End of Life Care Strategy
2017-2020
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1. **Introduction**

We live in an ageing society. In England around 500,000 people die each year. This will increase by 15% by 2035. The number of people with long term conditions (LTCs) is rising (by 2025 number of people with at least one LTC will rise from 15 million to 18 million; those with two or more LTCs will rise from 5 million to 6.5 million), leading to more complex end of life care for some of these patients. Around 10% of people over 65 years old are frail. Frailty is strongly linked to increased mortality.

Nationally, end of life care is a major public concern. Two major publications form the basis of current best practice; One Chance To Get It Right\(^1\) - which describes the five Priorities of Care (2014) and Ambitions for Palliative and End Of Life Care: a national framework for local action 2015 -2020\(^2\) (2015) - which describes the six Ambitions. Further, it is a distinct domain in CQC inspections.

In 2014 47% people died in hospital. In 2015 54% Hillingdon Borough residents died in hospital. The use of acute services in last year of life is substantial – 30% of all hospital inpatients are in the last year of life. 20% of all people in the last year of life are admitted to hospital at least five times in that last year. In 2015, 11% of all patients in Hillingdon CCG had three or more admissions in the last 90 days of their lives. This is the highest rate in the NWL STP footprint, and substantially higher than the national average of 7%.

The end of life care needs of the population we serve is rising, and The Hillingdon Hospital will deliver a considered and comprehensive approach in order to provide best care.

2. **Scope**

This strategy covers all adults under the care of the Trust who are approaching the end of their lives, and their loved ones. For those patients who die in the Trust, it also includes care after death.

3. **The Hillingdon Hospital’s vision for End of Life Care**

Patients at the end of their lives receive the best quality, patient centred, individualized care, with their loved ones involved and supported, all provided by staff who are prepared, able and confident to care.
4. Definitions

4.1 End of life

Patients are approaching end of life when they are likely to die in the next 12 months. This has been defined by the Leadership Alliance For Care of Dying People as including patients:

   a) Whose death is imminent (hours or days)
   b) Who have advanced progressive incurable conditions
   c) Whose general frailty and co-existing conditions mean they are expected to die within 12 months
   d) Who have existing conditions if they are at risk of dying from a sudden acute crisis in their condition
   e) Who have life threatening acute conditions caused by sudden catastrophic events

Furthermore, the General Medical Council also includes

   f) Who are diagnosed as being in a persistent vegetative state (PVS) for whom a decision to withdraw treatment may lead to their death

   and

   g) Extremely premature neonates whose prospect for survival are known to be very poor

The term ‘end of life’ is not diagnosis specific. It can be identified proactively.

4.2 Palliative Care - Generic and Specialist

Palliative care is the active, total care of patients with progressive advanced illness and their families, carers and friends. This includes symptom control and care in the last days of life, and should be a core skill of all clinicians.

Generic palliative care – palliative care delivered by generic staff involved in the day to day care of patients, but without specialist training.

Specialist palliative care is palliative care delivered by a multiprofessional team who have undergone specialist training. These services are involved in the care of patients with more complex and demanding care needs.
5. How this strategy was written

5.1 CQC Inspection 2014

In 2014 CQC Inspection rated The Hillingdon Hospital as Requires Improvement in EOLC. It was rated as Required Improvement in the domain Safe, Effective, Responsive and Well Led. It was rated as Good in the Caring domain.

5.2 The Hillingdon Hospital Baseline Review

Following this in 2015/16 a baseline review was carried out which incorporated the results of the

- CQC Inspection 2014
- CQC National Inpatient Survey 2015
- National Care of the Dying Audit 2015
- The Hillingdon Hospital End of Life Survey 2016
- End of Life Care Staff Confidence Questionnaire 2016
- Macmillan End of Life Care Service Review 2016
- Transform Programme for End of Life Care Gap Analysis

In 2016 the Trust Board recognised the need to improve EOLC across the Trust. The EOLC Improvement Project Team was set up with Executive (Director of Nursing) and non Executive Board support. This ran from April – December 2017 inclusive, supported by the NHSI End of Life Care Collaborative. Its remit was to create an End of Life Care action plan, implement it and refine the actions for rollout across the Trust.

5.3 Alignment with relevant national and local Strategies

A key principle for this Trust EOLC Strategy is that it aligns with national End of Life Care recommendations (Priorities of Care\(^1\) and Ambitions\(^2\)) and Trust, STP and local strategies including

- The Hillingdon Hospital Strategic Plan (focusing on the NWL STP Plan) 2017 - 2020
- The Hillingdon Hospital Quality and Safety Improvement Strategy 2016-2021
- The Hillingdon End Of Life Joint Strategy 2016-2020
- The Hillingdon Hospital Carers Strategy 2017-2020
- The Hillingdon Hospital’s CARES values
Figure 1 Outline of National recommendations and local Strategies relevant to End of Life Care

**National**

**NWL STP/ Hillingdon**

**Trust**

Priorities of Care for the Dying Person

1. Radically upgrading prevention and wellbeing
2. Eliminating unwarranted variation and improving the management of Long Term Conditions
3. Achieving better outcomes and experiences for older people
4. Improving outcomes for children & adults with mental health needs
5. Ensuring we have safe, high quality sustainable acute services

The 5 STP Strategy Delivery Areas:

- Developing a safety culture
- Safer staffing - with necessary competencies
- Working towards preventable deaths
- Proactively improving systems to reduce harm
- Improving patient experience - including EOLC
- Achieve best possible outcomes - including care of a dying person
- Ensuring people receive care in the right place - including EOLC

Hillingdon End of Life Joint Strategy:

- Identification of patients at EOL
- Access to care
- Care Planning and Co-ordination
- Staff Support, Education and Training
- IT Infrastructure

Quality Strategy

Carers as partners in care
We believe that carers should be acknowledged as equal members of the care team; be respected for their expertise; be included in decisions about care, and be treated with courtesy and respect.

Clear communication and accessible information
We believe it is essential that there is honest and clear communication between carers and professionals that carers are valued for the knowledge they provide, and that they have access to available information resources.

Positive carer experience
Supporting and signposting
We believe it is vital that carers are adequately supported for them to be able to continue their caring role without detriment to their own health and wellbeing.

Listening and learning
We believe each carer has a right to be satisfied that the person they care for is consistently receiving the best and most appropriate care possible, and know how they can raise concerns if we fall short of this.
5.4 The Hillingdon Hospital End of Life Care Strategy

This strategy was written using the learning from the baseline review and findings from the EOLC Improvement Project. It has also been closely aligned to national recommendations and local Strategies. EOLC is an integral part of all these strategies, and improvements in EOLC will directly contribute to the success of all these strategies and will be driven through the EOLC Action Plan.


As well as aligning with the Joint Strategy, the Hillingdon Hospital End of Life Strategy will run to the same review date: 2020. It is envisaged that a single comprehensive HHCP-wide EOLC strategy will be created for 2020 onwards.

EOLC is a Priority on the Trust’s Quality Schedule for 2017/18.

6. Ambition

6.1 What good end of life care looks like

As underpinned by the Hospital’s vision, good end of life care is assured when

- THH provides high quality care for patients dying in inpatient beds
- THH identifies patients likely to be in the last six months of life
- THH creates appropriate Advance Care Plans for these patients

By working with partners through the Hillingdon Health and Care Partnership (HHCP), including the Borough wide End of Life Forum (EOLF), THH fosters optimum conditions for patients to be managed in their usual place of residence as much as possible.

Emphasis will be on the likely last six months of life for the duration of this strategy. Advance care planning is relatively new for many clinical teams. Aiming to identify patients likely to be in the last six months of life initially (as opposed to last 12 months) will enable staff to focus on identifying patients potentially in most need.

6.2 End of life care Aims

The overarching aim is to be rated Good in all areas for the End of Life Care domain as defined by CQC, meet our key performance indicators where these are defined, rate ‘green’ where outcomes are based on a RAG rating, and receive positive feedback from patients and their families about the care they receive.

Taking into account national recommendations, relevant local strategies, the results of the trust baseline review and the work of the Trust / NHSI End of Life Care improvement project, this End of Life Care Strategy has two main aims, which have three primary drivers that act as a ‘sense checks’ – to ensure improvements are patient / user / staff centred (Figure 2)
6.3 Local Strategic Priority Statements

Local strategic priorities have been identified that will enable the THH End of Life Care vision to be achieved.

These priorities are encapsulated in 14 End Of Life Care Priority Statements.

These Statements have been cross referenced against relevant national and local recommendations and strategies, including CQC (see Table).

Figure 3 is a schematic that describes good End of Life Care and shows how the local strategic priorities are necessary to achieve this.
<table>
<thead>
<tr>
<th>END OF LIFE CARE PRIORITY STATEMENT</th>
<th>ALIGNMENT</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>S1. Proactively recognize individuals who may be in their last six months of life, being respectful of what matters to the individual and those important to them.</strong></td>
<td><strong>NATIONAL</strong></td>
</tr>
<tr>
<td>Ambitions</td>
<td>PCDP</td>
</tr>
<tr>
<td>None</td>
<td>Priority:</td>
</tr>
<tr>
<td><strong>S2 Where appropriate advance care plans are agreed between patients, their loved ones and the HCPs caring for them, and these plans are communicated to all relevant agencies</strong></td>
<td><strong>Ambition 4:</strong> Care is coordinated</td>
</tr>
<tr>
<td><strong>S3 Individual plans of care are holistic, including psychological and spiritual support, symptom control and access to medicines and equipment</strong></td>
<td><strong>Ambition 3:</strong> Maximize comfort and wellbeing</td>
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<tr>
<td><strong>S4 Discussions around interventions at end of life are sensitively undertaken, decisions are robustly documented, and improvements undertaken as a locality: including DNACPR forms, MCA documentation, Treatment Escalation Plans (ReSPECT document or similar)</strong></td>
<td><strong>Ambition 2:</strong> Fair access to care</td>
</tr>
<tr>
<td><strong>S5 High quality specialist palliative care support is available around the clock</strong></td>
<td><strong>Ambition 3:</strong> Maximize comfort and wellbeing</td>
</tr>
<tr>
<td><strong>S6 Ensure patients identified as in last hours or days of life have individual</strong></td>
<td><strong>Ambition 2:</strong> Fair access</td>
</tr>
<tr>
<td>Ambition 4: Care is coordinated</td>
<td>Ambition 6: Each community is prepared to help</td>
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<tr>
<td>Ambition 2: Fair access to care</td>
<td>Ambition 6: Each community prepared to help</td>
</tr>
<tr>
<td>Ambition 1: Person seen as individual</td>
<td>Ambition 2: Fair access to care</td>
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<tr>
<td>Ambition 3: Maximize comfort and wellbeing</td>
<td>Support Communication</td>
</tr>
<tr>
<td>Ambition 5: All staff are prepared to care</td>
<td>Safe Effective Responsive Caring</td>
</tr>
<tr>
<td>Staff are trained, supported and enabled to</td>
<td>- identify patients approaching EOL</td>
</tr>
</tbody>
</table>
- provide high quality holistic care in the last days of life

<table>
<thead>
<tr>
<th>S.12 Develop methods for measuring outcomes for our patients in order to achieve excellent integrated EOLC to patients and their loved ones</th>
<th>Ambition 5: All staff are prepared to care</th>
<th>Safe Well led</th>
<th>DA3: Better outcomes DA5 Safe high quality sustainable acute services</th>
<th>IT infrastructure</th>
<th>Best possible outcomes</th>
<th>Listening and learning</th>
<th>Patient centred care Loves ones involved and supported Staff prepared able and confident to care</th>
</tr>
</thead>
<tbody>
<tr>
<td>S.13 Trustwide engagement in EOLC – changing the perception of ‘death is failure’ to ‘a good death is a successful outcome’</td>
<td>Ambition 5: All staff are prepared to care Ambition 6: Each community prepared to help</td>
<td>Well led</td>
<td>DA3: Better outcomes DA5 Safe high quality sustainable acute services</td>
<td>Staff support, education and training</td>
<td>Improve pt experience Best possible outcomes</td>
<td>Patient centred care Loves ones involved and supported Staff prepared able and confident to care</td>
<td></td>
</tr>
<tr>
<td>S.14 Contribute to and support a system wide approach to EOLC – including Accountable Care Partnership work streams (older people, frailty, Single Point of Access) and opportunities with AHSNs and Brunel University</td>
<td>Ambition 6: Each community prepared to help</td>
<td>Well led</td>
<td>DA3: Better outcomes</td>
<td>Access to care Staff support, education and training</td>
<td>Improve pt experience Best possible outcomes</td>
<td>Carers as partners</td>
<td>Patient centred care Loves ones involved and supported Staff prepared able and confident to care</td>
</tr>
</tbody>
</table>
Figure 3: THH HOSPITAL EOLC - What good looks like

OVERARCHING REQUIREMENTS – Staff Training, Trustwide Engagement, Systemwide Approach

PATIENT IS ADMITTED TO HOSPITAL -> RECOGNITION: LIKELY LAST 6/12 OF LIFE

PROGNOSIS LIKELY 6/12

PATIENT IS DISCHARGED WITH CLEAR COMMUNICATION FROM HOSPITAL TO COMMUNITY VIA ACP, DISCHARGE SUMMARY OR EOLC OR BOTH (Requiring continued review in community)

USUAL CARE

RECOGNITION: PATIENT IS IN LAST DAYS OF LIFE

SPC ADVICE AROUND THE CLOCK

RAPID DISCHARGE HOME TO DIE?

NO: PATIENT CARE FOR USING CCP

YES: RAPID DISCHARGE PATHWAY

CCP COVERS ALL ASPECTS OF CARE

CARE ENVIRONMENT OPTIMIZED FOR PATIENT AND LOVED ONES

CARE AFTER DEATH

SPC ADVICE AROUND THE CLOCK

ACCP - ADVANCED CARE PLAN
CCP - COMFORT CARE PLAN (for care in last days)
SPC - SPECIALIST PALLIATIVE CARE
7. Listening, learning and audit

7.1 Feedback from patients and their families, carers and friends

This will be sought from a variety of sources including

- Friends and Family test – free text feedback
- Trust Bereavement Survey
- Cancer Patient Experience Questionnaire
- I Want Great Care feedback
- Complaints that have any end of life care component
- PALS concerns
- Mortality reviews

Findings from these sources will be reviewed at the THH End of Life Care Board and will be used to fine tune the action plan to improve end of life care across the Trust.

7.2 Clinical engagement

Generic palliative care delivered by all clinicians and patient / user facing staff is key to improved End of Life Care. Clinical engagement will be ensured through

- Awareness raising through a variety of means including General Bulletin updates, national Dying Matters week events, development of a Trustwide End of Life Care symbol, and Palliative Care Study Days,
- Divisional lead and key specialist team representation at the Trust End of Life Care Board

7.3 Audit

The Trust will take part in relevant National End of Life Care Audits, and measure its service against other Trusts. The results of the Trustwide Bereavement survey will be benchmarked against other providers. Relevant research and best practice guidance will be reviewed to ensure that trustwide guidelines and policies reflect the best of End of Life Care.

8. Measures of success

The overall measure for success will be Good rating by CQC in all domains for End of Life Care.

Secondary measures will be

1. Increased use in the Comfort Care Plan to care for patients dying in the Trust
2. Increased number of hospital discharge summaries with ACP information
3. Increased access to Comfort Care Plan by hospital staff

4. Increased numbers of staff receiving End of Life Care training

Access to Comfort Care Plan and training for staff is part of the Hillingdon Joint End of Life Care strategy dashboard. In order to further streamline work with our community partners we will also consider:

5. % deaths/ CCG in hospital

Similarly, in order to align with national agenda we will also consider the NHS England End of Life Care KPIs:

6. % patients with three or more admissions in last 90 days of life (will replace % deaths/CCG in hospital when digital ability allows)

7. % of CCGs with 7/7 visiting SPC service and 24/7 telephone advice in both acute and community settings

9. Leadership and governance

The NED responsible for End of Life Care is the Chair of the Quality and Safety Committee Dr Lis Paice. The Executive Director responsible for End of Life Care is the Director of Patient Experience and Nursing Prof Theresa Murphy.

Membership of the End of Life Care Board will reflect the necessary expertise in each hospital Division.

The End of Life Care Board reports to the Patient Safety Committee, which in turns reports to the Quality and Safety Committee and on through to the Trust Board (Figure 4).

10. Implementation / Implementation plan

End of Life Care is part of the core business of the Trust and how it is executed provides a clear window into the ability of the Trust to demonstrate its CARES values.

A high level implementation plan will outline prioritized actions, intended outcomes, key performance indicators leads and timelines. This will be monitored through the End of Life Care Board.
References


3. Treatment and care towards the end of life: good practice in decision making General Medical Council 2010

4. Tebbit, National Council for Palliative Care, 1999