Urgent and emergency care in hospitals for people who may be in their last months of life

Rapid Improvement Guide

December 2017
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About Hospice UK

Hospice UK is the national charity for hospice care. We believe that everyone, no matter who they are, where they are or why they are ill, should receive the best possible care at the end of their life. We work with and support over 220 local hospices to grow outstanding hospice care for adults and children across the UK, championing the expert, compassionate and free care they provide.

About NHS Improvement

NHS Improvement is responsible for overseeing foundation trusts and NHS trusts, as well as independent providers that provide NHS-funded care. We offer the support these providers need to give patients consistently safe, high quality, compassionate care within local health systems that are financially sustainable. By holding providers to account and, where necessary, intervening, we help the NHS to meet its short-term challenges and secure its future.

About The Emergency Care Improvement Programme

The Emergency Care Improvement Programme (ECIP) is a clinically led programme that offers intensive practical help and support to 40 urgent and emergency care systems across England leading to safer, faster and better care for patients.

More information

Visit the Hospice UK website for more information including:

• care for patients who maybe in their last months of life: why we need to focus on acute admissions
• care for patients who maybe in their last months of life: walking the patient / relative journey to give ‘fresh eyes’ on potential patient experience
• care for patients who maybe in their last months of life: casefile review and obtaining knowledge from hospital data
• case studies.

www.hospiceuk.org/ecip

Published by Hospice UK in December 2017.

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Summary

Improving the quality of care for patients who may be in their last three months of life who attend or are admitted to hospital in an emergency.

This guide is for acute clinical teams and has a focus on the lens of acute admissions for patients who may be in their last months of life. For some patients an acute hospital may be the most appropriate place of care. For others another setting or response may be better. We need to deliberately design Accident and Emergency (A&E) departments alongside other services to provide care for people for these groups of patients. The approach sits alongside community led initiatives and ward focused initiatives to improve quality of care for these patients.

Some years ago I nursed and cared for my daughter who had breast cancer. Wanting and needing to provide the best possible care for her I worked hard to ensure that this would happen. However due to fear and lack of knowledge, at the very end of her journey I had to call 999 which resulted in an emergency admission. The ambulance took four hours to arrive and my daughter died in a busy accident and emergency department on a Friday evening. This had a profound and devastating effect on me, leaving me with a heavy burden of guilt even to this day.

Instigating difficult conversation is something that none of us would chose to do, but often it is a necessity. I only wish that I had been brave enough to have spoken to someone earlier. I firmly believe that along with the conversation I would have received the knowledge and support that would have helped me to cope with the desperate situation. Maybe I would have recognised the warning signs and prepared to support my daughter until she died. How much gentler kinder and more dignified it would have been to have had the opportunity to lie beside her. I held her in the beginning and I could have held her to the end.

Roberta Lovick
1. Introduction

A&E departments and supporting acute admission units have been designed to deal with life-threatening emergencies. An increasing proportion of patients attending A&E may be approaching their last months or days of life. Patients with advanced frailty, multiple comorbidities or advanced life-limiting conditions may attend with an exacerbation or other presenting problem such as an infection, respiratory distress or syncope. We can broadly group these patients as presenting with:

- having an underlying health condition but the presenting problem is likely to be fully reversible
- having clinical uncertainty of recovery – there is limited reversibility so patient is at risk of dying despite treatment during this episode care or over the next few months
- being likely to be in last days or hours of life
- palliative care emergency (eg spinal cord compression).

Early recognition of these different groups supported with honest conversations will improve the quality of care and outcomes for patients and those important to them. A greater emphasis on uncertainty will facilitate improvement in communication as an active component of care and when a dual approach to care is appropriate (see Figure 1).

**Figure 1: Clinical uncertainty of recovery**

“Doctors and the public should be reminded of the inherent uncertainty in the pace of disease progression and that reversible and irreversible conditions can coexist and need to be assessed in the context of the patient’s wishes.”


From the AMBER care bundle. Used with permission © Guys and St Thomas’ Foundation Trust
2. How to diagnose the underlying problems for focused improvement

2.1 Identify existing initiatives for alignment to improve care for these groups of patients

Identify existing plans and initiatives to improve care for patients who may be in their last year, months or days of life including palliative and end of life care in the hospital and in the community (Figure 2) and acutely ill-patients and Safer Patient Flow. Box 1 illustrates how Safer Patient Flow can be applied to these groups of patients. Include relevant, specialty-focused improvement plans in the scope for potential alignment (e.g., frailty, cancer, cardio-pulmonary). Ensure improvements reinforce clinical systems and teams being able to provide individualised care for patients and those important to them.

Figure 2: Existing national frameworks for improving palliative and end of life care

The Ambitions for Palliative and End of Life Care

- **01** Each person is seen as an individual
- **02** Each person gets fair access to care
- **03** Maximising comfort and wellbeing
- **04** Care is coordinated
- **05** All staff are prepared to care
- **06** Each community is prepared to help

Transforming end of life care in acute hospitals

**Strategic approach**
- Strategy
- Education and skills
- Measurement and oversight

**Five enablers**
- Advance care planning
- Shared electronic records
- Recognising clinical uncertainty of recovery
- Priorities of care of the dying person
- Rapid discharges
2.2 Diagnose where to prioritise efforts

- Walk through the patient/relative’s journey with ‘fresh eyes’ will identify a number of easily resolved issues with the potential to have a big impact on experience.
- Analyse hospital activity data to identify potential volume of missed opportunities to plan ahead.
- Acute/emergency physicians jointly undertake a casefile review with specialist palliative care to identify clinical system issues for improvement.

2.3 Apply quality improvement methods

Based on the above, set clear aims that are measurable and design improvements that fit in the acute admissions environment. Small scale tests of change allow ideas to be tested prior to wider adoption in busy clinical environments. Focus on what is “doable”. Use ongoing measurement to show that proposed changes to clinical practice are an improvement.

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**Box 1: Applying Safer Flow for patients who may be in their last months/days of life**

**Senior review:** all patients to be reviewed daily by a senior clinician able to co-ordinate the MDT and take responsibility for developing a management plan.

**All patients:** to have honest conversations involving those important to them as appropriate which may include Expected Discharge Date and Clinical Criteria for Discharge, if discharge is appropriate and desired by the patient.

**Flow of patients:** will commence at the earliest opportunity from assessment units to inpatient wards. Wards that receive patients from assessment units will ensure the first patient arrives on the ward by 10am.

**Early discharge and handover:** patients identified for discharge should leave the hospital by 2pm with a safe handover of care to GP/community services. Rapid discharge in line with patient choice and advance care plan may occur in A&E, admission units or inpatient wards.

**Review:** systematic MDT review of patients with extended length of stay (>7 days ‘stranded patients’) includes consideration of clinical uncertainty of recovery.
3. Focused improvement activities

Diagnose the underpinning problems and align with existing initiatives as previously highlighted. Hospital Trusts tend to prioritise improving care in the last days of life or clinical uncertainty of recovery in the acute admissions environment depending on local priorities.

3.1 Involve specialist palliative care and others in improvement activities

- Jointly lead improvements with specialist palliative care.
- Invite these colleagues to understand the existing skills and practice in acute admissions: eg observation, conversations around casefile review or survey staff’s comfort in dealing with issues.
- Have a targeted focus on clinical and communication skills development.
- Work systematically to implement internal professional standards and to minimise variation.
- Daily handover or “White Board Rounds” in acute admissions are a good opportunity to build practical relationships, develop clinical skills and facilitate appropriate specialist input.
- Enable rapid access to both medical and nursing specialist palliative care advice.

3.2 Establish a clear model of care to recognise and proactively manage the care for patients who have clinical uncertainty of recovery

- Clear and early recognition that a patient is at risk of dying despite treatment due to limited reversibility allows a consistent application of standards.
- Patients may have limited reversibility for a number of reasons such as frailty, advanced chronic disease and multiple co-morbidities.
- Establish a model of care for the proactive management of this group of patients that facilitates a dual approach to care.
- Establish standards to include a focus on: understanding patient’s goals of care and communication preferences that build on any pre-existing plans, current plan of care, escalation planning for out-of-hours teams and clear multi-disciplinary team working.
- The standards should reflect the dynamic nature of the situation – with daily review and ongoing communication to patients and those important to them.
- Ensure good handover from acute admissions to specialty ward and primary/community care.
3.3 Recognition and proactive management of care for patients in the last days of life

- Clear recognition that a patient is likely to die allows the consistent application of standards and alignment to your hospital's approach to meeting Priorities of Care for the Dying Person.

- Understand how this can be best delivered in an acute admissions environment.

- For example, one hospital found prompt cards for clinical teams in A&E that covered what needs to be considered and how and when to access support helped consistency.

- Consider the patients' friends and family. For example, one hospital introduced 'Friends Boxes' in the acute floor for family members that included chargers, toothbrushes, etc.

- Establish standards and information for care after death.

3.4 Environment and information

- There are best practice examples of creating a “healing environment” for relatives’ rooms in A&E, bereavement offices, patients receiving palliative care and mortuary suites as part of the King's Fund's project.

- Consider colour palettes ‘calming colours’, side rooms, relative rooms and having accessible room for people to visit their deceased relatives/friends near A&E or the acute admissions unit for sudden deaths and the space feels looked after (eg no clutter).

- Consider information leaflets for families and friends of patients who are seriously ill with practical information about where to get food / drink, any special car parking dispensation, etc.

- Ensure signage is clear for visitors who may be distressed.

Figure 3: Contrasting environments: A&E and a relatives’ room in acute admissions

“I wanted to visit my husband after he died, as usual. Please don’t invite me to view him.”
3.5 Clinical information and handover

- Understand opportunities to improve acute admissions teams’ access to patient’s primary care records and/or pre-existing emergency treatment plans and patients’ preferences.
- Consider within-hospital electronic alerts for patients known to have palliative care needs to support individualised care planning.
- Consider ways to initiate patient-led advance care planning / emergency care treatment plans on discharge and in outpatients.
- Consider ways to avoid A&E for known patients in line with their emergency care treatment plans.
- Consider developing rapid discharge pathways from A&E or acute admissions.
- Consider gathering information around avoidable attendance and unwanted overnight stays for example: admissions from care home; family/ carers unable to cope; delays in discharge due to care home and inpatient hospice capacity. These are opportunities to learn and build a case for change.

Far more recently I was able to stay beside my mother-in-law in the hospital during her last days. The palliative care which she received was wonderful. I was able to assist with some of her care and she was treated with dignity and respect. I feel that I am able to look back without any guilt about her death knowing that it was almost as good as it could have been.

Roberta Lovick

Other resources

- Serious illness conversations
- Priorities for Care for the Dying
- AMBER care bundle for patients who have clinical uncertainty of recovery
- Kings Fund Project on Enhancing the Healing Environment
  » Cambridge University Hospitals NHS Foundation Trust's developments include the Perry Suite, a relatives’ room in acute admissions.