Intensive Care Society

Guidance for:

The decision making and transfer of critically ill adults to their preferred place of death

Endorsing organisations

UK Critical Care Nursing Alliance

BACCN CC3N Intensive Care Society NOrF PCCS Royal College of Nursing

Marie Curie

Supporting organisations

COLLEGE OF paramedics™
leading the development of the paramedic profession

Contents

Publication Date: July 2025
Review Date: July 2030

Authors

Dr Sam Clark – Consultant in Intensive Care Medicine with a Subspecialty Interest in Palliative Care, Mid-Cheshire Hospitals NHS Foundation Trust

Eleanor Furlong – Psychology Undergraduate Student, University of Plymouth

Dr Sophia Henderson – Associate Specialist in Intensive Care Medicine with a Special Interest in Palliative Care, Royal United Hospitals Bath NHS Foundation Trust

Dr Emma Jackson – Consultant in Intensive Care Medicine, Blackpool Teaching Hospitals NHS Foundation Trust

Professor Natalie Pattison – Professor of Clinical Nursing, University of Hertfordshire/East and North Herts NHS Trust

Professor Louise Rose – Professor of Critical Care Nursing and Head of Research Division (Applied Technologies in Clinical Care), at the Florence Nightingale Faculty of Nursing, Midwifery and Palliative Care, King's College London

Kate Tantam – Specialist Sister ICU, Rehabilitation Team, Critical Care at University Hospitals Plymouth NHS Trust

Kylie Williams – Highly Specialised Pharmacist in Medicines Safety and Palliative Care at Wirral University Teaching Hospitals NHS Foundation Trust

Contributors

Dr Helen Bonwick – Associate Specialist in Palliative Medicine, Marie Curie Hospice Liverpool, and Liverpool Heart and Chest Hospital NHS Foundation Trust. *Representing the Association of Palliative Medicine*

Acknowledgements

During the production of this document, we sought the experiences of various stakeholders in the decision making & transfer of critically ill adults to their preferred place of death at the end of life. Stakeholders were identified through organisations including 'Marie Curie', the 'Association of Palliative Medicine', the 'UK Critical Care Nursing Alliance', and the 'End of life and Palliative Care in Intensive care research Network', as well as informally through social media and clinical networks. We were fortunate to speak with family members who had direct experience of these transfers, as well as various professionals involved.

The document was also reviewed by the 'Association of Ambulance Chief Executives' and the 'National Ambulance Services Medical Directors' Group'. Mr Kieran Potts, Community Specialist Paramedic in Lancashire and Cumbria, and Regional Lead for Palliative and End of Life care offered support to the publication of this document and endorses the final version in his professional capacity. National and regional leads involved in adult critical care transfer have been consulted in the development of this guideline.

We also approached NHS Resolution, who offered advice on staff indemnity, alongside the Intensive Care Society's Legal and Ethical Advisory Group. The National Medical Examiner Office supported us with regards advice for care after death.

Finally, Dr Dale Gardiner, Associate Medical Director for Deceased Organ Donation, and his colleagues at NHS Blood and Transplant, kindly reviewed the guidance offering helpful feedback to inform our guidance from their organisation's perspective.

Glossary of terms

Advance care plan – A document that outlines an individual's preferences for medical care if they are unable to communicate their wishes due to illness or injury. It may include instructions regarding life-sustaining treatment, resuscitation, and other medical interventions, as well as preferred place of care and death.

Anticipatory medicines – Medications prescribed and given in advance of an expected event, such as the management of symptoms associated with a particular condition or treatment, including the dying process. These medicines are used to manage and prevent symptoms that may arise in the future.

End of life care – In the context of this document, this refers to that care delivered to patients who are deemed to have little or no chance of recovery, and for whom a senior decision has been taken to focus on quality of life in this final phase of a person's life.

Holistic needs assessment – A comprehensive assessment that considers all the physical, emotional, social, and spiritual needs of an individual, to develop a tailored care plan. It is often used in the context of end-of-life care, where the goal is to improve quality of life and provide holistic support.

Palliative care – In the context of this document, this refers to that care delivered to patients and their families, who are facing problems associated with life-limiting illness. The approach aims to improve the quality of life for the patient's and their families.

Preferred place of care – The place where a person would prefer to be cared for during the dying process.

Preferred place of death – The place where a person would prefer to die.

Priorities for care – Five priorities for care of the dying person as laid out in the Leadership Alliance for Care of Dying People' guidance – "One chance to get it right". These priorities are recognizing and communicating possibility of death, sensitive communication, involvement of the dying person and their family in decision making, meeting the needs of family and friends, and agreeing to an individual plan of care.

Record of care – Whilst this term might refer to the patients written or electronic hospital record, in the context of dying, we know that it is important that we enable key information to be known and shared, to give people more confidence in their end-of-life care, or the care provided to a family member (1). As such this document must be able to travel with the patient and/ or their family, across organisational and sometimes geographical boundaries, and include important documents such as Paper documents such as Advance Decisions or Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) orders.

Treatment escalation plan – A document that outlines a person's preferences for medical treatment as their condition worsens or changes. It helps healthcare professionals to know what treatments to provide or withhold in different circumstances, and to ensure that the person's wishes are respected. It may include information about resuscitation, hospitalization, and the use of medical interventions such as mechanical ventilation or intravenous medication.

Treatment priorities – The order of importance or urgency given to the different treatments that a patient requires, based on their individual needs and clinical condition. Treatment priorities may be determined by healthcare professionals, the patient, or both, and may be influenced by a variety of factors, including the severity of the patient's illness or injury, the potential risks and benefits of different treatments, the patient's preferences and values, and available resources.

Introduction

This document has been produced to provide guidance for multi-professional teams to facilitate decision making and actions for the transfer of a person reaching the end of their life in a critical care environment to a preferred place of death. We hope that it will encourage and empower the healthcare team to address what matters most to our patients, including ascertaining and realising their preferred place of death where this is feasible.

In producing this document, we acknowledge that transfer to a preferred place of death may not be possible for a variety of reasons, particularly for patients in critical care. This will include the time and resource implications on the critical care service and beyond. However, we are of the opinion that the wishes of the dying person should always be elicited. If transfer is asked for, but felt not to be possible, the reasons behind the request to go home, and resulting decisions, should be explored, and plausible alternatives considered (see Recommendation 9).

We also acknowledge that service components and provision vary widely across the country, and as such have not designed this document to be a 'one-size-fits-all' instruction manual. Rather, it should form the basis for regionally and/ or locally adapted guidelines, created through involvement of all interested teams, from hospital to community. We encourage all adult critical care networks, and Adult Critical Care Transfer Services (ACCTS) to support the development of this guidance. Where other ambulance service providers have been commissioned regionally for palliative and end of life care patient transport, these should be involved also in order to reduce potential burden on an already over-stretched frontline ambulance service

This guidance is intended for any adult critical care unit, regardless of levels of nursing dependency or organ support needs. We define end of life care as the care delivered to patients who are deemed to have little or no chance of recovery, and for whom a senior decision has been taken to focus on comfort and dignity in this final phase of a patient's life. This may include situations when withdrawal of life-sustaining treatment is planned.

Recommendations

These recommendations support currently available national guidance for palliative and end of life care, including aligning to the five Priorities for Care of the dying person, as laid out in the Leadership Alliance for Care of Dying People' guidance – "One chance to get it right":

The Priorities for Care are that, when it is thought that a person may die within the next few days or hours:

1. This possibility 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. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. 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(2).

Our recommendations also support guidance published by the National Institute for Health and Care Excellence for end-of-life care of adults in the last days to year of life(3) (4).When implementing this guidance, we recommend that local organisations also refer to relevant national guidance, including (but not necessarily limited to) that referenced in this document.

We have divided our recommendations into eight key themed areas.

A. Recognise and acknowledge end of life, and discuss what matters most

1. Standard practice must focus on early recognition of the potential for dying and sensitive exploration of the person's and/ or their family's wishes regarding priorities of care at the end of life. This could form part of treatment escalation planning discussions, or where feasible, advance care planning conversations. We suggest the use of the question "What matters most?". The wishes and/or best interests of the person should be the primary consideration in the decision-making process.
2. All adults in critical care reaching the end of their life should have the opportunity to explore where they would prefer to be cared for during the dying process (preferred place of care) and where they would prefer to die (preferred place of death). Healthcare professionals must involve the person and/ or their family in the discussions of the actualities of the decision and planning process where this is being considered.
3. Where the person is unable to engage in these conversations (For example due to receiving sedation, and it is deemed that they lack mental capacity in the context of this conversation), their wishes regarding their preferred place of death should be explored with their family and decisions made in their best interests (Refer to Intensive Care Society publication here(5)), according to the Mental Capacity Act 2005.
4. In the process of deciding whether transfer of the person to their preferred place can be realised, an individualised risk assessment must be performed and clearly documented in their record of care. Healthcare professionals should be honest about the uncertainties regarding the dying process where individuals are concerned (such as timing, and possible symptoms of the dying process). This component of the conversation must include the steps that would be taken to manage these risks and mitigate against distress for that person and their family. Consideration must be made for where the balance between the preferred place of death and degree of comfort lies.

5. Conversations regarding risks must include that of dying during transfer, and what the steps would be if this were to occur. It is usual that this would be completing transfer to the destination, and care after death as planned at that location.
6. Where a 'stop' en-route is being considered, this must be included in the risk assessment (In consultation for this guideline, we heard of patients who wished to visit a beach or park as part of their journey home), including the prevailing weather and any necessary modifications required. This should also consider the impact on the dying person, and any accompanying family or staff.
7. It must be sensitively discussed with the person and/ or their family, that transfer to a preferred place of death that is outside a hospital setting, would preclude solid organ donation, but not necessarily tissue donation. Health care professionals must first contact the organ donation team where withdrawal of life sustaining treatment is being considered, to ascertain suitability for organ donation.
8. It must be explained what will happen if following transfer, the family feel unable to cope. This would usually involve contacting the community/ palliative care team and arranging further support (however this may not be possible) or exploring transfer to a hospice (but which may not be immediately feasible). It should be explained that if transfer back to hospital is required, this would usually be via an admission route (i.e. emergency department or acute admissions team), and a bed cannot be 'kept available *just in case'.*
9. Where it is decided that transfer to the person's preferred place of death is not feasible, alternatives should be explored, such as transfer to another destination (such as a hospice), transfer to another environment in the hospital (for example to an outdoor space) (6), environmental modifications in the critical care unit, or a 'virtual visit' home.

B. Engage with the multi-professional team

10. Input from the specialist palliative care team, as well as that of Adult Critical Care Transfer Services (where established), and community teams (including the patient's general practitioner), should be sought in the local implementation of the recommendations outlined in this document.
11. The conversation and process for each person must involve all relevant staff from the multi-professional team.
12. The escorting team must meet the requirements for critical care transfer set out in the Intensive Care Society's Transfer of the Critically Ill Patient guideline, should be appropriately senior, experienced, and be capable of undertaking a transfer to a non-clinical environment. They must also be experienced in the end-of-life care of critically ill adults.
13. The escorting team, or suitable representatives, must consult with the patient's family and will often need to visit the preferred place of death (either physically or virtually) to assess suitability of access and care location.
14. A structured handover must be provided to all relevant members of the multi-professional team at a suitable time – in some cases (e.g. community nursing teams and general practitioner), this may be ahead of the transfer. Main points (including patient-specific plans for withdrawal of life-sustaining treatment and ongoing care requirements) should be written and these should be supplemented by an appropriate verbal handover. Recipients of this handover will vary depending on the individual patient and are likely to include, but are not necessarily limited to, transfer teams (where applicable), community nursing teams, and general practitioner.

C. A holistic needs assessment

15. A holistic needs assessment (including physical, social, psychological, and spiritual needs) must be performed at regular intervals and documented in the person's record of care. This will help to inform the evolving decision and planning process.

D. Physical needs of the dying patient

16. Critical care units must consider the standards and recommendations outlined in other Intensive Care Society guidance regarding the transfer of critically ill adults(7) (8) when adapting this guideline to local organisation policy. It is accepted that some standards or recommendations made in this more general document may not apply in the context of a person for whom the priorities are weighted towards best end-of-life care as opposed to goals of recovery. Careful consideration must be given to maintaining the safety of all involved (person and escorting team) throughout.
17. Consideration must be made of the physical location to which the patient is being transferred. The transfer team (or appointed deputy) must ensure that trolley access is possible, practical, and can be managed safely. This may require liaison with the service providing transport. They must also consider the manual handling requirements (these may necessitate additional members of the team, or may prevent transfer) during access, and whilst moving the patient from the trolley.
18. The necessary equipment required for the transfer must be considered on an individual basis and must include items to support the manual handling of the patient from trolley to bed when they reach their destination.
19. A plan must be made for the either removal prior to transfer, or ongoing maintenance of indwelling lines, drains, tubes, and devices at the destination. Hospital teams should ensure that community teams are competent and able to manage any that remain in situ.
20. Where withdrawal of life sustaining interventions is planned at the destination, then a clear plan must be made with the transferring team as to how and when this will be performed, and by whom. The point of handover after this has been performed must be clearly defined so that responsibilities for both the transferring team and community teams are clear.
21. Consideration must be made for the provision and disposal of necessary personal protective equipment for the duration of the transfer. This includes disposal of any other consumables used during the transfer (including at the destination) and after death consumables.

E. Medicines management

22. Consideration should be made to whether conversion of intravenous agents (in use for symptom management) to continuous subcutaneous infusion would be advantageous to the individual's situation and plan of care. For example, if care during the dying process will be taken over by the community team, the choice of route and choice of medicines must be something they are comfortable with managing, following the departure of the transferring team.
23. If choosing to convert from continuous intravenous to subcutaneous infusions, prescribers should be mindful that it may not be appropriate to do a direct conversion, as the dose required for sedation for (for example) endotracheal tube tolerance, may be much higher than the doses needed to manage person's symptoms (such as pain, agitation, distress, or breathlessness).
24. Where new medicines have been started, or changes to existing medicines (drug, dose, or route) made, a period of control of any distressing symptoms must be observed, prior to transfer.
25. In preparation of transfer, an adequate supply of anticipatory medicines (in a form that can be used by community professionals) and any medicines for continuous subcutaneous infusion must be ordered, received, and checked, to prevent any delays. These medicines must be stored in accordance with the local organisation's medicines management policy, in preparation for transfer.
26. Guidance for the prescribing, dispensing, storage, and administration of any controlled medicines, both for during the transfer as well as at the destination, must be agreed locally. This must include guidance for disposal of medicines after death.
27. The appropriate community medication authorisation and administration record must be completed as part of the hospital discharge process (liaise with pharmacy and/ or specialist palliative care team if unsure).

28. An adequate supply of anticipatory medicine for administration during the transfer must be available, including diluent and consumables for administration. It is important to consider that the transfer itself may exacerbate underlying symptoms. Such medicines may not routinely be carried by the ACCTS, or be stocked in transfer bags, so should be separately sourced and appropriately managed.
29. Any anticipatory medicines given during the transfer/ by the transferring team must be recorded clearly according to local guidance. We expect that this would include the community medication authorisation and administration record (so that recent administrations are clear to subsequent attenders), and within the person's record of care. Handover between the transferring team and community teams must detail any use of these medications to ensure that recent administrations are clear to subsequent attenders.

F. Social needs of the dying patient

30. If the preferred place is the home of the person and/ or their family, staff should take steps with the person's family to ensure that the environment is suitable and ready for transfer. Most often this will require a pre-transfer visit (virtually or in person) by members of the escorting team (which will likely need to include liaison with the service providing transport), to assess that ingress and egress is suitable (as this is often challenging and may actually negate transfer to that particular destination). Consideration must be given as to how the patient will be transferred when they reach their destination (for example, will a patient transfer slide or hoist be required?) and how this will be completed safely, maintaining safety for both the person and escorting team. You may also need to assess the suitability of the environment in other terms, including space for escorting staff, the presence of pets, or smokers in the household.
31. The need for any specialised equipment (such as bed/ mattress) must be identified and arrangements made for prompt delivery, ensuring they are in situ before transfer. This would usually be by the specialist palliative care team, or another team as identified in the local pathway for rapid discharge at the end-of-life, in liaison with the community nursing team.
32. Staff must ensure that the person's family are aware of the demands of caring for a dying person at home, and that they are prepared to support the person after transfer. This would usually be a combination of the general practitioner, community nursing teams, and community specialist palliative care teams, depending upon local provision.
33. The need for any additional package of care must be assessed and arranged where necessary and feasible, prior to transfer.

G. Psychological and spiritual needs of the dying patient

34. Staff must ensure that the person and/ or their family are aware of what the dying process might entail, and the uncertainties that surround it on an individual basis. This includes young children and the specific support they may require.
35. Staff must explore with the person and/ or their family whether there are any religious or cultural requirements whilst they are dying, or after death.
36. Staff must ensure that the person and/ or their family are aware of how they can seek support during the dying process (including once death has occurred) once the transfer team has departed the destination. This would usually be a combination of the general practitioner, community nursing teams, and community specialist palliative care teams, depending upon local provision.

H. Care after death

37. It must be agreed with the necessary individuals, and clear in the transfer plan, who will verify the person's death, and who will then be responsible for completing the medical certificate of cause of death. Where it is expected that the person may die in the care of the transferring team, contingency

must be made for situations wherein the dying process is longer than expected and occurs after they have departed. This will involve a conversation between the hospital and community teams, who must jointly agree the most appropriate person to complete the medical certificate of cause of death, in-line with current regulations according to the residing nation.(9) We recommend pre-emptive discussion with the Medical Examiner service (where available).

38. Each transfer must be completed by a staff debrief to celebrate what went well and to establish any components of the process which might be improved for future transfers. Any learning should be shared with the critical care network/ regionally.
39. All staff involved in a transfer should be offered wellbeing support, as these are rare and often emotive situations that are unusual for all involved.
40. Each case must be jointly reviewed at a morbidity and mortality review meeting. We recommend inviting the multi- professional team involved in the case to attend these meetings, including but not limited to the team responsible for the transfer (critical care team and/or ACCTS) and the palliative care team (hospital +/- community).
41. We recommend arranging to make follow-up contact with the person’s family, to elicit and address any outstanding concerns, and to gather feedback regarding management, for quality and improvement purposes. This will most likely take the form of a telephone call and might be made by a nominated member of the critical care team, the hospital palliative care team, or bereavement team.

Background

To date, research suggests that transferring critical care patients home to die is feasible, and staff in critical care environments should actively consider this option as part of end-of-life care(10). Approximately 20% of critical care patients demonstrate potential for transfer home as their preferred place of death, yet the decision-making protocol remains unclear for this complex process(11). Guidance varies internationally and is influenced by the local care system, culture, and religion(12).

Dying at home might be described as constituting a “good death”, with the aim to be surrounded by family and die peacefully(13). In one study, patients stressed that they preferred end-of-life care at home that allowed them to maintain some control over their own life, the decision making process, and to be seen as the person they always have been(14). Dying at home can be comforting to both patients and their families because it allows them to be together, in a familiar environment at the time of death. However, cultural expectations and limits in the healthcare system must be considered(15).

There are some recognised barriers to the transfer of a dying person to their home. These include a lack of evidence behind the practice, the culture within the critical care unit, and both practical and logistical factors, as well as the family members’ expectations. Facilitators to a transfer home include engagement with the multi-professional team, and the person’s own and their family’s wishes(15).

When it comes to healthcare professionals’ views on transfer home to die, those with previous experience of this practice tend to hold more positive views, and the professional role held seems to have additional influence. Approximately 51.6% of UK senior nurses and medical consultants that took part in a survey had experience of this practice or the decision making around it 16).

A proportion of patients transferred home will still be receiving ventilation and will be eligible for extubation at the end of life, such as in situations where patients have suffered extensive, irreversible neurological deficits and are likely to be unaware(17; 18; 19; 20). Consideration should be given to risk of immediate obstruction, oedema and pulmonary haemorrhage, and pain (19; 20) and any muscle relaxant should be stopped (assessing for any residual effects). While this practice is less evident in the UK, the key principle is assessing individual cases to understand whether this would be the most appropriate action (21). Stages may involve prescription of medicines to avoid dyspnoea, and adjustment of ventilatory support (reducing PEEP), and a spontaneous breathing trial (assessing this against the risk of significant airway obstruction resulting in distress or discomfort on extubation)(20; 22).

Although it can be positive, going home to die from the critical care unit can be a challenging experience for the family. Again, full collaboration between the dying person, their family, and healthcare professionals is essential to ensure the family are appropriately supported and prevents the family feeling vulnerable by placing the dying person’s wishes before their own(23). Time pressures can limit the choices of family members, so providing them with timely, ongoing, realistic updates for greater involvement is beneficial (24). Good communication between everyone involved has been seen to give patients a real choice about where they want to die, with repeated dialogues regarding preferences for end-of-life care being important throughout the care trajectory and the later phase(25; 14). If a family is unprepared, the reality of dying at home can change the family preferences for a home death rapidly, with tasks that are normally performed by trained healthcare workers, such as managing distressing symptoms, pain, and intimate personal care, becoming overwhelming for the family members caring for their loved one(13).

In some regions of the UK, transport providers are commissioned as part of care pathways to facilitate rapid discharge to a preferred place at the end-of-life. These has been supported by a template service specification by Marie Curie Cancer Care, as well as guidance from NHS England and the Association of Ambulance Chief Executives(26) (27).

Over recent years, Adult Critical Care Transfer Services (ACCTS) have been developed within England, Wales and Northern Ireland, with the aim to provide equitable access to all patients and all referring and receiving hospitals, for interfacility transfers of critically ill adult patients. Their service specification currently defines transfers for escalation, repatriation, continuation of care, or capacity reasons (28). The transfers in this document are covered in the continuation of care category that was specifically developed to include such cases, and it is known to the authors that some regional services have undertaken transfers of persons for the purposes of end-of-life care. In regions with established ACCTS, it should be anticipated that these services will lead on and deliver these complex transfers. We welcomed the input of ACCTS in the development of this document, with the expectation that their role in such transfers will develop as their services do.

References

1. **Compassion in Dying.** *Electronic end-of-life records: what people need.* London : Compassion in Dying, 2022.
2. **Leadership Alliance for the Care of Dying People.** *One chance to get it right: Improving people's experience of care in the last few days and hours of life.* London : Department of Health and Social Care, 2014.
3. **National Institute for Health and Care Excellence.** *Care of dying adults in the last days of life (NG31).* London : National Institute for Health and Care Excellence, 2015.
4. *End of life care for adults: service delivery (NG142).* London : National Institute for Health and Care Excellence, 2019.
5. **Intensive Care Society.** *Best interests decision guidance.* London : Intensive Care Society, 2019.
6. **Clark, Sam Reece, et al.** *Guidance for: Transfer of critically ill adults to an outdoor space during end of life care.* London : Intensive Care Society, 2022.
7. **The Intensive Care Society and The Faculty of Intensive Care Medicine.** *Guidance On: The Transfer of the Critically Ill Adult.* London : The Intensive Care Society, 2019.
8. **The Intensive Care Society.** *Guidance On: Transfer of Critically Ill Patients to the Outdoors.* London : The Intensive Care Society, 2021.
9. **Department of Health and Social Care.** Guidance: An overview of the death certification reforms. *Gov.uk.* [Online] 22 May 2024. [Cited: 6 June 2024.] https://www.gov.uk/government/publications/changes-to-the-death-certification-process/an-overview-of-the-death-certification-reforms.
10. *Doctors' and nurses' views and experience of transferring patients from critical care home to die: a qualitative exploratory study.* **Coombs, M, et al.** 4, April 2015, Palliative Medicine, Vol. 29, pp. 354-62.
11. *Transferring patients home to die: what is the potential population in UK critical care units?* **Coombs, M A, et al.** 1, 2017, BMJ Support Palliat Care, Vol. 7, pp. 98-101.
12. *Uncovering the decision-making work of transferring dying patients home from critical care units: An integrative review.* **Lin, Y, Myall, M and Jarrett, N.** 12, 2017, J Adv Nurs, Vol. 73, pp. 2864-2876.
13. *Where Americans Die - Is There Really "No Place Like Home"?* **Wachterman, M W, et al.** 11, 2022, N Engl J Med, Vol. 386, pp. 1008-1010.
14. *Preferences for home care to enable home death among adult patients with cancer in late palliative phase – a grounded theory study.* **Nysæter, T M, et al.** 2022, BMC Palliat Care, Vol. 21. 49.
15. *Transferring home to die from critical care units: A scoping review of international practices.* **Lin, Y, Long-Sutehall, T and Myall, M.** 2021, J Crit Care, Vol. 65, pp. 205-215.
16. *A national survey exploring views and experience of health professionals about transferring patients from critical care home to die.* **Darlington, A S, et al.** 4, 2015, Palliat Med, Vol. 29, pp. 363-70.
17. **MacIver, J R.** Withdrawal of ventricular assist device support. [book auth.] G M Rocker, et al. *End of Life Care in the ICU: From advanced disease to bereavement.* Oxford : Oxford University Press, 2010, pp. 258-61.
18. *Terminal extubation in 5 end-of-life patients in intensive care units.* **Fartoukh, M, Brun-Buisson, C and Lemaire, F.** 7, s.l. : Presse Med, 2005, Vol. 34, pp. 495-501.
19. *Sedation practice and discomfort during withdrawal of mechanical ventilation in critically ill patients at end-of-life: a post-hoc analysis of a multicenter study.* **Robert, R, et al.** 6, 2020, Intensive Care Med., Vol. 46, pp. 1194-203.

20. *Terminal weaning or immediate extubation for withdrawing mechanical ventilation in critically ill patients (the ARREVE observational study).* **Robert, R, et al.** 12, 2017, Intensive Care Med., Vol. 43, pp. 1793-807.
21. *The Durban World Congress Ethics Round Table: III. Withdrawing Mechanical ventilation- The approach should be individualized.* **Paruk, F, et al.** 6, J Crit Care, Vol. 29, pp. 902-7.
22. **Faculty of Intensive Care Medicine.** *Care at the end of life: A guide to best practice, discussions and decision-making in and around critical care.* London : Faculty of Intensive Care Medicine, 2019.
23. *Home to die from the intensive care unit: A qualitative descriptive study of the family's experience.* **Hutchinson, A L and Van Wissen, K A.** 2017, Intensive and Critical Care Nursing, Vol. 43, pp. 116-122.
24. *The decision-making process of transferring patients home to die from an intensive care unit in mainland China: A qualitative study of family members' experiences.* **Lin, Y, Long-Sutehall, T and Myall, M.** https://doi.org/10.1016/j.iccn.2023.103399, 2023, Intensive and Critical Care Nursing, Vol. 76, p. 103399.
25. *No place like home: A case study of a patient discharged from an Intensive Care Unit for end of life care at home.* **Smith, D, et al.** 3, 2018, Journal of the Intensive Care Society, Vol. 19, pp. 259-263.
26. **Marie Curie Cancer Care.** *Marie Curie.* [Online] 2012. [Cited: 21 10 2024.] https://www.mariecurie.org.uk/globalassets/media/documents/commissioning-our-services/publications/palliative-end-of-life-patient-transportpdf.
27. **National End of Life Care Programme.** *The route to success in end of life care - achieving quality in ambulance services.* London : National End of Life Care Programme, 2012.
28. **NHS England.** *Adult Critical Care Transfer service specification.* London : NHS England, 2021.
29. *Going home to die from surgical intensive care units.* **Huang, Y C, Huang, S J and Ko, W J.** 5, 2009, Intensive Care Med, Vol. 35, pp. 810-5.
30. *Transport Home and Terminal Extubation by Emergency Medical Services: An Example of Innovation in End-of-Life Care.* **Clemency, B M, et al.** 2, 2019, J Pain Symptom Manage, Vol. 58, pp. 355-359.

Appendix 1: Conversation template

Conversation template

The following is a suggested template for conversations to begin the decision making & transfer process

Making a decision

☐ Establish the person's clinical trajectory and treatment priorities – is the person likely to die in hours, days or short weeks?

☐ Has end of life care or withdrawal of life sustaining treatment been discussed with the person and their family*?

☐ If not already done, establish "what matters most" to the person and their family. Explore where their preferred place of death would be

☐ Establish whether transfer to the preferred place of death is feasible given the person's individual circumstances

☐ Identify potential risks (including risk of death during transfer), their likelihood, and mitigating measures (if any)

☐ Discuss this risk assessment with the patient and their family and confirm if transfer of the patient to their preferred place of death is still desired

*Family are those closest and most important to the patient. This may be close friends or staff from residential care.

Agreeing an action plan

Consider the following:

☐ Where will the transfer be to?

☐ When will the transfer take place?

☐ Who will be required to escort the patient, and who will meet at the destination?

☐ What family will be with the person, and will they need additional staff support?

☐ How will privacy and dignity be maintained during transfer?

☐ If withdrawal of life sustaining treatment is planned at the destination, how will this be performed and by whom?

☐ What equipment and monitoring will be required during the transfer? When and where will this be removed if withdrawal of life sustaining treatment is planned?

☐ If the person deteriorates during transfer, what steps will be taken? These may include temporarily increasing support measures or allowing a natural death.

☐ If the person dies during transfer to their preferred place of death, what action will be taken?

☐ What actions will be taken when the person dies?

Documenting each step

☐ Ensure that the conversation and resulting action plan are documented clearly within the person's notes, including either verbal consent or a best interests decision

☐ Ensure formal documentation of a resuscitation decision and treatment escalation plan, and that this is available to all involved in the transfer

Appendix 2: Steps towards a successful transfer to a preferred place of care and death

Steps towards a successful transfer to a preferred place of care and death

Patient and family involvement throughout process

Recognise
that the patient might be approaching end of life (i.e. within hours, days, or short weeks)

Acknowledge
That the patient might die with other members of the MDT, the patient, and their family

What matters most?
to the patient and/ or their family? Right now, and as end of life approaches

Discuss & agree
With the patient and/ or their family the potential of a transfer to a preferred place of care and/ or death ①

The items included in this appendix will assist in your risk assessment

Suitable for transfer home:

Person
Expressed wish to go home
Clinically suitable ('stable') for transfer

Timing
Sufficient time to arrange transfer

Destination
Suitable and accessible in context of all anticipated needs

Situation
Family understanding and able to support transfer home
Clinical team available to support transfer home

Transfer home less likely if:

- Planned organ donation
- Coroner with police involvement
- Intensive nursing needs e.g. wound care or need for repositioning, or manual handling difficulties e.g. obese person
- Is required outside of Monday-Friday business hours

But, this isn't always the case. You might also consider what alternatives would be acceptable to the patient and/ or their family e.g. hospice

Engage with the multi-disciplinary team

Critical care team	C	Transfer or ambulance service	T	General practitioner	GP
Hospital palliative care team	HP	Social care +/- discharge team	S	Community palliative care team	CP
Pharmacy team	Ph	Home oxygen team	Ox	Community nursing team	CN
Occupational therapy team	OT	Chaplaincy team	Ch	Bereavement service	B

① Refer to communication prompt sheet
② Refer to contact template sheet
③ Refer to patient information leaflet

Legal, Ethical & Professional Considerations

Mental Capacity Act
Assess the person's mental capacity to be involved in the decision-making process according to the Mental Capacity Act 2005

Best Interests Decision
Where mental capacity is lacking, explore the person's wishes, values and feelings with their family, making decisions in their best interests. Consider any past statements (written or otherwise) of the patient and consult with any attorney under an LPA if applicable.

Organ Donation
Does the patient and/ or their family understand that transfer out of the hospital would preclude solid organ donation, but not necessarily tissue donation? C HP

Written Documentation
Record of care
Hospital discharge letter
Emergency health care plan or advance care plan
DNACPR notice
C HP

Physical needs

Medicines
Order take-home prescription including anticipatory medicines

Complete community prescription chart

C Ph

Ongoing care
Inform community teams of intent
Consider joint visit
Ensure thorough handover
Ensure family know who to contact and how ②

C HP CN GP

Nutrition, hydration & elimination
Consider the ongoing need for nutrition or hydration
Ensure adequate mouthcare & continence supplies

C HP

Withdrawal of life sustaining treatments
How will treatments be withdrawn? By whom? When? And Where?
Plan for indwelling devices?

C HP T

Oxygen
Order oxygen supply and devices as required
Ensure delivery prior to departure

C Ox

Transfer equipment
Gather and check necessary equipment including PPE, consumables and facilities for disposal

C T

Transport
Book transport
Consider additional staff or family, and plan return journey

C T

Comfort
Wound care supplies
Consider prevailing weather conditions

C T

Social needs

Home
Is home suitable and ready for transfer?

C HP OT S

Care
Are family prepared to support patient at home or has a care package been arranged and in place?

C HP OT S

Equipment
Specialised bed/ mattress
Continence equipment

C HP OT S

Finance
Has requirement/ eligibility for financial support been considered?

HP

Psychospiritual needs

Psychological needs
Have any psychological needs been addressed?

C HP Ch

Spiritual needs
Are there any faith needs?
Are there any considerations for after death?

C HP Ch

Family support
Who will support the family at each stage?
Do the family know what to expect in the dying process

C HP CP

Young children or vulnerable adults
Have their needs been explored and addressed?

Care after death

Immediate Actions
Ensure family know who to contact in event of, and following death ②

Delayed Actions
Who will complete the MCCD?
Does a GP visit need to be arranged

C HP GP T

Bereavement Support
Arrange follow up contact with family
Signpost support ③

C HP

Legal, Ethical & Professional Considerations (cont.)

Resources
Consider staffing requirement for this patient, and others under the team's care

Utilise ACCTS where available

Staff Indemnity
Staff are covered under their organisation's membership of the Clinical Negligence Scheme for Trusts. It is worthwhile involving your legal team in developing local guidance

Staff Wellbeing
Consider visiting the Thriving at work resources on the ICS website here

Quality Improvement
Review all cases in department mortality review meetings

Involve the multi-professional team

Appendix 3: Record of care handover document for the dying person

Record of care handover document for the dying person

A record of care should be used to guide care and communication for all those who it is deemed are likely to be in the last days of life, and those closest to them. This document is designed to act as a pre-face to this, for persons transferred to their preferred place of death from an adult critical care unit.

This person (if they have the mental capacity), their family, and the multi-professional team agree that they are likely to be in the last hours or days of life and agree that that their care would be best supported using this individualised care plan.

Signed ………………………………………………… **Date** ……………………
Senior responsible decision maker (usually the critical care consultant)

Patient demographics

Patient name
Date of birth
NHS Number

Alternatively, affix label here

Attached documents

Please indicate whether any of the following documents are attached to this person's record of care.

Do not attempt cardiopulmonary resuscitation form (Must be valid in the community setting) ☐
Advance Decision to Refuse Treatment (ADRT) ☐
Lasting Power of Attorney (LPA) for Health & Welfare ☐

Recognise

Describe why the multi-professional team feel that this person is dying

To facilitate timely completion of after death documentation, consider what the cause of this person's death would be

1a ……………………………………………………………………………………………………
1b ……………………………………………………………………………………………………
1c ……………………………………………………………………………………………………
2 ……………………………………………………………………………………………………

Communicate

What has been communicated to the dying person and those closest to them? How did they respond?

Involve

What do this person and their family feel is most important at this time?
Consider whether there are any specific cultural or religious needs.

Support

What can we do to support this persons family at this time?

Plan & do

What has been communicated to the dying person and those closest to them regarding the plan for transfer to their preferred place of death? Include any plans for withdrawal of life sustaining treatments. Consider also:

- Timescales
- Risks (including dying during transfer) & mitigating measures
- Who will accompany the person
- What preparations will be required

Plan & do (checklist)

Critical Care Medical Team
(+Hospital Palliative Care Team)

Discharge medication

○ Inform pharmacy team of rapid discharge
○ Order medications for discharge including anticipatory medicines
○ Ensure sufficient supply of medicines to for WLST
○ Complete community prescription chart
○ Complete oxygen prescription and order (if required)

Liaison with GP

○ Contact GP in advance of discharge
○ Consider joint visit
○ Complete GP discharge letter

Agree plans for:

○ Indwelling lines
○ Bowel management systems
○ Urinary catheter
○ Nasogastric tube
○ Implantable cardioverter defibrillator or permanent pacemaker

Transport:

○ Contact transport provider at earliest opportunity
○ Ensure access to the destination has been assessed
○ Plan return transport for staff and equipment

This checklist is not comprehensive and may require adaptation according to local requirements

Critical Care Nursing Team

Liaison with community nursing team

○ Contact team at earliest opportunity
○ Ensure adequate nursing supplies needed for discharge
○ Assess need for nursing visit
○ Consider joint visit

Arranging care provision

○ If required, discuss with social care or discharge team
○ Confirm care package and provider, including start time, if required

Liaison with occupational therapy

○ If equipment needed, request urgent delivery

Day of Discharge Checklist 1

Transfer equipment

○ Fully stocked transfer bag
○ Portable ventilator
○ Portable suction
○ Adequate oxygen supply
○ Adequate power supply
○ Personal protective equipment
○ Waste receptacles

Day of Discharge Checklist 2

Medicines

○ Adequate supply of ongoing sedatives, analgesia, and inotrope/ vasopressor agents
○ Infusion devices (IV and SC) and adequate power supply
○ Infusion consumables
○ Anticipatory medicines

Day of Discharge Checklist 3

Documents

○ As detailed on the front of this record of care
○ Community prescription chart

Communication

○ Direct means of communication with critical care unit

Handover

Ensure that both a verbal and written handover has been provided to the following parties:

Hospital palliative care team ☐
Community palliative care team ☐
Community nursing team ☐
General practitioner ☐
Transfer service (where applicable) ☐

Appendix 4: Key contacts

Key contacts

The following is a template for documenting key contacts that might be of help throughout the transfer process and might form part of local guidelines.

Generic contacts (for all patients) *can be prefilled in local organisation version

Person/ department	Contact Number	Details
Hospital switchboard		
Critical care unit (direct line)		
Inpatient palliative care team		
Community palliative care services		
Occupational therapy team		
Discharge team		
Home oxygen team		
Community nursing team		
Transfer service/ ambulance service		

Teams for this patient

Person/ department	Contact Number	Details
Next of kin/ Key contact		
Alternative key contact		
GP		
GP out of hours		
Community palliative care team		
Community palliative care team out of hours		
Community nursing team		
Community nursing team out of hours		
Care provider		

The nearest 24-hour community pharmacy can be found at www.nhs.uk/service-search/pharmacy/find-a-pharmacy.

It may be helpful to provide some of these contacts to the patient and their family, depending upon local services and guidelines.

Appendix 5: Resources for bereavement support

The following is a list of organisations offering support in the context of bereavement. It might be helpful to signpost the person and/ or their family to these organisations, where required. This is not an exhaustive list, and it would be worthwhile exploring what is available locally.

ICU Steps: A charity providing support for ICU patients and families.

Visit their website at: www.icusteps.org

Child Bereavement UK: A charity supporting children and young people (up to the age of 25) when someone important to them has died or is not expected to live, and parents and the wider family when a baby or child of any age dies or is dying.

Telephone: 0800 02 888 40
Visit their website at: www.childbereavementuk.org

Sudden Bereavement: A charity providing help for suddenly bereaved people due to illness, sudden events, or suicide.

Telephone: 0800 2600 400
Visit their website at: www.sudden.org

National Bereavement Partnership: A support helpline, counselling referral and befriending service for all those suffering from bereavement, grief, and living loss.

Telephone: 0800 448 0800
Visit their website at www.nationalbereavementpartnership.org

CRUSE Bereavement Care: A charity providing bereavement support.

Telephone: 0844 477 9400
Visit their website at: www.cruse.org.uk
E-mail: helpline@cruse.org.uk

Notes

Intensive Care Society I Floor 2 I Bream's Buildings I London I EC4A 1DT
T: +44 (0)20 7280 4350 E: info@ics.ac.uk W: www.ics.ac.uk

Registered as a Company limited by Guarantee
Registered No: 2940178 (England) Registered Office as above
Registered as a Charity in England and Wales No: 1039236 and in Scotland No: SC040052