End of life.

Not end of choice.

Macmillan

End of Life Discharge Home

Dignified Death

Guidelines to facilitate a safe discharge home.

NoECCN
North of England Critical Care Network

Introduction 2

1. Consideration of patients suitability for transfer 3

2: Organising a discharge home to die 5

3: Transfer Home. 6

4: After discharge 7

References 7

Appendix 1 – Transfer home to die from Critical Care 8

Appendix 2 – Going Home to Die – Discharge Checklist 8

Appendix 3 – Useful Telephone Numbers 10

Appendix 4 – Critical Care Feedback Form 11

Appendix 5 – Adult Critical Care Transfer Request Proforma 12

Appendix 6 – Contents of Discharge Pack 13

Acknowledgments:

The work done at the Queen Elizabeth Hospital by Dr Kathryn Bartley and Sr Joanne Wilkinson

Southampton University

Introduction

Delivery of high quality, evidence-based end of life care in an international healthcare priority (Word Health Organisation,2004) with preferred place of care at the time of death a key consideration in end of life acre , it is important that transfer home be considered for critically ill patients who want this as part of their end of life care.

The mortality rate for patients admitted to critical care units in the UK is about 24% (Intensive Care National Audit and Research Centre (ICNARC) 2013). A deliberate decision to withdraw or limit care is made in a large proportion of these deaths, based on medical condition and response to treatment[1]. This means that death is often an anticipated and managed event within critical care areas.

When it is deemed that treatment cannot succeed or the patient does not wish the intervention to continue, considerable effort is being directed at providing patients and their families with a "good dignified death". What constitutes a "good dignified death" varies between individuals and dying in the familiar surroundings of their own home is highly valued by many patients[2]. Recommendations to support this include the Department of Health's (2008) End of Life Care Strategy: Promoting High Quality Care for Adults at the End of Their Life – which states that patients should be able to choose were to spend their final days wherever possible. This was strengthened by the recommendations from the National Institute for Health and Care Excellence (NICE) 2011 – Quality Standard for End of life Care for Adults and also the Leadership Alliance for the Care for the dying.

Due to the complexity of care given in critical care areas the patient's autonomy in end of life decisions, such as where they would like to die, was something that was very rarely considered as it was "too difficult to organise and not achievable." However, challenging this preconceived idea; barriers have been overcome allowing Critical Care patients to die in their own homes. This was achieved working collaboratively across systems enabling staff to help fulfil a patient's dying wish.

These guidelines are designed to assist with facilitating the process of discharging a patient home to die. However, it needs to be acknowledged that all cases will be different and this document is just a guide to the process.

This guidance can be divided into four sections:

1: Consideration of patients suitability for transfer

2: Facilitating safe transfer (preparation of home environment)

3: Actual transfer of the patient

4: Following transfer

1. Consideration of patients suitability for transfer

1.1 Assessing suitability for transfer

Patient stability and level of intervention are important factors in the decision-making process.

1.1.1 Patient groups in whom a discharge home to die MAY be possible

Patients with end-stage renal failure who do not wish to receive/are not appropriate for renal replacement therapy.
e.g. Patients with concurrent incurable malignancy, multiple co-morbidities.

Patients with end-stage respiratory failure in whom weaning from ventilatory support has failed.
e.g. patients with end-stage lung diseases or neuromuscular conditions affecting the respiratory muscle

Patients with end-stage cardiac failure who cannot be weaned off ventilatory support and / or single inotrope treatment.

1.1.2 Patient groups in whom a discharge home to die is NOT possible

Acutely unstable patients and / or patients requiring multi-organ support.

Patients who are considered too unstable to survive the journey to their home.

Patients who require hospital-based interventions for symptom control (unusual). For the purposes of this guideline this group includes patients who require oxygen therapy for symptom control*.

Patients whose families do not wish the patient to be discharged from hospital for terminal care at home.

**The complexities of risk assessing a home and then providing a secure supply of home oxygen mean that it is not a service that can be arranged in a timely enough fashion for terminal discharge from critical care. In addition, from previous experience, the provision of oxygen therapy complicates the clear message that the patient is going home to die, in comfort, not to receive on-going organ support.*

1.2 Is it achievable in practical terms?

1.2.1 Do the patient's family/people that live with them fully support the idea of a discharge home to die?

It is inappropriate to pressurise a family into accepting that their relative is sent home to die if the family are unhappy about the idea or feel they cannot cope with the dying process. Support is available (see later) but the majority of care at home will still be delivered by family/friends and this needs to be clearly explained to the family ensuring that they understand fully.

1.2.2 Is there time for the patient to get home before he/she dies?

Considerations include how far away the patient lives, whether he/she is stable enough for an ambulance transfer, and what arrangements will need to be put in place before discharge. The possibility of the patient dying in the back of the ambulance must be clearly understood by the patient and the family.

1.2.3 Are the patient's home circumstances appropriate for discharge home to die?

Is there someone who can provide care for the patient at home? Is the house accessible to the ambulance crew with a stretcher/wheelchair? Are sleeping and bathroom arrangements appropriate with minimal changes only?

1.2.4 Could necessary nursing care/symptom control be provided at home?

This is usually possible, but in some cases essential care will be beyond the capabilities of family/friends with the support of twice-daily district nurse visits. Such care may require a team of trained carers e.g. if a patient has uncontrolled diarrhoea or vomiting, if a patient requires multiple people to move/change/turn him or her. eg. morbidly obese, immobile patients.

1.3 Is it what the patient wants?

Only after establishing that discharge home to die is a practical possibility should the option be offered to the patient and their family. The most appropriate person to broach the issue with is the critical care consultant caring for the patient that day.

1.1.3 Before discussing discharge home to die, they must ensure that;

The patient already knows and understands that there is no further therapy that can be offered and that he/she is dying.

The family/carers of the patient are supportive of the idea of going home to die.

All practical conditions can be met.

Should the patient be keen for discharge home to die, it must be made clear to him/her and the family/friends involved, that whilst we will attempt to organise the discharge, sometimes it is not possible to achieve. This may be because the patient dies before arrangements can be set in place, or because an insurmountable problem becomes apparent during the process of organising the discharge. Often such discharges take place "out of hours"; will this be acceptable to the patient and family, or would they prefer to delay till the following day, bearing in mind the limited life expectancy of the patient?

2: Organising a discharge home to die

Once it has been established that the patient and his/her family/carers want us to organise for terminal discharge, the following should be considered:

2.1 There should be a current **DNACPR form**, which should have been discussed and agreed with the patient / family. The **original form** needs to accompany the patient; this will be needed for the transfer to the patient's home and is recognised by the North East Ambulance Service. The patient's home team should be aware of and in agreement with the decision to go home to die.

2.2 Home environment must be considered. Are the stairs/doorways wide enough to allow ambulance personnel access carrying a stretcher? Will the patient's bedroom need to be relocated to the downstairs of the house to permit access, and if so are bathroom arrangements adequate? In a block of flats, is the lift in good working order, and will it accommodate an ambulance trolley?

2.3 Death Certification plans must be made. The doctor issuing a death certificate must have seen the patient in the previous 24 hours. This may not be possible when a patient is discharged home to die. It is necessary to discuss with the coroner prior to discharge to agree that the discharging hospital doctor may need to issue the death certificate, or to agree that the GP will visit the patient at home immediately after discharge. The coroner may also have reasons why going home to die is not possible.

2.4 The GP needs to be informed of the planned discharge, and agree to take over the patient's continued care. Plans for death certification should be agreed (see above). A copy of the discharge summary and prescription should be faxed to the GP. There should be a discussion with the GP whether the community palliative care team needs to be involved.

2.5 The Discharge team for the hospital need to be involved as this will ensure the process is seamless. This team will organise delivery of all equipment needed for the patient at home (bed, mattresses, commode etc.) with the exception of syringe pumps (see District Nurses.)

2.6 The District Nurse Team needs to be consulted about the discharge. They need to know about the patient's diagnosis, symptoms and current condition, and estimated timescale to death. Specific handover of details about infusions, medications, dressings, presence of drains, urinary catheter, care needs and estimated time of discharge should be included. The district nurses supply syringe pumps as necessary. Assurance is required that the district nurse team are happy to continue necessary care at home. A copy of the discharge letter and prescription will be faxed to the district nurses.

2.7 Discharge medication needs to be organised with the help of the critical care pharmacist (or on call pharmacist out of hours). The Discharge Liaison Team will provide a "yellow form" prescription for medication in the community. The patient and his/her family will need to be shown the discharge medication, and receive explanations about the drugs to be used. Details of the prescription should be included in the discharge letter faxed to the GP and the district nurses.

3: Transfer Home.

3.1 Identify appropriate staff to take the patient home. If the patient requires on-going organ support then a suitably experienced doctor and nurse will be needed to escort the patient home. Once the patient is "settled in" and it is ensured that appropriate comfort care has been established, then organ support should be withdrawn (i.e. Patient taken off the portable ventilator, or inotrope discontinued), and the Critical Care team will leave the patient's home, handing over care to the family and district nurse team. The emotional demands of such a situation mean that senior and experienced staff are needed to undertake the transfer.

3.2 If there is no on-going organ support in progress then there may be no need for a medical escort from Critical Care.

3.3 It is likely that a family member will want to travel in the ambulance with the patient. This is at the discretion of the doctor organising the discharge, but should be encouraged. Discuss with ambulance control in advance, particularly number of seats available, so personnel accompanying the patient can be agreed. It may be that only one member of staff (nurse or doctor) is able to travel in the back of the ambulance with the patient to give a safe seat for a relative.

3.4 Ambulance Control should be contacted and an appropriate ambulance booked; usually there is no need fora paramedic ambulance. It should be made clear that the patient has a limited life expectancy and an urgent ambulance transfer is required to take them home.

Use Adult Critical Care Transfer Request Proforma

One hour before you want the ambulance to collect the patient, telephone **0191 4143144** (ambulance control) and request a G2 transfer. This call is a 30 minute warning of an ambulance booking. Request a job number. Inform ambulance control that the transfer involves taking a patient with a very short life expectancy home to die, and that a DNAR will be in place. Discuss seating available in the ambulance (see above).

When the patient is ready to go (i.e. Drugs, paperwork packaged and ready to go, patient on portable ventilator (if appropriate), patient settled on transfer trolley), ring ambulance control again to inform them that the G2 ambulance is now needed, and quoting the job number. The ambulance should attend within 30mins.

3.5 When the ambulance crew collects the patient from Critical Care, the nurse in charge should ensure that the district nurse team and the GP are telephoned to inform them that the patient has left the hospital and is en-route home.

4: After discharge

4.1 **Family support** must be available after discharge

.

4.1.1 The family and patient should be informed about the involvement of the district nurses and given their contact number.

4.1.2 If organ support (ventilation or single inotrope therapy) is to be withdrawn at home, then how this happens should be discussed with the family/patient. It must be made clear that the Critical Care team will leave as soon as this has been done, and on-going care is taken over by the family and district nurses.

4.1.3 Each day the nurse in charge of Critical Care will telephone the family at home to ensure they are receiving the necessary levels of support and to answer any questions, and the family should be informed so that they expect the calls.

4.1.4 In addition, the family should be informed that they are welcome to telephone the Critical Care for advice/help at any time, and given the appropriate contact details. It should be made clear that in the unlikely event that the patient or family change their minds about being at home to die, and then the Critical Care team will make arrangements for readmission to the hospital for appropriate care.

4.1.5 If appropriate they should be given information and contact details for other nursing and home support organisations (e.g. Macmillan nurses).

4.1.6 The family should be asked if they would mind completing a feedback form for us, so we can find out if there is anything we can do to improve the care they experience, and if they agree, this should be given to the family prior to discharge.

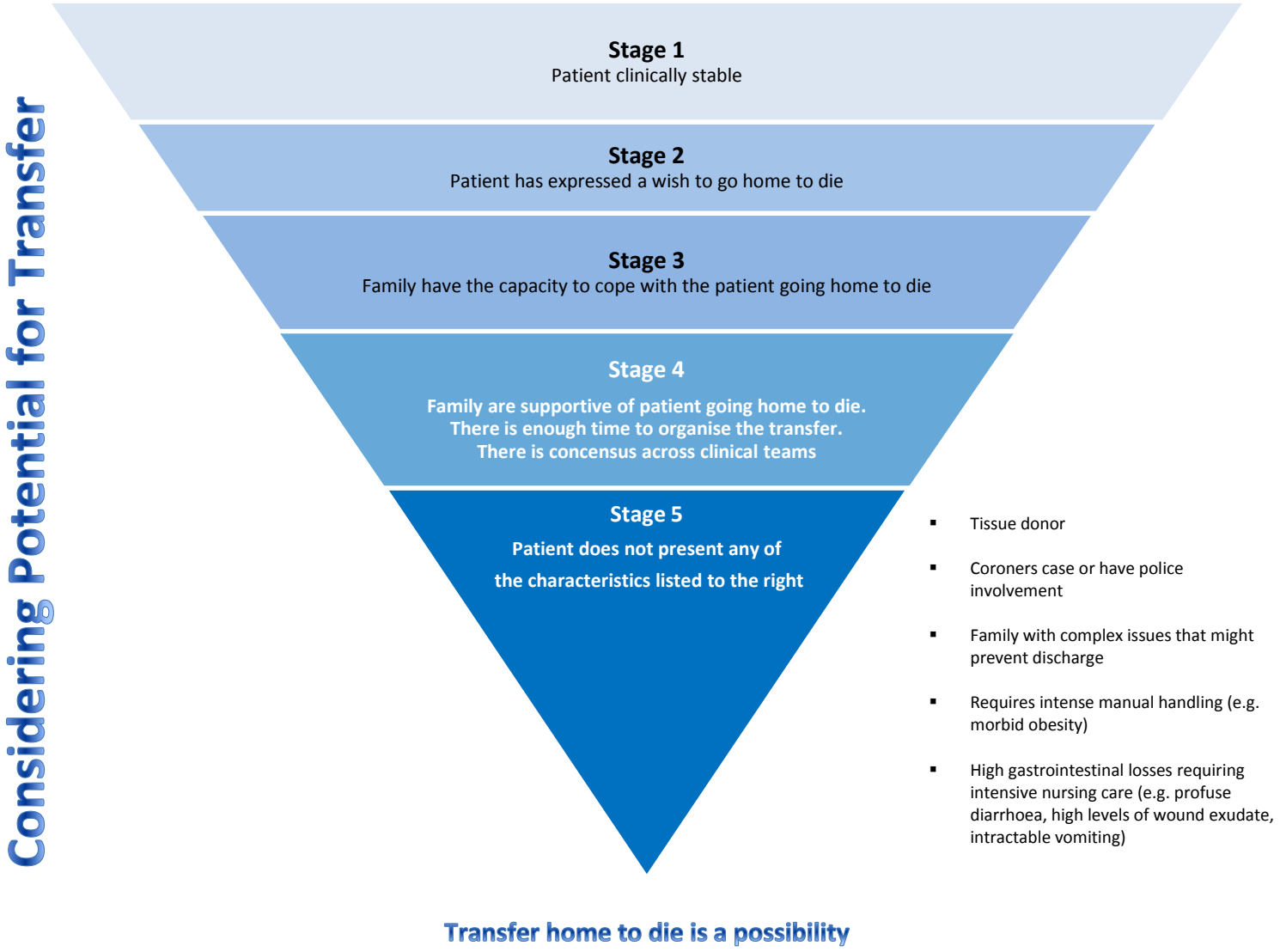
4.2 **Service evaluation** is essential so we can improve this service if necessary. It is clearly a difficult and emotional time for families, but most people recognise that any feedback they can give us is intended to help future families in the same position. Prior to discharge, the patient and family should be asked if they would mind completing a feedback form for us, and if they agree, one will be given in the "discharge pack", with a stamped envelope.

References

1. **Davis E, Higginson I.** *Better Palliative Care for Older People*: World Health Organisation , 2004.
2. **DoH.** *End of Life Care Strategy: promoting high quality care for adults at the end of their life.* London : Department of Health, 2008.
3. **NICE.** *QS 13 -Quality Standard for end of life care for adults.* London : National Institute for Health and Care Excellence, 2011.
4. **Leadership Alliance for the Care of Dying People.** *One Chance to Get it Right* : NHS England, 2014.

Appendix 1 – Transfer home to die from Critical Care

If the answer to any of the stages is "NO" the transfer is unlikely



PRE-TRANSFER ARRANGEMENTS
Follow rapid discharge checklist
PERI-TRANSFER ARRANGEMENTS
Follow NoECCN guidelines for Transfer of Critically Ill Patient
POST TRANSFER ARRANGEMENTS
Contact relatives for feedback Communicate with community teams, GP, community nurses – highlight learning points Clinical supervision for staff involved

Adpated from: Transfer home to die from Critical Care, University of Southampton.

Appendix 2 – Going Home to Die – Discharge Checklist

Going Home to Die – Discharge Checklist			
Patient Name:	**Hospital No:**		**Date :**

	Yes	No	Any Comment
Patient wishes to go home to die			
Family, Carers support and understand that the patient will be going home to die and they understand and are able to offer end of life care at home			
Are there any specific **religious or cultural needs**			
Critical Care and Home team support discharge decision			
Doctors have discussed with the **Coroner**, and they are happy with the plan			
GP aware of discharge and that the patient is expected to die: agrees to take over continued care.			
Home enviroment Good access to home, stairs, lifts etc. The patient can be safely transferred from ambulance to his/her bed.			
Rapid Discharge Liason Team informed (if available)			
Equipment Organised –bed, mattress etc. Relevant phone numbers and contacts added to contact sheet.			
Equipment Delivered			
District Nursing Team involved regarding medications, syringe dirvers, dressings, care needs. Estimated discharge time.			
Discharge Medication assessed and ordered and received			
DNCPR completed – orginal copy to go with patient			
All equipment is in place and services arranged			
Ambulance booked – follow the Ambulance Booking Proforma. Inform them of DNCPR status			
District Nursing Team & GP– Inform them of ETA so they can be at the home to accept the patient if possible.			
Discharge plan explained to family / carers. Aware of planned services and visits			
Information pack given to the family / carers with all contact numbers			
Medication education given to the patient, family carers as appropriate.			
Feedback . Family/ carers aware of follow-up calls and asked to complete feedback form			
Clinical supervision for staff involved with discharge			

Appendix 3 – Useful Telephone Numbers

Useful Telephone Numbers		
Patient Name:		
Service:	**Contact Name**	**Telephone Number**
Critical Care Unit		Direct line:
GP		Daytime No:
		Out of hours:
District Nurse		Daytime No:
		Out of hours:
Equipment supplies		
Others can be added:		
Discharge Liaison Team		
Marie Curie Nurses		
Macmillan Nurses		
Local Carers support		

Appendix 4 – Critical Care Feedback Form

Critical Care Feedback Form		
In order for us to improve the care and support we give to families, such as yours, who are prepared to care for a loved one who is dying at home: we would ask if you could spend a few minutes to complete this form and return it to us in the envelope provided. **We are very grateful to you for taking the time to fill in this form.**		
	Yes	No
Did you feel you were well informed throughout the process?		
If 'No' why?		
Did you feel you were prepared about what to expect?		
If 'No' why?		
Did you feel supported throughout the process?		
If 'No' why?		
Would more equipment have been useful?		
If 'Yes' what?		
Were you glad you were given the opportunity to take your loved one home to die?		
If 'No' why?		
Based on your experience, should critical care be offering discharge home to more patients who are dying?		
If you can, please tell us the reasons behind your answer to this question		
Would you like a member of the critical care team to contact you in the future to discuss your experience further/ answer any queries you may have?		
If "yes", please provide a contact telephone number and when is best to call.		

Thank You

Appendix 5 – Adult Critical Care Transfer Request Proforma

Adult Critical Care Transfer Request Proforma	
Patient name	
Patient Number	
Consultant Requesting transfer	
Identify and confirm bed with receiving hospital and receiving Consultant	
Hospital:	
Unit:	
Consultant:	
Pre alert NEAS that a critical care transfer is necessary, give 30mins notice if possible: 0191 4143144	
Pre –alert NEAS number:	
Person Giving Pre Alert	**Name:**
Speak to Operator	**Name:**
Date and Time:	
When the patient is stable on the transfer trolley inform NEAS that you are now ready for transfer:	
0191 4143144	
"This is a Critical Care Transfer using the Transfer Trolley requiring a G2 response.	
A paramedic crew is not required"	
Dispatch NEAS job number:	
Time:	
Person Requesting Ambulance	**Name:**
Operator	**Name:**
Referring Department	
Picking up point	
Receiving Hospital	
Receiving Department	
Name of Patient	
Principle diagnosis	
Who is accompanying the patient.	
How much Oxygen is required	
Ambulance Arrived:	**Time:**
Ambulance Delayed – Follow-up Calls	
Time:	
Person Requesting Ambulance	**Name:**
Speak to Duty Manager	**Name:**
Problem - ETA	
Time:	
Person Requesting Ambulance	**Name:**
Operator	**Name:**

Appendix 6 – Contents of Discharge Pack

Contents of Discharge pack	
1	Copy of Critical Care Department Discharge Letter
2	Copy of Critical Care Department Discharge Prescription
3	List of Useful Telephone Contact Numbers
4	Feedback form and Return envelope
5	Original DNCPR form