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<th>End of life care strategy update</th>
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<td>Status</td>
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<td>History</td>
<td>This strategy was reviewed at Quality Committee and at Trust Management Executive in June 2016</td>
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<td>Board Lead(s)</td>
<td>Dr Tony Berendt Medical Director</td>
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# Executive Summary

1. This paper sets out the End of life care Strategy for the Trust.

2. End of life care is part of the core business of the Trust and a clear window into the ability of the Trust to meet its promise to “deliver compassionate excellence”

3. The strategy describes the local and national context for end of life care and aligns with other Trust strategies and strategic priorities.

4. The strategy is built to mirror the five priorities of care of the dying person, as described in the national report *Priorities of Care for the Dying Person*. Clinicians caring for patients at the end of life are asked to Recognise; Communicate; Involve; Support; Plan and Do.

5. These five priorities for the care of the individual are translated into five strategic priorities for the Trust to consider in supporting staff and stakeholder organisations to design and deliver the highest possible quality care for patients at the end of life.

6. **Recommendation**  
The Trust Board is asked to agree the End of Life Care strategy and the presentation of an annual report 2015-16, and an annual plan 2016-17, to the Quality Committee in August 2016.
End of Life Care Strategy

1. **Purpose.**

   1.1. The purpose of this paper is to set out a strategy for developing and sustaining high standards of care for patients at the end of life and for their family, partners, carers or friends.

2. **End of life care is our business.**

   2.1. Patients are considered to be “approaching the end of life” when they are likely to die within the next 12 months. This group of patients encompasses those:

      2.1.1. Where death is imminent
      2.1.2. Who have advanced, progressive, incurable conditions
      2.1.3. Who have general frailty and multi-morbidity
      2.1.4. Suffering an acute crisis in a longer term condition
      2.1.5. With life threatening acute conditions

   2.2. “End of life care” focuses in particular on patients at the end of life, but the delivery of good end of life care relies heavily on the recognition that a patient is approaching the end of life. Without this recognition, it is less likely that all the necessary elements of communication and care will take place in the patient's final days or weeks to make their death as comfortable as possible.

   2.3. Clinicians are encouraged to recognise patients approaching the end of life by asking themselves if they would be surprised if the patient died within the next year.

   2.4. A death is a critical event in the life of a family. Care of the dying patient and their family is part of our core business as a hospital, and this is recognised by the fact that the Care Quality Commission includes End of Life Care as one of the eight core services it inspects in acute hospitals.

   2.5. Dame Cicely Saunders (1918 - 2005), founder of the modern hospice movement, drew attention to the profound impact that the experience of death has on those who witness it, with the statement “How people die remains in the memory of those who live on”.

   2.6. Aspiring to excellence in the provision of end of life care is thus not only a human and moral obligation towards the dying; it is equally a compassionate and foresighted action towards those who are left, and those who will care for them. Ensuring excellent care of the dying will require that healthcare workers are themselves supported in this difficult work, with expected improvements in their wellbeing. Finally, as none of us can predict with certainty where or when our own life will end, it makes
sense for us all to work together to ensure that end of life care is provided at an equally high standard as care for all other conditions.

3. Background

3.1. Approximately 50% of patients dying in Oxfordshire die while a patient in Oxford University Hospitals NHS Trust (OUH). 75% of those deaths are expected deaths – though in some patients the healthcare staff may only be able to diagnose impending death a few hours or days before it occurs.

3.2. For approximately 3000 people each year who were identifiably approaching the end of life, the Trust has the opportunity to deliver high quality care to patients, and to deliver compassion, support and information to the patient’s family before and after their relative’s death. For the additional c.1000 patients who die in the Trust with who were not in the categories listed in section 2.1, the Trust can still deliver great care to suddenly bereaved families.

3.3. At the 2014 CQC inspection of the OUH Trust, end of life care was rated across the Trust as “Good”. Since that time, new quality standards and national audit data have been produced that demonstrate the need for continuous improvement.

3.4. The number of deaths each year is expected to rise by 17% between 2004 and 2030, linked to the aging population.

3.5. Although many people would currently choose to die in hospital because of concern for their family or in order to have better symptom control, population-based studies of preferences for place of death indicate that over 60% of people (including those who were not facing life-threatening illness at the time) would prefer to die at home. In the 2012 British Social Attitudes survey, 60% of those who stated that they would prefer to die at home would change their mind if sufficient support from family, friends or social and medical professionals were not available. The need to be pain free (24%) came a close second to the presence of family and friends (28%), in terms of the most important aspects of their end of life care.

3.6. Death in hospital is not incompatible with compassion or excellence, but there are pitfalls. The experience of dying in hospital is at significant risk of being “medicalised” as a response to the stresses and anxieties inherent in the organisation of care within a hospital; teams of nurses, doctors and other staff caring for large numbers of patients with varying diagnoses, prognoses and acuity of illness. In this situation, clinical staff, fearing subsequent criticism for withholding treatment, may default to a range of interventions that would, on more careful reflection and after appropriate discussion with the patient and family, have been deemed unnecessary or even inhumane.

3.7. In addition to the suffering to patient and family that well-intentioned overtreatment can cause, there is a substantial use of resources entrained by such behaviours. This can include advanced imaging, surgery,
admission to intensive care, and attempted cardiopulmonary resuscitation; all expensive interventions that use resources which could instead be providing more comfort, dignity and personalised care to the dying patient.

3.8. Equally, it is important to recognise that adjusting to the fact that a patient is approaching the end of life is not an easy matter for most patients, carers, or healthcare staff. For many, the desire to deny that death is approaching is strong, and the promise of precious extra days, weeks or months of life, a compelling offer.

3.9. The difficulties in striking the right balance between under- or over-investigation/treatment are well illustrated by the fact that complaints from relatives, and stories in national media, draw from both of these polarities. Healthcare workers and managers are charged with providing individual care and systems of care that support patients and staff in making good decisions around end of life care and being able to offer the right care in the right environments at the right time.

3.10. In this context there is a need for a strategic approach to the planning and delivery of high quality end of life care within the OUH Foundation Trust and outside its walls in close collaboration with partner organisations. There is also a need for these collaborative approaches to be reflected in conversations with the wider public as part of more general discussions on death and dying.

4. Our vision

4.1. Our vision is to be known and trusted as a highly reliable partner in and provider of excellent, compassionate, end of life care

5. The need for a strategy

5.1. As set out above, the general context of end of life care requires a strategic approach to make and embed changes in patterns of care across the Trust

5.2. This strategy reflects the fact that end of life care is a major area of public concern and national effort, as illustrated by a series of documents including most recently:

5.2.1. One Chance to Get it Right (June 2014, Leadership Alliance of the Care of Dying People)

5.2.2. Priorities of Care for the Dying Person (June 2014, Leadership Alliance of the Care of Dying People)

5.2.3. Ambitions for Palliative and End of Life Care (2015, National Palliative and End of Life Care Partnership)

5.3. At a system level, current work on the Sustainability and Transformation Plan also includes consideration of how to make changes to ensure that the whole system can support high quality end of life care wherever the patient is located

5.4. At a local level, the ongoing Trust Strategic Review process is developing a number of themes all of which have direct relevance to ensuring high quality end of life care:
5.4.1.  *Home Sweet Home* (moving care closer to home; in this case supporting those patients and families where the patient chooses to die at home)

5.4.2.  *Focus on Excellence* (raising standards across the board, and developing world class centres of excellence; in this case recognising that provision of high quality end of life care should be a core service competence and is a CQC expectation)

5.4.3.  *Go Digital* (adoption of digital technology; in this case, recognising the need to support seamless information transfer as patients transition between care environments in what are often complex pathways of multi-disciplinary and multi-agency care, at a time when good communication is critical)

5.4.4.  *Masterplan* (reviewing use of estate and physical “footprint”; in this case, being sensitive to the needs of end of life care patients and their families in any estates reconfigurations and redesigns)

5.4.5.  *High Quality Costs Less* (recognising the raising quality reduces waste and allows the generation of savings to invest in further care; in this case, avoiding unkind, futile, and wasteful over treatment, while providing the best quality end of life care)

5.5. Finally, end of life care has been identified as one of the Trust’s quality priorities, has been agreed by the Foundation Trust Governors as their key priority for 2016-17, and is the subject of a locally commissioned CQUIN (commissioning for quality improvement) initiative for 2016-17.

6.  **Key principles for the OUH end of life care strategy**

6.1. Our first priority is to provide excellent end of life care for patients and families; providers and commissioners should work together without boundaries to achieve this

6.2. Staff skills and support are central, and essential, to their ability to deliver reliable, excellent, compassionate end of life care

6.3. The strategy should be internally aligned, logical and memorable, functioning as a living document that helps patients and staff to set and meet expectations

6.4. The strategy should align to other key Trust strategies on workforce, leadership, nursing, and the 2016 Strategic Review

6.5. The strategy should align to national end of life care recommendations and strategies, in particular that articulated for the whole system

6.6. Partnership and collaboration is a core principle; with patients, families, other providers, and stakeholders across the system

6.7. The strategy will therefore be dynamic as our external and internal contexts change.

7.  **Elements of the strategy**

7.1. The document *Priorities of Care for the Dying Person* sets out a framework of five priorities that clinicians should attend to as part of the end of life care for every patient.

7.2. These are:

7.2.1.  **Recognise**: identifying the possibility that a patient is approaching the end of life
7.2.2. **Communicate**: sensitive communication between staff, the dying person, and people important to them

7.2.3. **Involve**: involving the dying person and those important to them in decisions about their care

7.2.4. **Support**: identifying, respecting and as far as possible, meeting the needs of the dying person and those important to them

7.2.5. **Plan and Do**: ensuring there is an individual plan of compassionate care for all aspects of the patients dying and death

7.3. The Priorities of Care for the Dying Person are set out in the schematic below (Figure 1)
7.4. While these five priorities are articulated for clinicians treating individual patients, we consider that these also provide a compelling and comprehensive description of the key strategic actions we need to take as an organisation to raise the quality of end of life care.

7.5. By making this link, patients and staff who use the five priorities in caring for patients will immediately understand the strategic activities the Trust as a whole is taking; while patients, staff, managers and the general public who read our strategy will immediately understand what process of care should be expected for individual patients.

7.6. The five priorities, “recast” in an organisational context, are shown schematically in Figure 2 below.
8. **Strategic Priority 1: Recognise.**

8.1. We recognise the critical place that end of life care plays in the services we offer our patients and those important to them; care of the dying “is our core business”

8.2. We aspire not only to recognise, but to be recognised; for the reliability, excellence and compassion of the care we deliver

8.3. We recognise that our ambition is given urgency by the high expectations of patients, clinicians, commissioner and regulators, as set out in the National Ambitions for End of Life Care. We will ensure that we reference our work to the these standards and ambitions.

8.4. We recognise that the care we deliver may be good but can often be improved; we will use national and local audit to identify any shortcomings and correct them

8.5. Delivering our ambition will require that all staff are trained to appropriate levels of awareness and expertise, and that they are supported and engaged in providing excellent care. We will identify and deliver relevant training.

8.6. Recognising the importance of place of death, we will also review our ward environments to identify how they might cost-effectively be improved with the needs of end of life care patients in mind

9. **Strategic Priority 2: Communicate.**

9.1. We will ensure that our strategy, improvement plan and services for end of life care are widely communicated within and outside the Trust,
including to our Governors, our staff, commissioners, other providers, patients and the public

9.2. We will use the full range of available media and will seek to promote open discussion in our local communities on death, dying and end of life care through educational and discussion events

9.3. We will provide a range of mechanisms for listening to, and learning from, feedback from patients and those important to them, and from our partner organisations; and will communicate this learning back to our staff

9.4. Because seamless communication across healthcare team and organisational boundaries is so important, we will intensify our work to achieve high standards of personal, telephonic and electronic communication for all handovers of care, in particular the transition from hospital to community environments and vice versa.

9.5. We will ensure our staff are aware of, and access, the Oxfordshire Care Summary and any associated advance care plans whenever patients are admitted for care.

9.6. We will ensure that as we further transition from paper-based to digital healthcare records, we take full advantage of the opportunities to improve communication that this will bring, allowing us to provide end of life care more effectively and, more often, out of hospital where so chosen.

10. **Strategic Priority 3: Involve**

10.1. We will continue the work of our end of life care group and extend its membership to ensure all Divisions and Directorates in the Trust are involved.

10.2. We will continue to involve Governors, staff, patients, the public, and our stakeholders (including third sector organisations) in our evolving strategy and our plans for end of life care

10.3. We will continue to be involved in collaborative work with stakeholders to ensure that our strategy remains aligned with those of our partners and to achieve maximum effectiveness in our joint working, whether inside or outside the physical walls of the Trust

10.4. Working with stakeholders, we will work to improve the provision of end of life care in the community as well as in the Trust

10.5. We will ensure we involve our Academic Health Sciences Network partners in our work to be able to share, and benefit from, improvements and innovations in end of life care made in any part of the AHSN

10.6. We will ensure that other academic partners are aware of our work and have the opportunity to be involved in it to encourage further learning and improvement

11. **Strategic Priority 4: Support**

11.1. We will develop improved means of support for our patients and their loved ones, in part directly, but in part through the education of our staff as above

11.2. We will implement additional methods of support for our staff, including the introduction of Schwartz Rounds, as a further means to improve
reflective practice, alongside clinical supervision, and health and wellbeing initiatives.

12. **Strategic Priority 5: Plan and Do**

   12.1. We will agree and roll out an education and training plan that provides the necessary level of awareness and training for each staff member.

   12.2. We will ensure that all clinical teams caring for patients at the end of life can access specialist palliative care support within 24 hours of the admission of any patient.

   12.3. We will encourage innovation in compassionate end of life care using a continuous quality improvement “Plan-Do-Study-Act (PDSA)” approach to develop local ownership and expertise.

   12.4. We will develop our programme of communication and learning, to include an annual symposium, regular patient/public engagement events, and regular bulletins.

   12.5. We will establish an annual plan, and provide an annual report, that sets out the trajectory for improvement that we anticipate, and that makes our end of life care work transparent and accountable.

13. **Progress to date.**

   13.1. This strategy is a living document and much work is already underway, overseen in the main by the Trust’s End of Life Care Group.

   13.2. The Board receives contemporaneous updates linked to the quality priorities via the Board Quality Report.

   13.3. A full annual report of the activities undertaken in 2015-16, linked to the annual plan for 2016-17, will be presented to the Quality Committee in August 2016. Although elements of this are already contained in the Quality Report, this will provide a more accessible overview of all end of life care-related work.

14. **Recommendations.**

   14.1. The Trust Board is asked:
   
   14.2. To agree the End of Life Care Strategy.

   14.3. To approve submission of the annual End of Life Care Report 2015-16, and the End of Life Care Plan 2016-17, to the Quality Committee in August 2016.

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