

## “My father had a lovely death”

Author: Carole Ribbins, Deputy Chief Nurse

Sponsor: Eleanor Meldrum, Acting Chief Nurse

Trust Board paper D

### Executive Summary

This patient story originated from a compliment and is about a family's experience following their relative's admission and the individualised high standards of end of life care he received from staff in UHL. The key themes identified are positive in this story but are areas identified in the End of Life Care in Hospitals Improvement Programme (ELCHIP) which require improvement across the Trust to enable outstanding end of life care in UHL.

### Why Has This Patient Story Been Selected for Trust Board?

This patient story has been selected as it is a positive experience about end of life care and the involvement of the patient in decision making about their care and support for the patient and their family throughout their end of life journey.

### What are the Key Themes in the Patient Story and How Applicable are they across the Trust?

- Involvement in decision making and care.
- Effective communication to identify what is important
- Effective multi disciplinary team working.
- Recognition of deterioration and end of life.
- Specialist input from Palliative Care Team.
- Use of Amber Care bundle.
- Individualised care planning.

### Conclusion

Throughout his time in hospital the patient was involved and informed about his care and involved in decision making whenever he was able to do so. His family were given time on most days by the medical team to receive an update on his condition and the current plans of care. This was reflected in the nursing care, especially in the later stages of his care where it was documented that the family had been involved and supported when on the ward. The patient's daughter details in the video how nothing was too much trouble for the staff on the ward and that they listened to her father's wishes and considered the family as well. They were given open visiting and were able to stay overnight the night before he died. When he died he did so in a peaceful manner with all of his family around him, which met his wishes.

### For Reference

Edit as appropriate:

1. The following **objectives** were considered when preparing this report:

- Safe, high quality, patient centred healthcare [Yes/No/Not applicable]
- Effective, integrated emergency care [Yes/No/Not applicable]
- Consistently meeting national access standards [Yes/No/Not applicable]
- Integrated care in partnership with others [Yes/No/Not applicable]
- Enhanced delivery in research, innovation & ed' [Yes/No/Not applicable]
- A caring, professional, engaged workforce [Yes/No/Not applicable]
- Clinically sustainable services with excellent facilities [Yes/No/Not applicable]
- Financially sustainable NHS organisation [Yes/No/Not applicable]
- Enabled by excellent IM&T [Yes/No/Not applicable]

2. This matter relates to the following **governance** initiatives:

a. Organisational Risk Register [Yes/No/Not applicable]

**If YES please give details of risk ID, risk title and current / target risk ratings.**

Datix Risk ID	Operational Risk Title(s) – add new line for each operational risk	Current Rating	Target Rating	CMG
XXXX	There is a risk ...			XX

**If NO, why not? Eg. Current Risk Rating is LOW**

b. Board Assurance Framework [Yes/No/Not applicable]

**If YES please give details of risk No., risk title and current / target risk ratings.**

Principal Risk	Principal Risk Title	Current Rating	Target Rating
No.	There is a risk ...		

3. Related **Patient and Public Involvement** actions taken, or to be taken: [Insert here]

This patient story consists of feedback directly from a patient’s family and their experience of end of life care within the Trust.

4. Results of any **Equality Impact Assessment**, relating to this matter: Not Applicable

5. Scheduled date for the **next paper** on this topic: Not Applicable

6. Executive Summaries should not exceed **1 page**. [My paper does/~~does not comply~~]

7. Papers should not exceed **7 pages**. [My paper does/~~does not comply~~]

## End of Life Care at UHL- ELCHIP findings and actions

**Author:** Julia Grant, Consultant in Palliative Medicine

**Sponsor:** Carole Ribbins, Deputy Chief Nurse

**Trust Board paper D**

### Executive Summary

#### Context

The Leadership Alliance defines end of life care as “Care given in the last 12 months of life”. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions
- General frailty and co-existing conditions that mean they are expected to die within 12 months
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition
- Life threatening acute conditions caused by sudden catastrophic events

Approximately 1 in 10 patients admitted to hospital as an emergency die during that admission and 1 in 3 will die within the following twelve months. For patients >85y, there is an almost 50% chance of dying within a year of an emergency admission<sup>1</sup>.

Increasing numbers of people are living with long term conditions, requiring complex care for prolonged periods before they die<sup>3</sup>. The final year of life is often poorly recognised, punctuated by frequent acute admissions, particularly for the most deprived, and the experience of care is often not as good as it might be<sup>2</sup>, being a frequent cause for complaints<sup>3</sup> and identified locally as a theme in “Learning from Adult Deaths in our Care”. The Care Quality Commission found end of life care at UHL as requiring improvement in 2016, identifying areas where actions were required.

In LLR, between 46-49% Leicestershire deaths occur in hospitals, 24% at home, 19-23% in a care home, 3.7-4.7 in hospice<sup>4</sup>. Although home may be the preferred place of care for some people, hospital can be somewhere patients feel safe and looked after. With increasing numbers of deaths predicted in the next ten years, it is essential that this area of care is seen as part of the core business of the Trust as it is not where we die but HOW we die which is of paramount importance to us all.

1 Clark, D Armstrong, M Allan, A Graham, F Carnon, A Isles, C Imminence of death among a national cohort of hospital inpatients. Palliative Medicine, 2014, 28 (6). 474-479. ISSN 0269-2163

2 Macmillan Cancer Support. The Final Injustice. Variation in End of Life Care in England. 2017  
[https://www.macmillan.org.uk/assets/mac16904-end-of-life-policy-report.pdf?utm\\_source=The%20King%27s%20Fund%20newsletters&utm\\_medium=email&utm\\_campaign=8965193\\_NEWSL\\_HMP%202017-12-12](https://www.macmillan.org.uk/assets/mac16904-end-of-life-policy-report.pdf?utm_source=The%20King%27s%20Fund%20newsletters&utm_medium=email&utm_campaign=8965193_NEWSL_HMP%202017-12-12)

3 Institute for Public Policy Research. May 2018. End of Life Care in England. A Briefing Paper.

4 National End of Life Care Intelligence Network [http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place\\_of\\_Death/atlas.html](http://www.endoflifecare-intelligence.org.uk/profiles/CCGs/Place_of_Death/atlas.html)

#### Questions

1. What do the End of Life Care Hospital Improvement Programme (ELCHIP) results tell us about end of life care at UHL?
2. How can we use these results to inform our strategic plans?
3. How do we ensure that end of life care remains a priority for the Trust?

## Conclusion

1. Findings from ELCHIP have demonstrated that there are significant opportunities to improve the overall experience of care for patients and families. These include:
  - 1.1. Improving the identification of patients who may be in the last months of life, having courageous conversations and involving them in planning their care in outpatient and inpatient settings before their final admission to hospital
  - 1.2. Improving the recognition of uncertain recovery at admission
  - 1.3. Better planning for deterioration
  - 1.4. Improved communication with patients to identify what is important to them
  - 1.5. Earlier identification of dying patients and use of the Individualised Plan of Care to support their last days and hours
  - 1.6. Improved use of data
2. A draft strategy has been developed to share with stakeholders, informing the plans of the End of Life and Palliative Care Committee. Work has already started on many elements of the strategy.
3. QI work in ED has been slow to get started but priority areas have been identified and key stakeholders identified.
4. A draft Dashboard has been developed to start to capture the data we need to track our progress across the Trust.
5. A Business Case is underway to build the Palliative Medicine workforce to allow the specialist palliative care team to continue to build the clinical service and support improvement work across the trust.

## Input Sought

1. Please note and support the contents of this report
2. How can the Board lead on prioritising palliative and end of life care? Could the Board begin by asking how might any project or business case affect patients who could be in the last year of life?

## For Reference

Edit as appropriate:

- |  |       |
|--|-------|
| 1. The following <b>objectives</b> were considered when preparing this report: |       |
| Safe, high quality, patient centred healthcare                                 | [Yes] |
| Effective, integrated emergency care   | [Yes] |
| Consistently meeting national access standards                                 | [Yes] |
| Integrated care in partnership with others                                     | [Yes] |
| Enhanced delivery in research, innovation & ed'                                | [Yes] |
| A caring, professional, engaged workforce                                      | [Yes] |
| Clinically sustainable services with excellent facilities                      | [Yes] |
| Financially sustainable NHS organisation                                       | [Yes] |
| Enabled by excellent IM&T  | [Yes] |

2. This matter relates to the following **governance** initiatives:

a. Organisational Risk Register [Yes /No /Not applicable]

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b. Board Assurance Framework [Yes /No /Not applicable]

**If YES please give details of risk No., risk title and current / target risk ratings.**

Principal Risk	Principal Risk Title	Current Rating	Target Rating
No.	There is a risk ...		

3. Related **Patient and Public Involvement** actions taken, or to be taken: Stakeholder engagement in the development of the UHL End of Life Care Strategy to be taken

4. Results of any **Equality Impact Assessment**, relating to this matter: [Insert here]

5. Scheduled date for the **next paper** on this topic: [N/A]

6. Executive Summaries should not exceed **4 sides** [My paper does comply]

7. Papers should not exceed **7 sides.** [My paper does comply]

## **End of Life Care Hospital Improvement Programme (ELCHIP)**

### **Background**

Acute admissions areas are designed to deal with life-threatening emergencies but are increasingly dealing with patients with multiple co-morbidities, including frailty, who may be dying or whose recovery may be uncertain. Early recognition of these patients supported with honest conversations will improve the quality of care for patients and those important to them. There are many areas of good practice and innovative working around end of life care at UHL and the overall work around end of life care at UHL aims to recognise and share this as well as to identify ways in which we can improve.

### **What is ELCHIP and what does it involve?**

UHL was one of eight trusts from around the UK invited to participate in the End of Life Hospital Improvement Programme (ELCHIP), supported by Hospice UK and NHS Improvement (NHSI). Each of these trusts was included as a result of an “inadequate” or “needs improvement” rating from the CQC. The work itself has a number of elements including a diagnostic phase and a quality improvement phase up to October 2018.

### **ELCHIP Findings**

Findings have demonstrated that there are significant opportunities to improve the overall experience of care for patients and families. These include:

- Improving the identification of patients who may be in the last months of life, having courageous conversations and involving them in planning their care in outpatient and inpatient settings before their final admission to hospital (62% of patients who died at LRI in the twelve-month period assessed had contact with UHL in the 3 months prior to their final admission)
- Improving the recognition of uncertain recovery at admission (56% of plans failed to acknowledge death as a possibility, 44% cases reviewed had unnecessary investigations or treatments)
- Better planning for deterioration (60% cases reviewed had no escalation plan)
- Improved communication with patients to identify what is important to them (in 65% cases, there were missed opportunities to identify patient priorities)
- Earlier identification of dying patients and use of the Individualised Plan of Care to support their last days and hours (most patients were identified as dying on the same day as death and although death was expected in all but one case, only 28% had a plan in place)
- Improved use of data (routine collection and reporting of quantitative and qualitative data is needed to track progress in end of life care)

The ELCHIP “Fresh Eyes Walkthrough” generated some very positive comments and also some important observations about how we might make small improvements with big impacts for patients which we are currently reviewing.

Quality Improvement work has been slow to start but priority areas have been identified alongside the Emergency Department and this will inform the plan of work for the EOLPCC for 2018 and beyond.

### **Strategy**

ELCHIP findings have helped to inform a draft strategy to assist the End of Life and Palliative Care Committee in identifying important actions and themes of work. The draft strategy is included for the Board.

## Dying Matters Awareness Week 14-18<sup>th</sup> May 2018

Talking about dying, death and bereavement is a challenge for staff and patients. Dying Matters was set up in 2009 by the National Council for Palliative Care with the aim to help people to talk. Every year, during Dying Matters Awareness Week, hundreds of events take place across the country to encourage us all to talk about what we want towards the end of our lives; to think about how we want to be remembered; to consider the funeral we would want and to make plans for after death such as registering for tissue and organ donation and ensuring we all have a will. UHL ran a successful week of events to support Dying Matters which included:

- information put out on social media to inspire our staff and public. The Communications team has produced a report to demonstrate the reach of this work.
- daily press releases throughout the week highlighting the importance of end of life care at UHL.
- “roadshow” events at the three sites, providing practical information and asking visitors to the stand to identify their “bucket list” ideas and to pledge to do something to support the key messages of Dying Matters week (around 50 bucket list tags were hung on the trees on the stands in all and pledges were tweeted and retweeted).
- “Dying to know more...?” was an education event for staff on 18<sup>th</sup> May at LRI and Claire Henry, MBE (Hospice UK) presented the first session. Over fifty members of staff attended and feedback was extremely positive. Staff were asked to identify areas of good practice and where we need to improve as part of their feedback and in addition what they could do to improve end of life care.

A review meeting is planned this week and plans for a bigger, better event for next year will begin.

### Staff Information and resources

- **InSite pages** for end of Life Care have been reviewed and updated, linking to trusted external websites and internal pages.
- **EPMA alert-** Medications used “as needed” in the last days or hours of life are usually prescribed as a range, with the smallest dose tried first to assess its effectiveness when a symptom develops. In around 13% of prescriptions reviewed on EPMA earlier this year, there was evidence that patients had received a first dose at the upper end of the range, against NICE guidance and demonstrating poor practice. A larger audit is planned, but in the meantime, EPMA has been changed to generate an alert for staff. Prescribing guidance has been updated to include an instruction that the lowest effective dose is to be used and education reviewed to ensure this message is clear.
- **Last Days of Life Policy-** updated in line with NICE QS144 along with prescribing guidance. Prescribing guidance is due to be tried as a A5 booklet, to see if staff would find this a more useful format.
- **Medicines authorisations for discharge-** agreement has been obtained to allow use of the LLR medication authorisation sheets. Although there are still some issues, the availability of this paperwork via the InSite pages will ensure patients being discharged can receive medications in a timely way from community staff.
- **McKinley T34 syringe drivers: policy, procurement, monitoring, education-** McKinley T34 syringe drivers are used to provide a continuous subcutaneous infusion of medications when patients who require symptom management are unable to take oral medications. Access to these drivers has been an issue and this and the use of inappropriate pumps, was identified by the CQC as an area for concern. A process has now been agreed to allow access to this equipment out of hours; the policy has been reviewed; teaching has been provided throughout the trust and more pumps have been procured. A procurement plan to replace lost and broken pumps has also been drafted.
- **Enhancing the use of the Butterfly symbol-** for a number of years, UHL has used a Butterfly symbol to alert staff that a patient is in the last days of life and to ensure that patients and families receive the best care. Building on this and gaining inspiration from other local trusts,

we hope to develop ward-based resources to support patients and families including comfort kits for relatives and the ability to take a handprint or lock of hair from the patient where this is desired. This will require resources but we anticipate will give wards an opportunity to provide truly individualised care. Some of these resources are already available but access is not currently consistent.

### Staff education and skills

- **Ward education-** The End of Life Care Nurses have continued to provide ward-based education including use of the McKinley T34 syringe driver and the Individualised Plan of Care for the Dying Patient.
- **Champions Days** continue to run regularly through the year.
- **Priorities for Care Study Days** continue to run regularly.
- **Dying Matters education** to be planned for 2019.
- **Other education-** The team has also been part of other education events at LOROS including study days and F1 teaching, Oncology StR Communication skills training.
- **Plan for a training needs analysis** and development of education plans for UHL.

### Continuity/planning

- **Draft Strategy-** complete and ready to share with stakeholders.
- **Palliative Care Business Case-** in development to ensure the SPCT has the staff to support improvement work and clinical need.
- **Vacant nursing posts in the SPCT have been appointed to.**
- **Ongoing work with IT-** linking UHL with SystemOne, SCR2.
- **QIP in oncology-** supporting a CT1/StR in promoting GREAT discharges for patients who may be nearing the end of life, prompting conversations and actions.
- **Links with Frailty work stream and Integrated Community Palliative Care Team** to ensure continuity and reduce duplication of effort.
- **Starting review of Rapid Discharge** and data collection.
- **Networking-** engagement of UHL Clinical Lead for EOLC with CCG EOLC Leads.
- **Innovation-** The role of a Specialist Palliative Care Ward, similar to one working in Liverpool, is being considered.

### Audit/evaluation

- **National Audit of Care at the End of Life** commences in June
- **SPCT** to develop an audit plan

### Risk

- **Risk register for EOLC-** items on Trust Risk Register pertaining to EOLC to be discussed at EOLPCC regularly
- **Complaints and Incidents already part of EOLPCC-** proposed to be part of dashboard

### Patient information

- **UHL website-** updated to better inform patients about end of life and palliative care
- **DNACPR leaflet** reviewed with Resuscitation lead
- **Last Days of Life leaflet** updated and printed
- **ITU Last Days of Life** updated and awaiting review
- **Plans for Rapid Discharge patient information** to be developed



**Draft Dashboard**

Lack of data to describe how we deliver end of life care at UHL makes planning and evaluating change a huge challenge. Using a dashboard shared by one of the previous Trusts involved in ELCHIP as a starting point, we are hoping to have the beginnings of our ongoing data collection to help us track our work. A draft is included for information. The Dashboard will be discussed at EOLPCC on a regular basis.

<b>Name</b>	<b>Numerator</b>	<b>Denominator</b>	<b>Source</b>
<b>Demographics</b>			
Deaths in ED	Deaths in ED per month	Total deaths per month	
Crude death rate of inpatients	Emergency admissions	Total discharges per month	
	Non-emergency admissions		
Emergency admissions form care homes	Number of deaths per month where the patient was admitted to ED from a residential/nursing home		
	Number of deaths per month where the patient was admitted to ED from a residential/nursing home (by day of admission)		
<b>Service</b>			
Length of stay of patients in the last 100 days of life	% of patients with LOS <24 hours	Total number of inpatient deaths per month	
Number of referrals to SPCT per month	Number of referrals per month		
Proportion of non-cancer/cancer referrals	Number of patients referred to SPCT with a non-cancer diagnosis per month	Number of patients referred to SPCT with a cancer diagnosis per month	SPCT
Proportion of SPCT referrals seen within 24 hours of referral	Number seen within 24 hours per month	Number of referrals per month	SPCT
SPCT Education delivered each month	Number of staff and role (e.g. student nurses, F1 doctors, Grand Round)		SPCT
Consultant in Palliative Medicine outpatient activity data			CHUGGS
Referrals for rapid discharge	No of patients referred for Rapid Discharge		Discharge Team
	No of patients referred for Fast Track		
Source of support for rapid discharge	No of patients supported by Hospice at Home for rapid discharge	Total no of patients supported by rapid discharge	Discharge Team
Average time to discharge from referral for Rapid discharges	Average time from referral to discharge (hours)	Total number of patients referred for Rapid	Discharge Team

		Discharge per month	
Death Certificates produced within agreed timescale	Number of death certificates produced within required timescale	Total number of inpatient deaths per month	Bereavement Office
Patient Experience			
Number of patients who move wards three or more times who die as an inpatient	Number of patients who moved ward three or more times during spell	Total inpatient deaths per month	
Average number of bed days of patients in last 100 days of life	Average number of bed days	Total inpatient deaths per month	
Emergency readmissions	Number of patients readmitted within 30 days and 3 days of a previous discharge during last 100 days of life	Total inpatient deaths per month	
DNACPR: Evidence of discussion with patient and relatives	Number of discussions evidenced in notes	Sample of DNACPR forms in place	Resus Team
Complaints and incidents	Number of complaints involving EOLC		Risk Mx/ Complaints Team
	Number of incidents involving EOLC		
If we could change one thing about how patient was cared for in the last days of life, what would that be?			Medical Examiner
Bereaved relatives experience	Proportion of relatives rating care as good/very good	Total numbers providing feedback	Bereavement Support CNS

# Draft End of Life Care Strategy 2018-2021



“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).”

‘Every Moment Counts’ National Voices, National Council for Palliative Care and NHS England<sup>4</sup>

# Background

University Hospitals Leicester NHS Trust (UHL) is committed to delivering high quality care to patients and those identified as important to them, across all our services. The care provided at the end of life is an important priority for us. When patients are reaching the end of their life, we aim to work together to ensure that every individual receives safe, effective, coordinated, compassionate and dignified care.

At UHL, we have robust mechanisms in place to ensure that avoidable deaths are prevented. However, when preventing death is no longer an appropriate option, it is equally important that we continue to treat and support our patients throughout their last months, weeks and days. This strategy refers to how we look after adult patients at the end of life.

Palliative care involves identifying what matters to each person diagnosed with an incurable illness. Palliative care includes assessing and managing physical symptoms (such as pain or breathlessness); psychological symptoms (feelings and how we manage them); social concerns (who you are and what you do) and spiritual needs (meaning and connection with others). When this support is needed towards the end of life, this is called end of life care. End of life care aims to use this holistic approach to help people to live well until they die and to die with dignity.

The Leadership Alliance<sup>2</sup> defines end of life care as 'Care given in the last 12 months of life'. This includes patients whose death is imminent (expected within a few hours or days) and those with:

- Advanced, progressive, incurable conditions.
- General frailty and co-existing conditions that mean they are expected to die within 12 months.
- Existing conditions if they are at risk of dying from a sudden acute crisis in their condition.
- Life-threatening acute conditions caused by sudden catastrophic events.

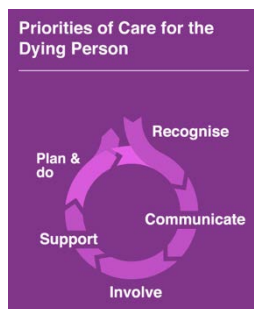
Around 9000 people die across Leicester, Leicestershire and Rutland each year. Most deaths are in older age groups and more than 2/3 are from a diagnosis other than cancer<sup>3</sup>. Almost one half of deaths occur within hospital and many patients in the last months of life will have contact with hospital services either as inpatients or outpatients.

We work collaboratively with our community partners and with other care providers to deliver individualised care, especially with regards to preferred place of death, recognising that some patients may wish to be at home or in a hospice but for others hospital can be the right place for them as it is somewhere a patient and family feels safe and supported. We aim to ensure that patient wishes are met wherever possible<sup>4</sup>.



The Ambitions for Palliative and End of Life Care - A National Framework for local action 2015 – 2020<sup>1</sup>, describes how care in the last months of life needs to become more consistent, and proposes six ambitions. The Trust is committed to ensuring that as an organisation we make these ambitions a reality, through strong leadership, commitment, education and empowerment. These six ambitions are:

- Each person is seen as an individual.
- Each person gets fair access to care.
- Maximising comfort and wellbeing.
- Care is co-ordinated.
- All staff members are prepared to care.
- Each community is prepared to help.



In addition, the 'One Chance to get it Right'<sup>2</sup> document (2014) describes five priorities of care for those patients in the last days of their life.

1. **RECOGNISE** – this possibility that a person may die within the next few days or hours 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. **COMMUNICATE** – sensitive communication takes place between staff and the dying person and those identified as important to them.
3. **INVOLVE** – the dying person and those important to them are involved in decisions about their care to the extent that the dying person wants.
4. **SUPPORT** – the needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. **PLAN AND DO** – 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.

One team Shared values



## Our Vision

At University Hospitals Leicester, NHS Trust (UHL), we believe that when someone is dying, caring for them and those important to them is everyone's responsibility. Every member of staff has a key part to play to ensure that these ambitions become reality.



This will be embedded further by utilising the core principles of our core values:

**'We treat people how we would like to be treated'**

**'We do what we say we are going to do'**

**'We focus on what matters most'**

**'We are one team and we are best when we work together'**

**'We are passionate and creative in our work'**

One team Shared values



University Hospitals Leicester NHS Trust aims, with its partners, to ensure that patients are able to say:

**"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)."**

'Every Moment Counts' National Voices, National Council for Palliative Care and NHS England<sup>4</sup>

By embedding these values throughout our approach to the care of dying patients, we will ensure that we will continually evaluate and improve upon the quality of the care that we provide.

**This vision will be realised by focusing on the following areas:**

- Supporting our staff
- Personalised end of life care
- Environment
- Communication and Information

**We have areas of exemplary practice within our organisation and want to ensure**

One team Shared values



that we get it right for patients every time. In order to emulate good practice across the whole organisation for patients in the last months of life, we have identified the following key areas to prioritise.

## Supporting our staff



- Promote the culture that care of the dying is everyone's responsibility.
- Ensure that effective specialist leadership is in place, led by the Deputy Medical Director and Deputy Chief Nurse, supported by the Clinical and Nurse Leads for End of Life Care, to instil the Trust vision and ambitions for end of life care at all levels across the organisation.
- Collect and provide quantitative and qualitative data to support the on-going resource requirements and evaluate the quality of palliative and end of life care at UHL using evidence-based practice.
- Review the provision of palliative and end of life care at UHL.
- Ensure that all staff dealing with patients and those identified as important to them have the skills, knowledge, tools and resources to address their individual needs, involving key partners such as specialist palliative care, chaplaincy and bereavement support.
- Ensure that staff at every level are trained, supported and valued for their contribution to end of life care.
- Ensure that medical and nursing staff at all levels, where appropriate, feel confident to discuss advance care planning and treatment options with patients and those identified as important to them, through specific communication skills training.
- Use reflective practice and other models to support staff in caring for dying patients and those identified as important to them, taking into account patient feedback.
- Continue to support the End of Life Care Champions in clinical areas around the trust.

## Personalised End of Life Care

One team Shared values



- Commit to working in partnership with our Clinical Commissioning Group, local hospice and general practitioners in developing and promoting advance care planning and delivering individualised, seamless care to those approaching the end of their lives and within UHL to help staff to identify, record and share patient priorities.
- Identify patients who may be facing an uncertain recovery following emergency admission, offering a conversation and support, identifying what is most important to the patient and agreeing an escalation plan.
- Identify patients approaching the last days of life as early as possible, ensuring that they and those identified as important to them have the opportunity to discuss and create a personalised care plan which takes into consideration the five priorities outlined in the 'One Chance to get it Right' document.
- Working in partnership with community colleagues, embed processes to enable the rapid discharge of patients whose wishes are to return home to die.
- Allow expression of spiritual needs by patients and those identified as important to them in ways which are appropriate to them without them feeling awkward, ashamed or different to others.
- Provide individualised end of life care in a culturally sensitive way, ensuring comfort and dignity.
- Ensure that patients' wishes are fulfilled to the best of our ability, regardless of age, ethnicity, social circumstances, background or diagnosis.
- Continue to offer and review seven-day, face to face specialist palliative care assessment and, working with LOROS Hospice, ensure 24-hour access to specialist palliative care advice when needed.
- Grow the success and availability of our Volunteers at Life's End (VALE) who support patients whose family are unable to visit regularly or who need to have a break.

## Environment

- Identify ways of offering patients and those identified as important to them as much privacy as possible during their last days of life and resources to support individualised care, building on our "Butterfly" symbol in use throughout the trust.
- Investigate the role of a specialist palliative care ward at the Trust.
- Ensure those identified as important to the patient have information regarding meals, parking and open visiting access when patients are in the last days or hours of life.

## Communication and Information

One team Shared values





- Participate in the national annual “Dying Matters Week” promoting conversations about dying, death and bereavement within the organisation and within the local community.
- Utilise staff education and repeated clinical audit measures to embed the use of the individualised care plan throughout the Trust.
- Work with partners to improve electronic and other forms of communication between colleagues outside the Trust for those within our patient population who are reaching their last year of life, supporting improved information for admitting teams and community colleagues following discharge to ensure a seamless transition of care.
- Provide written information for patients and those identified as important to them regarding palliative care, resuscitation decisions, end of life care, advance care planning and rapid discharge.
- Ensure that palliative and end of life care information available on internal and external websites is updated to support staff and visitors.
- Ensure that end of life care work is integrated with other work across the trust such as Frailty, Learning Disability and carer support.
- Review bereaved relatives feedback on a monthly basis to ensure families feel supported and satisfied with care, and act on any issues identified.
- Support staff to identify where cardiopulmonary resuscitation would not be appropriate for particular patients and ensure that this decision is discussed with patients and families, recorded appropriately and communicated effectively.
- To those identified as important to the patient, aim to provide as much information and support as possible including advice and support around finances.
- Aim to support the needs of bereaved relatives and those identified as important to the patient.



# Indicators of Success

In order for the Trust to demonstrate the delivery of high quality end of life care, indicators of success have been identified. These will be used to monitor and evaluate the impact of end of life care delivery.

- Positive feedback from bereaved relatives and those identified as important to the patient.
- Reduction in end of life care related complaints.
- Improvement in the identification of a patient's preferred place of care when dying.
- Increase in the percentage of patients dying in their preferred setting.
- Increase in engagement with advance and individualised care planning.
- Increase in numbers of patients having an individualised care plan in the last days of life.
- Successful and constructive participation in local and national audit and research.
- Confirmation that all relevant healthcare professionals have undertaken training in end of life care where it is role specific.
- Increased knowledge and confidence for our staff in providing care.
- Improved feedback from inspection processes.



## Next Steps

University Hospitals Leicester NHS Trust is committed to delivering high quality care to patients and those identified as important to them, in the last months, weeks and days of life.

We aim to ensure this period is as comfortable, dignified and individualised an experience as possible and are committed to continually monitor and further improve the care we deliver.

We will promote the culture that care of the dying is everyone's responsibility and provide the skills and tools to enable our staff to consistently and compassionately undertake this.

Outcome measures will be used to monitor and evaluate the impact of end of life care delivery against the strategic objectives identified in the strategy. The Trust will work collaboratively to ensure the implementation of this strategy and measure the impact. The timescales for this work will be clarified through the development of a strategic implementation plan which will outline the key actions for the application of this strategy.

This implementation plan will be developed through consultation across University Hospitals Leicester NHS Trust and with partners to ensure it meets the needs of patients, those identified as important to patients, and staff. The implementation plan will include specific actions for areas such as education and training, leadership, workforce and communication and will be delivered through the End of Life and Palliative Care Committee.

**“At the end of the day people won't remember what you said or did, they will remember how you made them feel”.**

Maya Angelou

## Glossary

**Advance care planning** - A voluntary process of discussion about future care between an individual and their care providers. If the individual wishes, those identified as important to them may be included. It is recommended that with the individual's agreement this discussion is documented, regularly reviewed, and communicated to key persons involved in their care.

**DNACPR** – Do Not Attempt Cardiopulmonary Resuscitation



## References

1. National Palliative and End of Life Care Partnership (2015). The Ambitions for Palliative and End of Life Care - A National Framework for local action 2015 – 2020.
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3. Better Care Together (2016). Health Needs Assessment for End of Life Care across Leicester, Leicestershire and Rutland
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5. National Voices and The National Council for Palliative Care (NCPC) and NHS England (2015). Every Moment Counts: A narrative for person centred coordinated care for people near the end of life.

