Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust

End of Life: Guidelines for the Management of Patients in last hours/days of life

This procedural document supersedes: PAT/T 65 v.2 – Guidelines for the Management of Patients who are End of Life.

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The Trust discourages the retention of hard copies of policies and can only guarantee that the policy on the Trust website is the most up-to-date version. **If, for exceptional reasons, you need to print a policy off, it is only valid for 24 hours.**

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Amendment Form

Version	Date Issued	Brief Summary of Changes	Author
Version 3	28 June 2019	• Title change • Review of policy and updated education and training • Removal of AMBER care bundle • Update Rapid discharge	Stacey Nutt Karen Lanaghan
Version 2	30 January 2017	• Slight changes in grammar and terminology. • Appendix 2 – Individualised plan of care in last hours/days of life has been removed.	Stacey Nutt Karen Lanaghan
Version 1	18 March 2015	• This is a new procedural document, please read in full.	Stacey Nutt Karen Lanaghan

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1. INTRODUCTION

The Trust serves a catchment population of approximately 430,000 delivering services at Doncaster Royal Infirmary, Bassetlaw District General Hospital and Mexborough Montagu Hospital. Across these sites there are approximately eight deaths per day. In 2014 the Leadership Alliance was formed and given the responsibility for removal of the Liverpool Care Pathway. The Leadership Alliance developed a new strategy of care for patients in the last few days of life with five underpinning principles that are known as the '5 Priorities of Care'. The End of Life Care coordinator is responsible for reviewing all the Trust's documentation and changing it in order to embed the five priorities of care into the care of the dying patients' journey within our Trust.

This policy will inform staff, across all Trust sites of the standards and expectations of the Trust in caring for patients who are in the last few days/hours of life.

2. PURPOSE

The purpose of this document is to give evidence based rationale for following certain procedures associated with end of life care.

By standardising processes and documentation the intention is to raise standards to ensure high quality end of life care is provided consistently across the organisation. This will be done by taking a proactive approach to individualist holist care by embedding the five priorities of care into clinical practice.

This policy will detail the use of the Individualised plan of care for the last days/hours of life and outline the role of the End of life Care Team. It will also make recommendations for certain interventions to take place prior to identifying that a patient is in the last few days/hours of life. Preferred place of death will also be discussed, identifying the process for 'rapidly' discharging a patient home, if this is their preferred place of end of life care.

3. DUTIES AND RESPONSIBILITIES

End of Life Care Team:

- Implementation of this policy and any national recommendations made concerning end of life care
- Education and training of all appropriate Trust staff
- Responsibility to ensure all patients receive an equitable and high quality service
- To be alerted to all patients who are identified as being in the last few days/hours of life.

Lead Nurse Cancer, End of Life Care (EoLC), Specialist Palliative Care (SPC), Acute Oncology Service (AOS), Chemo:

- To take responsibility for managing the End of life Care team
- Escalate any incidents regarding end of life care to the relevant clinical governance groups
- Ensure management support is given and promote service development and standards.

Specialist Palliative Care Consultant:

- Act as a clinical expert in end of life care
- Provide education and training to medical staff.

DBTH End of Life Care Strategy Group:

- This group is to meet every three months to discuss end of life matters in accordance with its terms of reference.

Matrons and Ward Managers:

- To promote excellent standards of end of life care on all wards and departments as appropriate
- Ward managers to release staff when required in order to participate in education and training.

All staff directly involved on caring for patients who are dying:

- All staff to demonstrate empathy and good communication when dealing with patients deemed to be in the last few days/hours of life and also their relatives
- To ensure all patients commenced on the individualised plan of care for the last few days/hours of life, are entered on to the dashboard so that the EoLC Team (and SPC Team) is alerted so that she/he can attend the patient to offer full support and guidance.

4. PROCEDURE

4.1 Individualised Plan of Care in Last Hours/Days of Life

From 14th July 2014 the Liverpool Care Pathway is no longer in use in England to plan care for people in the last few hours/days of life. This decision followed an independent review, published in July 2013. The review recognised that where the Liverpool Care Pathway was used properly many people had a peaceful and dignified death. But in many cases, the Liverpool Care Pathway was associated with poor experience of care, partly because of the lack of tailored, personalised care and the pathway appeared to become a tick box exercise.

To improve the care of the dying individual and meet the important and sometimes neglected needs of their relatives and carers, the Leadership Alliance for the care of dying (a coalition of organisations) set clear expectations for a high standard of care for dying individuals. In a system wide response to the independent review, the Alliance has agreed priorities that all health and care staff should focus on when caring for dying patients. These are very much about the core principles of good care, rather than following processes and protocols.

Five priorities of care for dying people (see Appendix 1)

- The 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 individuals needs and wishes. These are regularly reviewed and decisions revised accordingly.

- Sensitive communication takes place between staff and the dying individual and those identified as being important to them.
- The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent the dying person wants.
- The needs of families and others identified as important to the dying individual are actively explored, respected and met as far as possible.
- An individualised plan of care which includes food and drink, symptom control and psychological, social and spiritual support is agreed, coordinated and delivered with compassion.

Since the publication of the five priorities of care, as a Trust we have produced an individualised plan of care for the last few hours/days of life. This individualised plan of care incorporates the five priorities of care for all patients within our Trust; these five priorities must be paramount.

An end of life alert system was established and put in place in June 2014.

- It is compulsory that nursing/medical staff enter an end of life patient onto the end of life dashboard as soon as they are identified dying (this is entered by accessing the Nursing Metrics Dashboard via the intranet). This will then send an alert via email and text message to the EoLC Team.

Compliance with this is audited on a monthly basis and for any patient not put on the dashboard a Datix incident is completed and escalated to the relevant Matron for further action.

Chaplaincy department are also informed via the same process and visit all end of life patients to establish whether future support is required.

When the alert is received by the EoLC CNS, they visit the patient at the earliest opportunity and discuss the care plan, medications, nutrition and hydration. We would expect to follow up on 90% of all alerts within 4 hours with 100% by 24 hours. They also ensure the needs of the relatives/carers are met and that they are aware of how to contact the EoLC team when they feel it necessary. They also provide support and guidance to patients and relatives and also to ward staff, addressing any concerns or lack of knowledge of the care plan that they may have. They aim to visit the patient and their relatives/carers at least on a daily basis, undertaking continual assessments of the individualised plan of care. If urgent advice and support is required the End of Life Care Team can be contacted on mobile number 07768965979, 7 days a week 09:00-18:00 Monday to Friday and 09:00 – 17:00 weekends and Bank Holidays. Outside of these hours, there is an on call specialist palliative care consultant on call, available via the switchboard.

Appendix 2 demonstrates a process flowchart of expectations of actions.

4.2 Rapid Discharge

When the individual enters the dying phase (the last hours or days), it is vital that those caring for them recognise that they are dying and deliver the appropriate care. How someone dies remains a lasting memory for the individuals' relatives and carers as well as staff involved. Rapid discharge was one of the 5 key enablers for route to success in acute hospitals. In some wards or departments, staff at all levels may lack the knowledge, skills and experience to deliver high quality end of life care. There can also be a failure to recognise when continuation of treatment is not in the person's best interest. In other cases, inadequate planning or lack of discharge coordination, means that individuals are denied the chance to die at home even if they express the wish to do so.

For these patients 'home' might mean a care home. These problems can be remedied by senior clinical decision making, close to the patient. A decision that the patient is dying and their care is to be supported by an individualised plan of care for the dying patient, incorporating the five priorities of care.

This should be taken by a senior clinician with appropriate training in end of life care and use of the care plan. The decision should be taken after discussion with the patient (where possible) and their loved ones and they should continue to be involved in decision making. Relatives and carers should be informed of likely changes as the patient approaches death. If the care planning and rapid discharge arrangements are discussed early enough then a patient can often be discharged to die at home with the support that will prevent unnecessary distressing and expensive emergency readmission (The route to success in end of life care – achieving quality in acute hospitals 2010).

A Rapid Discharge alert System has been established and put in place:

- It is compulsory that nursing/medical staff enter an end of life patient who wishes to go home or back to the nursing home to die are entered onto the end of life dashboard as soon as they make this wish known (this is entered by accessing the Nursing Metrics Dashboard via the intranet under the alert tab for new IPOC patients). This will then send an alert via email and text message to the EoLC Team, Occupational Therapy team (OT) and Integrated Discharge Team (IDT). A collaborative approach is then had and the patients/ relatives have the conversation once rather than several times to different professionals, this ensures a seamless discharge appropriate to the patients individual's needs.

Appendix 3 demonstrates a step by step walk through of the process of a patient undergoing a rapid discharge.

PATIENTS LACKING CAPACITY

Sometimes it will be necessary to provide care and treatment to patients who lack the capacity to make decisions related to the content of this policy. In these instances staff must treat the patient in accordance with the Mental Capacity Act 2005 (MCA 2005).

- A person lacking capacity should not be treated in a manner which can be seen as discriminatory.
- Any act done for, or any decision made on behalf of a patient who lacks capacity must be done, or made, in the persons Best Interest.
- Further information can be found in the MCA policy, and the Code of Practice, both available on the intranet.

There is no single definition of Best Interest. Best Interest is *determined on an individual basis. All factors relevant to the decision must be taken into account, family and friends should be consulted, and the decision should be in the Best interest of the individual. Please see S5 of the MCA code of practice for further information.*

5. TRAINING/SUPPORT

The EoLC team is responsible for delivering learning to all Trust staff on end of life care specific to role and in line with the Trust's training needs analysis. There is an annual programme of education detailed in the end of life strategy and includes planned sessions on preceptorship, foundations of care and person centred care. Education and training is delivered by various means, for example structured sessions and on a 1:1 basis for individual wards and staff members. Education and training records are kept for the purpose of audit.

6. MONITORING COMPLIANCE WITH THE PROCEDURAL DOCUMENT

What is being Monitored	Who will carry out the Monitoring	How often	How Reviewed/ Where Reported to
Compliance with patients being entered onto the dashboard when they have been commenced on the plan of care	End of Life Care Coordinator	Daily	Any incidents where patients are not entered onto the dashboard will be reported on Datix web system and manager informed. Reports will be fed back via clinical governance groups and EOL strategy group.
Communication between professionals and patients/carers with regards to conversations had around the dying process	End of Life Care Coordinator	3 monthly	Feedback from patient experience bereavement questionnaire and via audit of the care plan. Reported back to DBH EoL strategy group, executive board and Key Stakeholders.

Reduction in patient/carers complaints regarding end of life care	Lead Nurse Cancer, Chemo, EoL, SPC, AOS	Ongoing	Lead Nurse Cancer/SPC/EOL to be copied into all Trust complaints regarding end of life care. Reports generated identifying themes and fed back to clinical governance. Root Cause Analysis (RCA) meetings to be held in order to individualise education pertinent to lessons learned.
Audit of response times. 90% of patients to be seen within 4 hours of receiving an alert and 100% within 24 hours	EoLC Co-ordinator	Annually	Reviewed at SPC/EOL/Haem clinical governance and reported to EOL strategy group.

7. DEFINITIONS

EoL – End of Life
EoLC – End of Life Care
SPC – Specialist Palliative Care
OT – Occupational Therapist
IDT – Integrated Discharge Team
AOS – Acute Oncology Service

8. EQUALITY IMPACT ASSESSMENT

An Equality Impact Assessment (EIA) has been conducted on this procedural document in line with the principles of the Equality Analysis Policy (CORP/EMP 27) and the Fair Treatment For All Policy (CORP/EMP 4).

The purpose of the EIA is to minimise and if possible remove any disproportionate impact on employees on the grounds of race, sex, disability, age, sexual orientation or religious belief. No detriment was identified. (See Appendix 4)

9. ASSOCIATED TRUST PROCEDURAL DOCUMENTS

Mental Capacity Act 2005 Policy and Guidance, including deprivation of liberty safeguards (DoLS) - PAT/PA 19.
Privacy and Dignity - PAT/PA 28.
Care after Death and Bereavement Policy: Operational Policy for Staff to follow in the event of a Patient Death - PAT/T 60.
Breaking Significant News (Best Practice Guidelines) - CORP/COMM 9.
Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) Policy – PAT/EC 8.
Fair Treatment for All Policy – CORP/EMP 4.
Equality Analysis Policy – CORP/EMP 27.

10. DATA PROTECTION

Any personal data processing associated with this policy will be carried out under 'Current data protection legislation' as in the Data Protection Act 2018 and the General Data Protection Regulation (GDPR) 2016.

For further information on data processing carried out by the trust, please refer to our Privacy Notices and other information which you can find on the trust website: https://www.dbth.nhs.uk/about-us/our-publications/uk-data-protection-legislation-eu-general-data-protection-regulation-gdpr/

11. REFERENCES

Actions for End of Life Care 2014-16 – NHS England.

End of Life Care Strategy (2008) DoH.

National end of life care programme (2010) The Route to success in end of life care – achieving quality in acute hospitals.

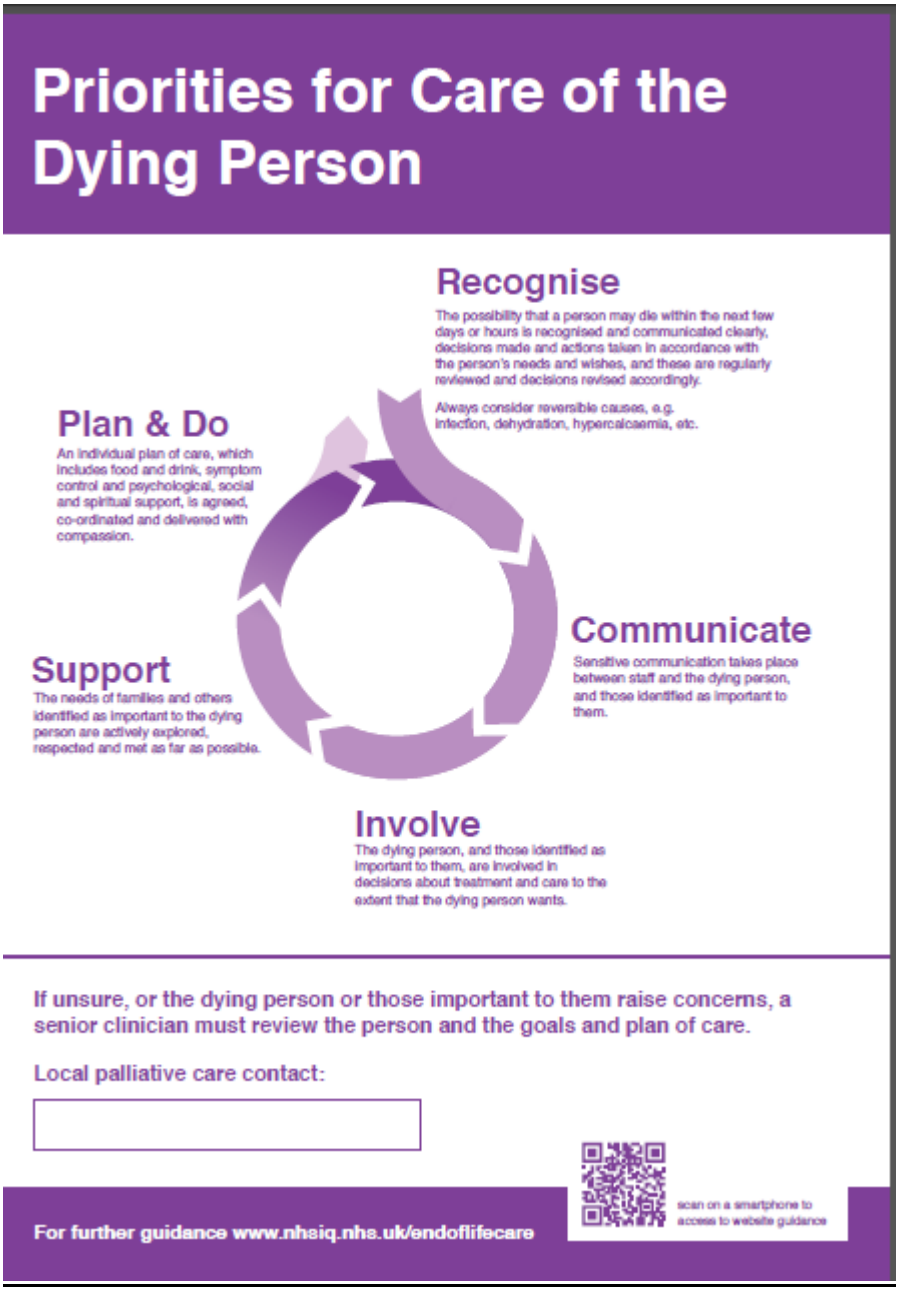
Priorities of Care for the Dying Person (2014) Leadership Alliance for the Care of Dying People.

The Route to Success in end of life care – achieving quality in acute hospitals – National End of Life Care programme. (2010).

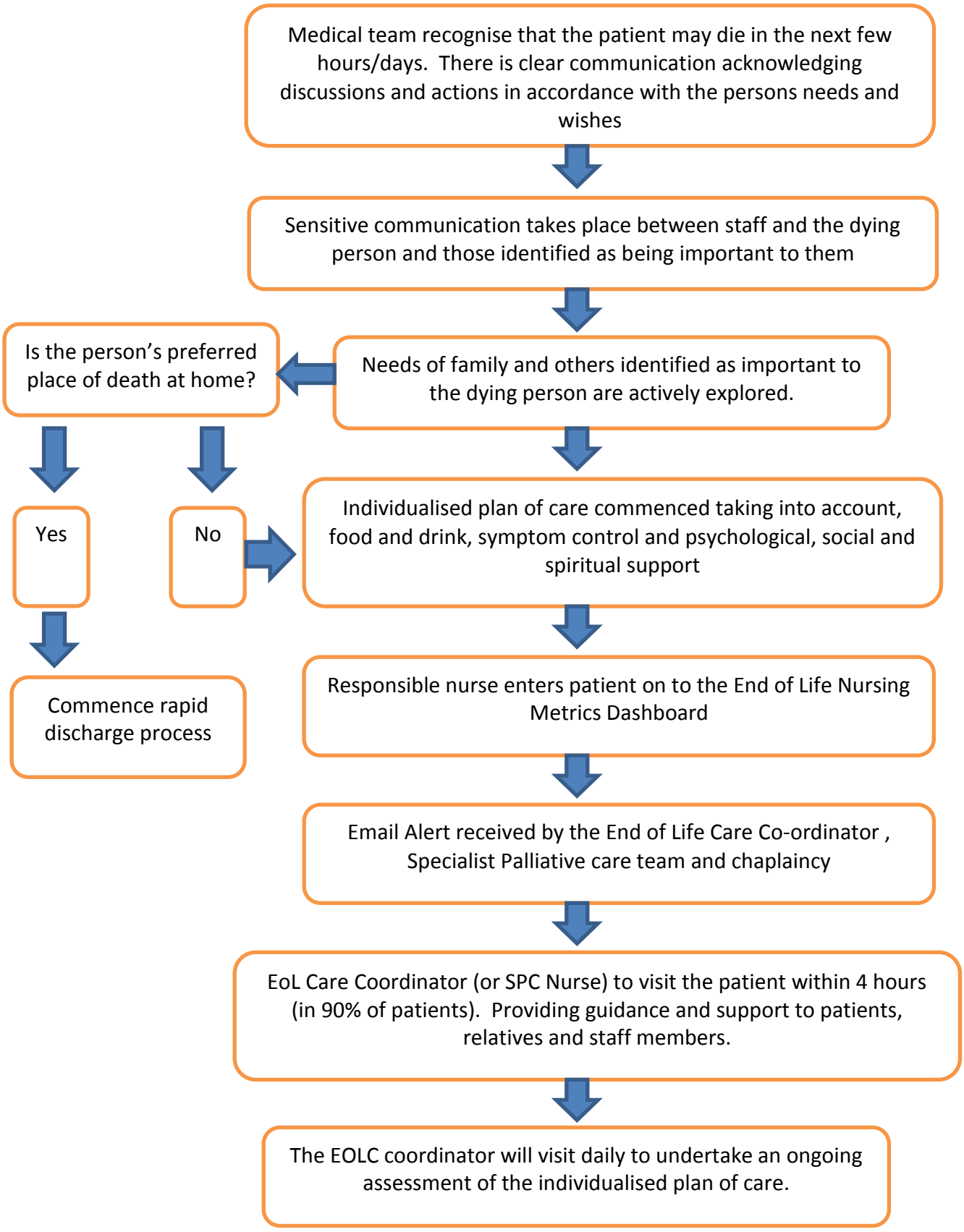
Department of Constitutional Affairs
Mental Capacity Act (2005): Code of Practice, 2007 www.dca.gov.uk.

APPENDIX 1 – PRIORITIES OF CARE FOR THE DYING PERSON

Leadership Alliance – Five Priorities of Care



APPENDIX 2 – FLOWCHART OF EXPECTED ACTIONS



APPENDIX 3 – RAPID DISCHARGE PROCESS

Patients identified as being in the last few days of life are able to undergo a Rapid Discharge in order for them to go to their preferred place of death. Below is a step-by step guide to how this process evolves:

1. On review by the EoLC coordinator (or ward nurse), patient identifies that their preferred place of death is at home/ nursing home, consultant completes 'Fast Track' documentation.
2. 'Fast Track' documentation faxed to IDT (integrated discharge team), the case is then allocated to an IDT coordinator.
3. Occupational Therapist and Medical Social Worker informed.
4. Immediate case conference held with IDT (integrated discharge team), OT (occupational therapist), MSW (medical social worker) and EoLC coordinator always with relative/carer participation focusing on an individualised, holist approach.
5. Full discussion with patient (if able).
6. Individualised care package established and requested following case conference discussion and fed back to continuing health care.
7. Await care package confirmation from continuing health care.
8. Pre-emptive medications prescribed and individualised by medical/surgical team and requested from pharmacy.
9. Equipment needs assessed and ordered by OT.
10. EoLC coordinator has full and open discussion around the ambulance journey and potential for rapid deterioration whilst on transfer.
11. Constant individualised updates to patient, relatives/care and ward staff, throughout the process.
12. Care package allocated and in place.
13. Equipment confirmed as being in place.
14. Pre-emptive medications on the ward.
15. Patient is ready for discharge.
16. GP and out of hours GP informed of individualised plan of care and all relevant information including copy of ReSPECT document to be faxed.
17. District nurse and community Macmillan referral completed and faxed.
18. End of Life ambulance contacted and informed patient is ready for discharge.
19. Patient discharged home with ReSPECT Document, end of life care plan and pre-emptive medications.

Timing of the pathway can be variable but minimum time to establish full process is about four hours.

APPENDIX 4 – EQUALITY IMPACT ASSESSMENT - PART 1 INITIAL SCREENING

Service/Function/Policy/Project/ Strategy	Division/Executive Directorate and Department	Assessor (s)	New or Existing Service or Policy?	Date of Assessment
End of Life: Guidelines for the Management of Patients in last hours/days of life – PAT/T 65 v.3	Medicine	Karen Lanaghan	Existing	07/06/2019

1) Who is responsible for this policy? Name of Division

2) Describe the purpose of the service / function / policy / project/ strategy? - Trust-wide Guidance

3) Are there any associated objectives? Legislation, targets national expectation, standards - Local Standards

4) What factors contribute or detract from achieving intended outcomes? None

5) Does the policy have an impact in terms of age, race, disability, gender, gender reassignment, sexual orientation, marriage/civil partnership, maternity/pregnancy and religion/belief? - No

- **If yes, please describe current or planned activities to address the impact** [e.g. Monitoring, consultation]

6) Is there any scope for new measures which would promote equality? [any actions to be taken] – No

7) Are any of the following groups adversely affected by the policy?

Protected Characteristics	Affected?	Impact
a) Age	No	
b) Disability	No	
c) Gender	No	
d) Gender Reassignment	No	
e) Marriage/Civil Partnership	No	
f) Maternity/Pregnancy	No	
g) Race	No	
h) Religion/Belief	No	
i) Sexual Orientation	No	

8) Provide the Equality Rating of the service / function /policy / project / strategy – tick (✓) outcome box

Outcome 1 ✓	Outcome 2	Outcome 3	Outcome 4

If you have rated the policy as having an outcome of 2, 3 or 4, it is necessary to carry out a detailed assessment and complete a* **Detailed Equality Analysis form in Appendix 4

Date for next review: June 2022

Checked by: Stacey Nutt **Date: 07/06/2019**