilities which allow overnight stays
- When a death occurs there should be appropriate spaces for relatives to sit quietly and undertake the required administrative procedures

The following key factors required for success were highlighted

- The need to for a team approach involving a range of staff
- De-cluttering of spaces
- Consultation and engagement to establish the needs and preferences of patients and carers
- Quality assurance and sustainability
- Look to the longer term and give staff the opportunity to get involved in environmental improvement projects

4 End of Life Care and palliative care for specific communities

The NHS Improving Quality7 organization have produced a guidance and advice on end of life care for those working with specific communities.

In a review of equity in the provision of palliative care in the UK, Dixon et al (2015) found that while many people receive high quality care there are still significant gaps in provision, and estimate that around 92,000 people a year in England who would benefit from palliative care do not receive it.

The authors conclude that palliative care interventions are cost-effective and extending specialist and core palliative care services to those who would benefit could result in net savings of £36m in England.

There are a number of specific communities who may face challenges to accessing end of life or palliative care for various reasons. Whilst numbers may be small, it is important to consider how local services can meet the needs of common groups such as people with dementia, BME or LGBT patients, as well as prisoners, children and homeless patients.

4.1 People with dementia

Dementia has a significant impact on an individual's health and quality of life (see Dementia JSNA, October 2015). It can result in a range of health and social problems which can be challenging for the person with dementia, their carers, and health and social care professionals. People with dementia are likely to have significant physical and mental comorbidities, such as depression, hypertension and diabetes.

Estimates of rates of dementia vary. Whatever the true underlying prevalence is, services will currently be engaging with the majority of those at the more severe end of the spectrum. The number of these is likely to **increase by 55% across the three boroughs over the next 15 years** given national projections of local population changes.

This increase in the number of people with dementia means that diagnostic, treatment and care service provision may need to expand proportionately to meet this increasing need. This will include end of life care and palliative care services.

The importance of end of life care for people with dementia is also highlighted in the National Dementia Strategy (Department of Health, 2009) where improved end of life care for people with

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[7] NHS Improving Quality http://www.nhsiq.nhs.uk/ (accessed 15/07/2015)

dementia, and the involvement of people with dementia, their families and carers in care planning is included as an objective in the strategy.

Research by the Alzheimer's Society and Marie Curie(Alzheimer's Society & Marie Curie Cancer Care, 2014) identified a number of barriers to receiving high quality end of life care for people with dementia, categorized into three themes. These are shown in the table below.

Table 4: Barriers to end of life care for people with dementia

Theme	Barriers
Identification and planning	• lack of timely and appropriate diagnosis • poor recognition of dementia as a terminal condition • failure to identify dementia as a cause of death • ineffective advance care planning
Inequality of access…	• to palliative care • to hospice care • to funding • discrimination
Quality of care	• inconsistency in care standards in hospitals • inappropriate hospital admissions • lack of continuity of care • poor pain management • inappropriate interventions • failure to adapt practice to reflect the different nature of dementia • lack of support for carers

The report concludes that the way services are designed, delivered and commissioned needs to change in order to ensure that people receive the care they need and meet the future challenges posed by the increase in dementia. A call for action is made to remove the barriers that prevent many people with dementia from accessing the high quality end of life care they need; transform core services that have primarily been designed in response to cancer patients; and work in partnership to raise understanding and awareness of dementia and end of life care.

Research conducted on the views of carers and professionals (Raymond et al., 2014) found that:

- A lack of communication between professional and carer may lead to a poor experience. Professionals should establish the carers' perspectives and wishes on the care of the patient.
- Cultural backgrounds, beliefs and experiences of professionals may influence choices over what kind of support and care is desired
- Advance care planning may be helpful to all parties, but may not always be desired

- Professionals need to be aware of the possibility of elder abuse or poor quality care when supporting people with dementia and should know their responsibilities
- Professionals may benefit from skills development and access to resources in seeking to implement a holistic approach to end-of-life care for people with dementia

Recommendations

One of the gaps identified in the dementia JSNA was a lack of sufficient resource to support end of life care for people with dementia across the three boroughs. From this, the following recommendation was made:

"Ensure that there is a clear end of life care pathway for people with dementia with appropriate advanced care planning and powers of attorney and clinicians are responsive to these wishes."

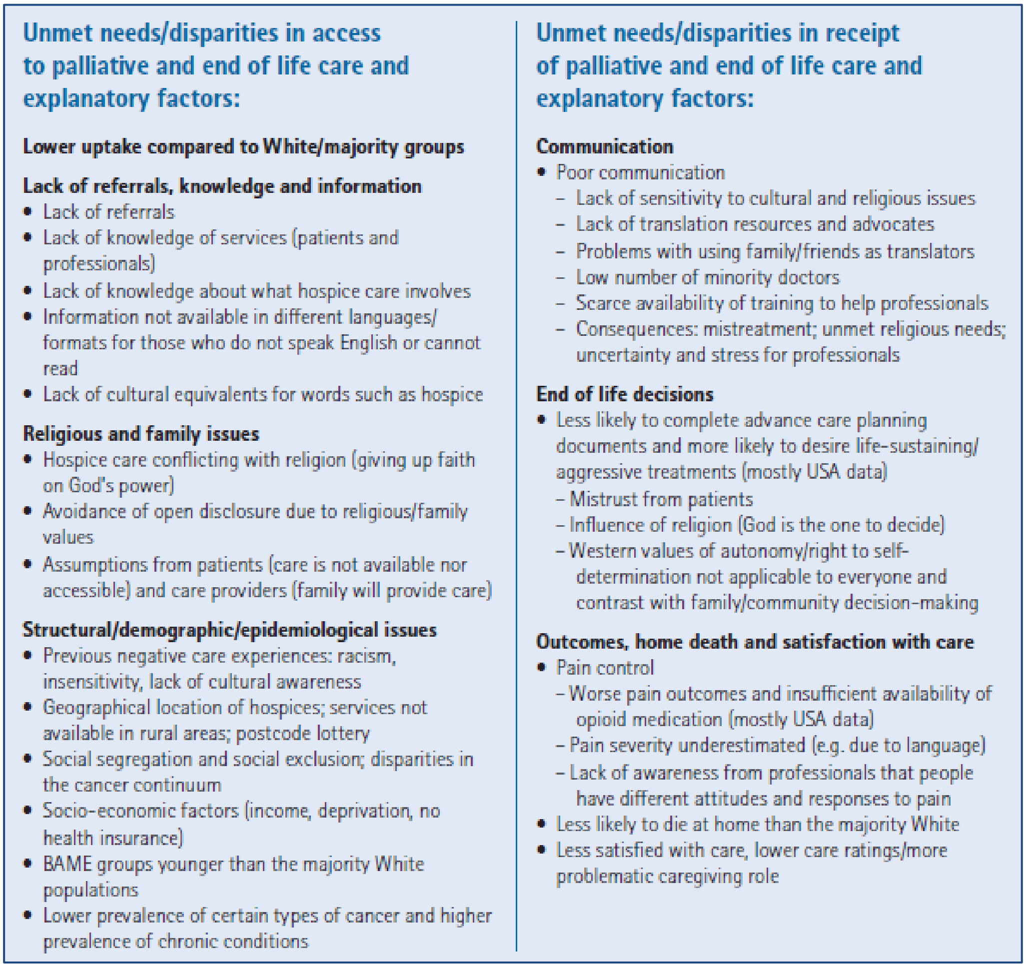
4.2 Black and Minority Ethnic (BME)

Although there are numerous potential barriers to accessing palliative care services for people from BAME backgrounds, such as cultural and religious sensitivity, quantitative evidence suggests that people from BAME backgrounds have similar access to palliative care as people of 'White' ethnicity. Locally, a disparity was not found between people whose country of birth was outside the UK and people born in the UK, proportionate to the age group.

However, in a review of equity in the provision of palliative care in the UK, Dixon et al (2015) found that people from BAME background were less likely to consider care in the last 3 months of life to be 'Outstanding' or 'Excellent'.

Recent research undertaken by the Cicely Saunders Institute (Calanzani et al., 2013) reviewed the evidence base to identify the unmet needs and disparities regarding palliative and end of life care. The table below summarises these findings:

Table 5: Unmet needs/disparities in end of life and palliative care (Calanzani et al, 2013)



Unmet needs/disparities in access to palliative and end of life care and explanatory factors:

Lower uptake compared to White/majority groups

Lack of referrals, knowledge and information
- Lack of referrals
- Lack of knowledge of services (patients and professionals)
- Lack of knowledge about what hospice care involves
- Information not available in different languages/ formats for those who do not speak English or cannot read
- Lack of cultural equivalents for words such as hospice

Religious and family issues
- Hospice care conflicting with religion (giving up faith on God's power)
- Avoidance of open disclosure due to religious/family values
- Assumptions from patients (care is not available nor accessible) and care providers (family will provide care)

Structural/demographic/epidemiological issues
- Previous negative care experiences: racism, insensitivity, lack of cultural awareness
- Geographical location of hospices; services not available in rural areas; postcode lottery
- Social segregation and social exclusion; disparities in the cancer continuum
- Socio-economic factors (income, deprivation, no health insurance)
- BAME groups younger than the majority White populations
- Lower prevalence of certain types of cancer and higher prevalence of chronic conditions

Unmet needs/disparities in receipt of palliative and end of life care and explanatory factors:

Communication
- Poor communication
  - Lack of sensitivity to cultural and religious issues
  - Lack of translation resources and advocates
  - Problems with using family/friends as translators
  - Low number of minority doctors
  - Scarce availability of training to help professionals
  - Consequences: mistreatment; unmet religious needs; uncertainty and stress for professionals

End of life decisions
- Less likely to complete advance care planning documents and more likely to desire life-sustaining/ aggressive treatments (mostly USA data)
  - Mistrust from patients
  - Influence of religion (God is the one to decide)
  - Western values of autonomy/right to self-determination not applicable to everyone and contrast with family/community decision-making

Outcomes, home death and satisfaction with care
- Pain control
  - Worse pain outcomes and insufficient availability of opioid medication (mostly USA data)
  - Pain severity underestimated (e.g. due to language)
  - Lack of awareness from professionals that people have different attitudes and responses to pain
- Less likely to die at home than the majority White
- Less satisfied with care, lower care ratings/more problematic caregiving role

Calanzani et al (2013) caution against a number of assumptions that are made in research and practice, including:

- That people who mistrust the system are mistrustful (habit to "blame the victim")
- Using the 'hard to reach' stereotype infers they are the people who are not accessible, not us (habit to shift the burden of change to the patient)
- Think that all in a particular ethnic group share the same values
- Not appreciate that the same beliefs can be shared by different groups
- Use of culture and ethnicity as predictors of behaviour

There is a lack of robust evidence for interventions to address the barriers faced by BAME groups (Calanzani et al., 2013; Evans, Meñaca, Andrew, et al., 2012) and is often limited to examples of local initiatives with no evidence of effectiveness.

Recommendations

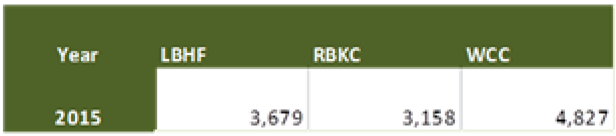
Further research is needed to understand why people from BAME communities are less likely to experience high quality care in the last three months of life (Dixon, King, Matosevic, Clark, & Knapp, 2015)

4.3 People with Learning Disabilities

People with a learning disability are more likely than the general population to experience a range of health conditions, including heart disease, diabetes, respiratory disease, epilepsy, mental illness, dementia, and sensory impairment. Consequently this will have an impact on the end of life care needs of this group.

Number of people aged 15 years and over with Learning Disability in 2015, LA resident population

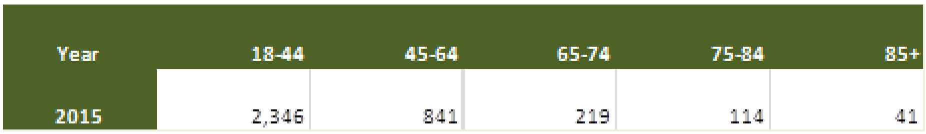
Number



Year	LBHF	RBKC	WCC
2015	3,679	3,158	4,827

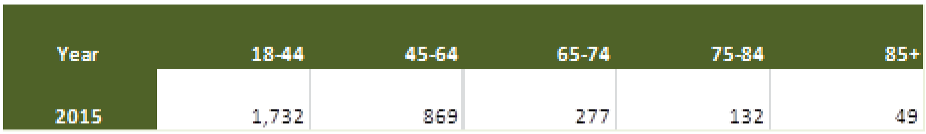
By age group:

Hammersmith & Fulham



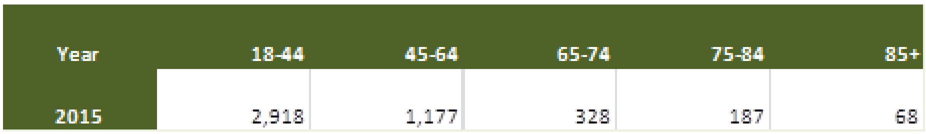
Year	18-44	45-64	65-74	75-84	85+
2015	2,346	841	219	114	41

Kensington and Chelsea



Year	18-44	45-64	65-74	75-84	85+
2015	1,732	869	277	132	49

Westminster

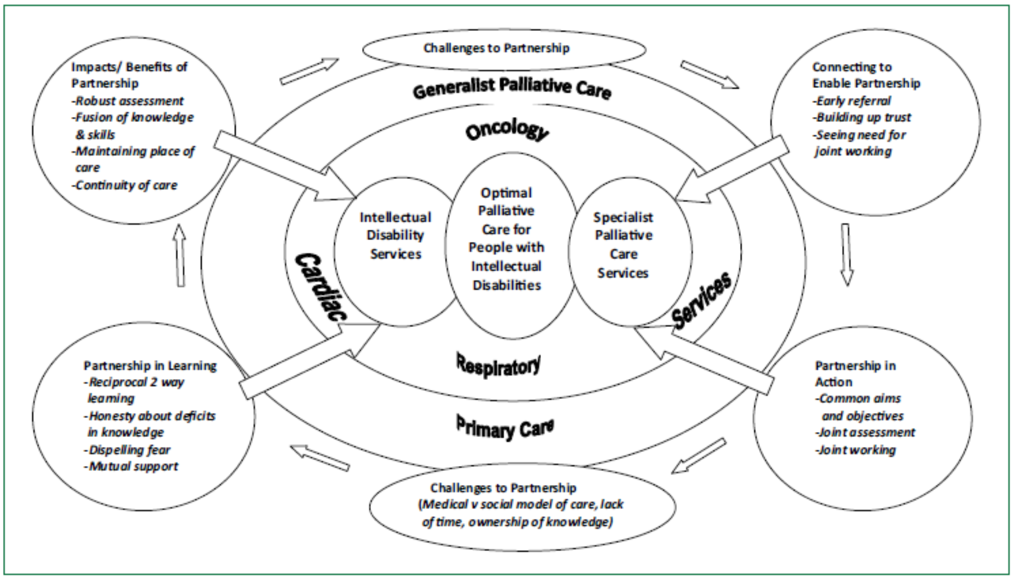


Year	18-44	45-64	65-74	75-84	85+
2015	2,918	1,177	328	187	68

The NHS IQ report is framed around the end of life care pathway and highlights issues to consider under each of the six steps and the practitioner's role in providing care. Overall, a number of challenges (the "5 Cs") to providing end of life care for people with a learning disability are highlighted which, if addressed, may lead to a "good death" for the person with a learning disability and their family or carers. These are described in Appendix B.

The partnership between specialist palliative care services and learning disability services is also highlighted in a UK mixed-method study (McLaughlin, Barr, McIlfatrick, & McConkey, 2014). Based on the findings from a questionnaire sent to a sample of 66 services in one UK region (including learning disability services, specialist palliative care services, and nursing homes for people with a learning disability) and semi-structured interviews with 30 selected health and social care professionals, the authors developed a partnership framework for learning disability and specialist palliative care services:

Figure 5: A framework for partnership practice between specialist palliative care and intellectual disability services



The study found examples of good practice existed but that partnership practice between services was infrequent and a number of unmet educational needs were identified. For palliative care teams this included understanding how and where to access local learning disability services, and issues around communication and assessment. For learning disability services, this included knowledge of pain and symptom management, bereavement care, and self-care to cope with death and professional grief.

Key factors for success were joint working and learning between services.

Recommendations

- Review of services against the “5 Cs” for end of life care for people with a learning disability
- Increase joint working between palliative care teams and Learning Disability services

4.4 Lesbian, Gay, Bisexual and Transgender (LGBT)

The End of Life Care Strategy Equality Impact Assessment (Department of Health, 2008b) identifies sexual orientation and gender identity as the most likely area for inequality and discrimination to occur in end of life care. One of the key areas reported was that the nature of LGBT relationships may well be concealed, with the consequence that practitioners and staff may exclude key individuals from involvement in a person’s care.

NHS Improving Quality reports that LGBT experiences can be characterised by a number of factors which are likely to have an impact. These include living alone, social isolation, barriers to services and a lack of consultation, negative experiences related to their sexual orientation or gender identity, and ageism.

The NHS IQ report (NHS Improving Quality, 2014a) highlights a number of recommendations and issues to consider for end of life care in the LGBT population:

- The importance of avoiding the assumption that someone is heterosexual
- The enhanced privacy rights for transgender people provided by the Gender Recognition Act (2004)
- Avoiding the common misunderstanding that a next of kin needs to be a person related by blood or marriage
- Challenges faced if a person has not previously ‘come out’ – the need for end of life care can mean private domestic arrangements are subject to wider scrutiny
- Recognising that ‘coming out’ may result in LGBT people being isolated from their families of origin and therefore relying on other support networks
- The danger of not recognizing the significance of a relationship, which may result in a bereaved person’s grief going unrecognised

4.5 Homeless people

Homelessness is a particular issue in London with half of England’s rough sleepers located in London, and two-thirds of London’s rough sleepers in the three boroughs

There are approximately 3,450 rough sleepers in Hammersmith and Fulham, Kensington and Chelsea and Westminster according to the CHAIN (Combined Homelessness and Information Network) database. Westminster has the largest concentration of rough sleepers in the country, accounting for three quarters of those in London.

Homeless people experience poorer levels of physical and mental health than the general population, and there is a substantial international evidence base which documents multiple morbidities (Brodie et al., 2013). Research largely finds the average age of death of a homeless person as between 40-42 years of age. Crisis identified the average age of death for homeless people in England as 47 compared to 77 for the general population (Crisis, 2011).

Many homeless people die from treatable medical conditions, HIV, liver and other gastro-intestinal disease, respiratory disease, and consequences of drug and alcohol dependence (Brodie et al., 2013).

The National End of Life Care strategy (Department of Health, 2008a) states that high quality end of life care “should be available wherever the person may be: at home, in a care home, in hospital, in a hospice or elsewhere”.

Recognising that homeless people are often overlooked when developing policy and are not often engaged in service development, and that consequently the implementation of the strategy poses particular challenges in relation to homeless people, the National End of Life Care Programme report a range of key considerations for end of life care for homeless people, including:

- The existing environment may not encourage privacy or be suitable for care and it may not be practicable to consider rebuilding or remodelling hostels. What other measures could be taken?
- Access to services may be problematic because of other professionals' misconceptions– for instance, homeless people are often stigmatised as non-compliant and unreliable. How can this be overcome?
- The homeless population often decline to engage with health services. What would encourage them to engage?
- Access to placement at end of life for people with substance misuse problems can be difficult because many care facilities do not accept people with drug or alcohol issues. Staff need to be aware of those providers who do accept and provide for this.
- Some outreach services can have bureaucratic barriers. How can these best be overcome?
- Many hostels tend not to retain residents for a long time but help them move to supported or independent living. With collaborative working and planning this should also be possible for those with end of life care needs
- Many residents have very complex needs including a high incidence of learning difficulties, mental health problems and dependency issues. As a result hostels may not offer the best environment for end of life care

Recommendations

Review EOLC services for the homeless population and implement specific actions

4.6 Prisoners

The local needs assessment on prison health care, published in 2013, identified that there is little evidence regarding the prevalence or need for palliative or end of life care within the prison environment (Sayers, 2013).

However, as the number of older prisoners within the prison population increases and the likelihood that this will result in an increase in long term conditions it is likely that the number of prisoners requiring end of life and palliative care could increase in the future.

Wormwood Scrubs Prison in Hammersmith & Fulham has a total population of 1,183 (31 March, 2013). Nationally, 12% of prisoners are aged 50 years and over (4% aged 60 and over).[8]

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[8] Ministry of Justice https://www.gov.uk/government/statistics/offender-management-statistics-quarterly--2

An evaluation by Lancaster University[9] concluded that compared to the general population the needs of prisoners for palliative or end of life care is small, however, does make some recommendations around policy, practice, training and research.

The HM Inspectorate of Prison's report, 'No problems - Old and Quiet' (2004), makes reference to the state of palliative care in prisons in the UK. It mentions that all prison healthcare centres are required to have a policy for palliative care.

The NHS Improving Quality report (2014b) for prisons highlights this growth in the older prison population and that prison staff will increasingly be required to manage the end of life care needs of prisoners. As with their other reports a number of key considerations are outlined to ensure that policies and processes have been addressed to support good end of life care:

- Are prisoners and their environment safe? This overrides all other principles of care and staff must be accountable for the safe custody of the prisoner and that of the whole prison environment
- What are the particular security requirements within that prison for individuals, visitors, and medical staff coming in with prescribed medication and for assessment and review purposes?
- What access is there to required end of life care/symptom control medications? Also, what is the policy on using morphine/syringe drivers in custody?
- Have assessments included the prisoner/ patient's physical condition as well as likelihood of violence?
- What are the policies relating to dignity and privacy for the individual/the environment management strategy/the use of the open door policy?
- Does a prison officer always have to be present during visits/medical treatment and death?
- What is the agreed communication process?
- What is the process for considering whether release is appropriate on compassionate grounds as per PSO 6300: Release on temporary licence (HM Prison Service, 2005)?
- What is in place to provide for the needs of the family/carers? Also, how will these be identified and recorded?
- Are there measures to aid communication with those for whom English is not their first language, those who have speech and language difficulties and those whose understanding may be compromised due to cognitive impairment or a learning difficulty?
- Is there access to appropriate training, education and support for prison staff?

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[9] Turner M, Payne S. Kidd H, Barbarachild Z. Dying behind bars: an evaluation of end of life care in prisons in Cumbria and Lancashire http://www.lancaster.ac.uk/shm/research/ioelc/groups/media/mturner_150410.pdf

4.7 Children with terminal illness

The numbers of children who die locally are very low, and include neonates who die shortly after birth. Deaths in those aged 0-17 represent less than 1% of all deaths, and 0.04% of the population in this age group (compared to 11% in those aged 85 years and over). As you can see in Figure 8 in the Technical Document, most of the deaths in those aged 0-17 years are babies.

Table 6: Deaths in 2014 in residents aged 0-17

Borough	Deaths (0-17 yr old)
LBHF	8
RBKC	6
WCC	9

However, end of life care services need to be aware of different issues when working with children who are dying. The General Medical Council's guidance on End of Life Care[10] includes guidance on Neonates, Children and Young People. The best practice recommends balancing the need to safeguard children's health and wellbeing with enabling them to take part in decision making, listening to them and taking account of what they have to say about things that affect them if they have full capacity.

When dealing with infants and neonates, it is key to give parents or carers information and support and consistent and clear messages about their child's care on condition.

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[10] General Medical Council http://www.gmc-uk.org/guidance/ethical_guidance/end_of_life_neonates_children_and_young_people.asp

5 Appendices

Appendix A: Advice to Government on the steps needed to deliver choice in end of life care (*What's important to me. A Review of Choice in End of Life Care*)

For the individual	• That each person who has consented to and wishes to specify choices and preferences in their end of life care has these recorded in their individual plan of care, with its details held on an Electronic Palliative Care Coordination System (EPaCCS) or equivalent system. • That each person in need of end of life care has a named responsible senior clinician who would have overall responsibility for their care and their preferences. • That each person in need of end of life care is offered a care coordinator who would be their first point of contact in relation to their care and their preferences. • That each person who wishes to express their end of life care choices and preferences in advance is offered a way to do this through access to their own medical records and plans of care and the ability to add and amend information on personal choices and preferences
For family and carers	• That carers for people at the end of life should be formally identified as such by the relevant services, that their eligible needs for support be met in line with the provisions of the Care Act 2014, and that support be provided for carers following bereavement. • That family members, carers and/or those important to the individual should be involved in discussions about care preferences where the dying person has said they should be, if this is appropriate and helpful.
For the workforce	• That Health Education England, Local Education and Training Boards and Skills for Care ensure that staff responsible for the delivery of end of life care have training focused on the key elements of their roles which enable choice such as early identification of needs, advance care planning, communications skills, shared decision making, the use of coordination systems (e.g. EPaCCS) and working in partnership with people and other organisations to design and deliver person-centred care. • That there be greater joint working between palliative care specialists and other clinical staff, and between secondary care and primary care staff, to identify people who may need end of life care as early as possible. • That Health Education England, in planning for future workforce numbers, should:

	○ work with commissioners and providers to agree both specialist and non-specialist palliative care workforce requirements, in acute and community settings, to deliver improvements in end of life care. ○ take into account how breaking down organisational boundaries can allow staff working in acute settings to play a greater role in delivering care in community settings.
For health and social care organisations	• That all key decision-makers and commissioners at every level, including in Clinical Commissioning Groups, Health and Wellbeing Boards and providers ensure a universally good end of life care service exists in all relevant settings as a platform for delivery of a national choice offer to all dying people. • That EPaCCS or equivalent system coverage is increased to 100% of localities by April 2018 to enable the recording and sharing of people’s choices and preferences. • That EPaCCS or equivalent systems are fully accessible to view and update for all involved in the provision of end of life care services, in particular social care organisations, and that they align with the information on care plans offered to people with long term conditions and any social care assessments. • That by the end of 2019, every local area should establish 24/7 end of life care for people being cared for outside hospital, in line with the NICE quality standard for end of life care, which supports people’s choices and preferences. • That NHS and social care organisations work in closer partnership with the voluntary sector to support hospices in providing the services required to meet people’s choices. • That local areas who already have the systems and services in place to offer and deliver choice as outlined in the proposed national choice offer do this at the earliest opportunity, sharing their expertise with others through a central knowledge hub. • That Health and Wellbeing Boards consider enabling choice, better coordinated care and integrated models of end of life care in making strategic plans for their local areas. • That the potential for the use of personal budgets should be more fully explored and that provider organisations should consider how they can best support people to use personal budgets to enable their choices and preferences to be met. • That health and social care commissioners include initiatives aimed at increasing community resilience and involvement in end of life care in their plans

For the Government and national organisations	• That the £130million additional investment identified as needed to enable the national choice offer in end of life care to be made by April 2020 be identified in the next spending review. • That the national choice offer be supported through a new right in the NHS Constitution for everyone to be offered choice in end of life care and have these choices and preferences recorded and held in their individual plan of care. The offer should be included in the NHS Choice Framework and supporting information for patients should be published on the NHS Choices website. • That NHS England's new guidance for Clinical Commissioning Groups makes explicit reference to enabling preferences at the end of life, and preferences at the end of life be considered in ongoing work on the NHS Standard Contract, new palliative care currencies, the service specification for specialist palliative care and the updated commissioning toolkit for end of life care. • That, in reviewing the Quality and Outcomes Framework consideration be given to how identification of palliative care needs, people's preferences at the end of life and better coordinated care can be appropriately incentivised, potentially with regard to the use of EPaCCS or equivalent systems. • That the work on individual-level outcome and experience measures for palliative care, being led by NHS England and Public Health England, should incorporate real time feedback and also measure the extent to which a person had been offered choice and whether their choices had been met. These measures should also provide meaningful data to monitor the impact of a national choice offer on health inequalities. • That indicators be developed for the NHS and Adult Social Care Outcomes Frameworks to hold the health social care system to account for delivering choice and improving experience for all at the end of life. • That the Government implement a clear policy to make access to social care for people at the end of life fast and free. • That the *Five Year Forward View* 'Models of Care Board' explores the integration of health and social care at the end of life as one of the models of care that has the potential to be transformative in delivering care closer to home. • That the CQC inspection regime for acute and community trusts, primary care and adult social care (which includes hospices and care homes) uses the offer of choice to individuals in end of life care and the ability of organisations to facilitate and support coordinated care as signifiers of quality. • That there be further work on costs and savings to support implementation of the choice offer, building on both the existing

	costing work and covering uncosted elements of this advice such as staff training, named responsible senior clinicians and care coordinators.
For society and community	• That the Dying Matters Coalition has a key role to play in widening public understanding and supporting the development of choice and so should be encouraged, supported and sustained, as should initiatives aimed at building the confidence of health and care professionals on these issues. • That there should be further funding for research into palliative and end of life care, focusing on the priorities identified by the James Lind Alliance

Appendix B: The "5 Cs": challenges to providing end of life care for people with a learning disability

Complexity	Having a learning disability may complicate the care that is required and the knowledge which professionals require to be able to deliver it across a range of settings. **Education and training** is key for all those involved.
Communication	Learning disability and palliative care professionals each have their areas of expertise in terms of communication. Whilst these overlap there will be areas in which either team knows less than they need to in providing best end of life care for people with learning disabilities. **Teamwork** (which includes the person as a central member) will be crucial to ensure distress is minimised and best care, in keeping with the person's preferences, is achieved.
Compliance	Assumptions about the person's ability or desire to comply with treatments or in decision making can lead to the person not being offered the full range of interventions that they would if they did not have a learning disability. This might include some end of life care placements; e.g., hospice day care. It will be important to consider that the 'non-compliant' behaviour may better be interpreted as an expression of how the individual is feeling and may indicate an **unmet emotional or symptom-control need.**
Consent	The person's capacity to understand and consent to various elements of end of life care may be impaired by their learning disability but is likely to be more seriously impaired by assumptions or over-protective attitudes of carers (both family and paid). Professionals will need to employ clear thinking about what decisions need to be made by whom as well as a willingness to be creative in finding ways to help the person understand their options and be active in deciding which ones they prefer. Above all consideration needs to be given not just to the individual's level of cognitive ability but to their life experience and their previously **expressed views and wishes on issues** related to end of life care. This applies whether the person can make the decision themselves or whether carers need to act in their best interests.

Choice	Often deprived of choice about all aspects of their lives it is crucially important for everyone involved in the end of life care of someone with a learning disability to give primacy to the individual's choice. Whilst a professional's duty of care mitigates what is important for the person this should not be at the expense of a commitment to ensuring that **what is important to them** is also realised.

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