Royal College of Emergency Medicine

Best Practice Toolkit

# RCEM End of Life Care Toolkit

May 2025

# Contents

# Introduction

*Cure sometimes, relieve often, care always.*

*- Hippocrates*

The presumption in Emergency Medicine is that our aim is to prolong life. However, we should also recognise that alleviating suffering and prioritising ***quality*** of life is just as important. Patients may attend the ED at the end of life because of sudden unpredictable events, like a subarachnoid haemorrhage, or more commonly because of a deteriorating chronic disease such as COPD or heart failure **[1]**. In these scenarios, death can be inevitable, so should not be seen as a failure of emergency care, but our paradigm of care needs to change to one actively and holistically focusing on comfort and dignity rather than cure.

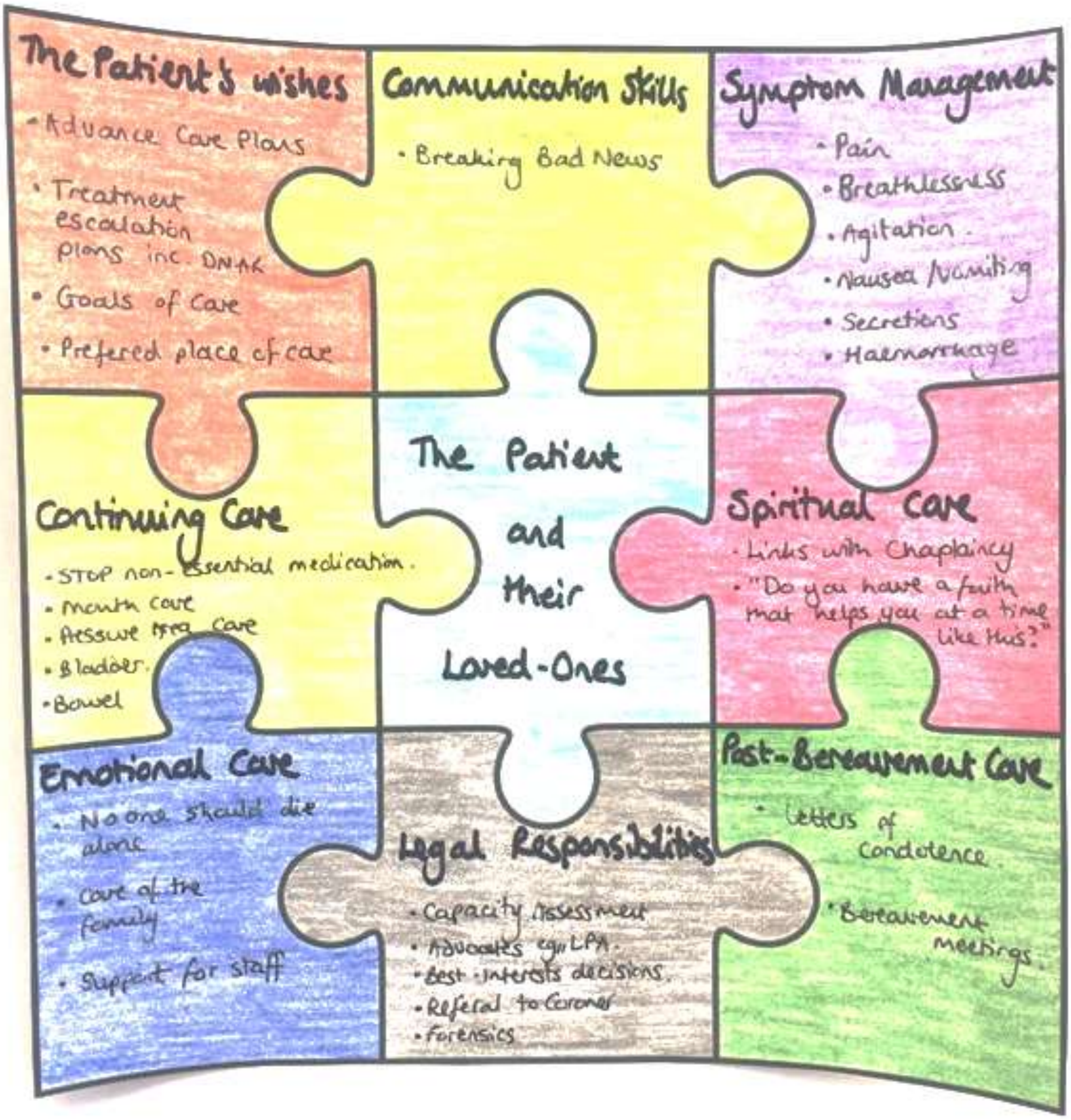
The emergency department provides some unique challenges to the delivery of end-of-life care, not least because of the environment which has been described as volatile, uncertain, complex and chaotic. The need for staff to constantly react to changing circumstances within the department, often of a time critical nature, adds another layer of challenge. With departments under ever increasing pressures due to crowding and long waits for appropriate ward beds, larger numbers of patients are residing in our EDs than ever before, in what is likely to be their final illness. It is especially important when dealing with these patients and their loved ones that we strive to deliver empathetic, person-centred care in an environment which is as calm as possible. While recognising that we must balance the needs of all in the ED, when it comes to dying, we only have one chance to get it right.

Providing end of life care in the ED should go beyond simply managing symptoms and should consider many other equally important facets, some of which will be unique to the ED. These can be represented by the end of life care jigsaw (*see page 5*). The jigsaw has the patient and their loved ones at the centre of the picture, surrounded by eight pieces of equal size and value, all of which should be considered for those identified as dying. This allows us to look holistically at the situation and involve the patient and their loved ones in decisions about their care wherever possible and appropriate, thus ensuring an individualised person-centred plan is achieved.

As emergency physicians, the decisions we make and treatments we initiate will not only set the narrative for what happens in the ED, but also during onward care. We have a key role in making and documenting goals of care and end of life decisions to reduce the likelihood of future harm from inappropriate escalation.

We do not need to manage these patients alone however. Working as part of a team with our Trust's Specialist Palliative Care Team, Spiritual Leaders/Chaplains and Specialist Nurses in Organ Donation means we can streamline end of life communication and delivery to provide compassionate and patient centred care **[2]**. As ED lengths of stay worsen, there is a strengthening argument for Specialist Palliative Care Teams to have dedicated clinicians working at the front door of the hospital **[3, 4]**. This will help ensure early access to their expertise for patients with palliative care needs, disseminate skills through role-modelling and education with ED staff, improved discharge rates to the patients' preferred place of care, length of stay and patient experience **[5-8]**. In their absence, clear local pathways for specialist palliative care input are a minimum requirement.

# End of Life Care Jigsaw



## Recognising when a patient is dying

A patient from a nearby nursing home is brought into the resuscitation room of your ED by emergency ambulance. The pre-hospital assessment indicates that the patient has a very high Early Warning Score (EWS). However, when you look at the patient, she is very frail, unresponsive and has deeply mottled skin. You wonder if this patient is dying, rather than someone in emergent need of resuscitation.

Appreciating the difference between someone who needs end of life care (also known as "care around dying" in Scotland) rather than a "Structured Response to the Deteriorating Patient" is a significant challenge facing the modern Emergency Physician, especially when there is limited information to hand.

It can be tempting simply to default to initiating resuscitation in every case **[9]**. That's what we are good at after all. Tempting too to think that recognising dying is "someone else's job" or that we are just too busy in an already overstretched system to consider end of life care. We do however retain an ethical obligation **[10]** to our patients who might be approaching the end of life, specifically around:

1. Autonomy – respecting the patient's care preferences and maintaining their dignity.
2. Avoiding Harm – when escalating care would confer no benefit.
3. Resource Management – using intensive or high dependency level of care only when it is appropriate to do so.

The key to recognising when a patient is dying is to examine the ***context*** of their presentation. Even in a busy resuscitation room, it doesn't take long to establish a patient's past medical history, their co-morbidities and their dependence (if any) for activities of daily living. Where possible, build a comparison of what they are like now compared to 6 months ago – and we're starting to get an idea of ***trajectory***. Further consideration of specific conditions such as:

1. End-stage organ failure
2. Advanced progressive neuro-degenerative disease
3. Moderate to severe frailty
4. Cancer that is no longer being actively treated

all add to the development of an overall picture for each individual patient.

There is no single factor or criterion to establish the imminence of dying, nor is there a specific "rule-in" test. The context, as described above, allows us to use our clinical judgement to make the right decisions with our patients, provide the comfort measures they might need and avoid the ***consequences*** of inappropriate escalation of care **[11]**. There is mounting evidence to support the validity of this approach. For example, patients with higher Clinical Frailty Scale scores are less to survive emergency laparotomy or to achieve hospital discharge after successful CPR **[12, 13]**.

We are also likely to have frail patients in our departments for long periods. Recognising which ones warrant treatment escalation should they further deteriorate in our care, while also identifying those who need a supportive care approach nearing death, is an increasingly relevant and important part of Emergency Medicine practice.

- The Gold Standards Framework: proactive identification guidance
- Supportive & Palliative Care Indicators Tool
- St Mungo's blog post; why is this dying patient in my Resus Room?

## Communication Skills

*"How are things compared to six months ago?"*

*"Do you have any particular fears about what's happening?"*

Communication skills at the end of life should not be viewed as just breaking bad news; it is also the opportunity to open up conversations about patients' wishes and priorities.

Explaining to the patient and their loved ones what is likely to happen next, by having open and honest conversations, is not about taking away hope, but setting realistic expectations. This can help with letting-go rather than clinging-on, something that will make a "good" death more likely when the time comes.

Patients' self-assessment of prognosis in acute care settings is often poor, yet having a good awareness of illness severity is associated with better informed decisions about care, improved ability to cope with illness and increased acceptance of illness **[14, 15]**.

When death does not appear imminent, but considered likely during this admission, it is helpful to explore illness trajectory with the patient and their loved ones.

The following questions might be used:

> *"What is your understanding of the current situation?"*
>
> *"How are things now compared with 6 months ago?"*
>
> *"Do you have any particular fears about what's happening?"*

Reflecting on the information gained will help with planning how best to proceed. It also means the patient/their loved ones are involved in the decision-making; their wishes can be respected and dignity can be preserved. About 10% of people will not want to have this conversation and we should respect that **[16]**. A substantial majority however will welcome it.

Their answers to such open questions will help you establish their health literacy and therefore pitch your explanations appropriately, using the terminology they use and are familiar with, avoiding medical jargon. It is useful to establish how much they want to know: for example, are they someone who likes all the detail, or just the headlines **[17]**?

Answering the "how long have I/they got?" question is fraught with difficulties though. It is recommended to firstly explore the reasons why this question is being asked: for example, will they still be alive to see an important event like the birth of their grandchild, or the arrival of a loved one enroute from a distant location? Rather than giving specific predictions, use ranges: hours to days, days to weeks or weeks to months.

When sharing unwelcome news, we should be prepared for, and acknowledge, emotion.

*"I can see you're shocked at the news. I wish things were different too."*

Our responses should be non-judgemental, as we cannot know or fully understand their feelings, personal history or the relationships within the family. Not all will be positive.

Our brains are programmed to be disproportionately upset when we lose things – this is a cognitive bias known as loss aversion. With this in mind, we should phrase our conversations about goals of care, treatment options and resuscitation status in ways that do not play to this bias (see CPR Decisions).

## Managing uncertainty

*"The situation is serious; your mum is sick enough that she may die."*

A more common scenario in Emergency Medicine is to be presented with a patient whose recovery is uncertain, for example frail older adults with sepsis or exacerbations of COPD. We recognise that there is a significant chance that they may not survive, but the situation has some potential for reversibility and is not without hope. In these circumstances we should acknowledge the uncertainty in discussions with the patient and their loved ones and involve them in decision making about their future. Our language needs to be clear and thus avoid euphemisms; the phase "sick enough to die" is a simple and unambiguous way to convey the seriousness of a situation **[18]**.

An "I hope… and also I worry" structure to sharing uncertain news is another tool that allows emergency physicians to convey the potential for poor prognosis in an empathetic way without taking away hope **[15]**.

For example:

> *"You have a very serious chest infection. I can see from the blood tests we took from your wrist that your body is struggling to cope. I hope that the antibiotics will work, and you will recover, but I also worry that you are much more unwell than last time you had this, and are so sick that you might die.*
>
> *[Pause]*
>
> *I would like to make sure we understand what you would want if things were to get worse; if we were to recognise that you were dying."*

The AMBER Care Bundle (*see page 10*) is a useful communication tool used in many hospitals that can allow information to be shared easily between teams and ensure patients and their loved ones are regularly updated when active treatment is still deemed appropriate, yet the outcome uncertain.

## Common Communication Challenges

Challenges to good communication include hearing impairment, language barriers and sharing information with those who have a cognitive impairment.

Simple tools like a portable personal listening device can be transformative for those with older age hearing loss (presbycusis) who do not have a working hearing aid, and are useful to have stocked in the ED. The author used departmental charitable funds to purchase these for her department at a cost of £100-130 (*see links in the next page*).

The gold standard when faced with a language barrier is to use a face-to-face professional interpreter, however the reality of emergency medicine is that the urgency and timing of these necessary conversations may preclude this. A fluent member of clinical staff or telephone interpreter are viable alternatives. Efforts should be made to avoid using family members and friends to interpret, as information may not be conveyed as intended, perhaps in a well-meaning attempt to protect their loved one. However, if a patient's condition is deteriorating rapidly, the clinician may have no option other than to use family or friends and will need to judge the nuance of the situation in front of them. Even if using a member of staff or a professional interpreter, one should bear in mind that local minority communities may be small, and the patient and their family may be known to them. Good practice would be to brief the translator before the conversation takes place to warn them of the context of the discussion and how you would like the translation to work. It is also recommended, when possible, to check-in with them afterwards, as such topics will not be the norm even for professional interpreters.

Vulnerable groups, such as those with a cognitive impairment or learning disability, sometimes receive a poorer standard of care **[19]**. Treatment decisions should be based on the individual's wishes, rather than on blanket assumptions based on the underlying disability or health condition. Accordingly, we must pay particular attention as to how we communicate, and be receptive to both verbal and non-verbal cues. Involving their loved ones and carers will help us understand how they take in information and express themselves, so we are best able to identify their needs and wishes **[20]**. Having information available in accessible easy read formats can support discussions, as can involving specialists such as a Learning Disabilities Nurse or Dementia Liaison Nurse.

Breaking bad news over the telephone should be avoided as we lose the subtleties of facial expression and body language. If unavoidable, check if it's a good time to talk: where are they? Is anyone with them? Use short sentences at a slower pace and check understanding frequently; just as they cannot see your body language, you cannot see theirs. Using pauses to give the listener time to digest the information is just as important as it would be in a face-to-face scenario, however it can be difficult to show you are still attentive and present during periods of silence. Phrases such as:

> *"I can hear how upset you are at this news; I am just going to give you some time. I am right here on the phone, let me know when you are ready, and we can talk about the next steps."*

may be helpful to allow these necessary pauses.

- Evidence Based Advice for difficult conversations (Covid-19)
- REDMAP communication tools
- REDMAP: care planning in the last days of life
- Communicating terrible news: St Emlyn's blog post
- The AMBER Care bundle
- RNID Devices to make conversations clearer
- SPICT: Talking with people by phone
- Dying Matters: talking about death and dying to someone with dementia
- Caring for people with learning disabilities at the end of life
- Northamptonshire Easy Read Advanced Care Plan (NHFT)

# Respecting the Patient's Wishes

*"What do I need to know about you as a person, to be able to care for you best today?"*

*"Given all that has been happening to you and your health, what are your thoughts about what might lie ahead and how you would like to be cared for and treated?"*

We should firstly ask the patient what their wishes are, involving any family members if the patient agrees. This conversation leads on from sharing our perspective on the patient's current illness and possible adverse prognosis to now include goals of care, appropriateness of escalating treatments and exploring where they would prefer to be cared for.

## Goals of care

> *"Given this situation I want to hear more about what's important to her, what worries she would have if she could talk to us, what hopes she would have and what made life meaningful for her, so that we can create a plan that honours her wishes* [21]*."*

A plan of care most appropriate to the patient as an individual, that identifies and addresses the key issues most important to them, should be agreed. Some patients may prioritise extending life at all costs; others instead want comfort to be the priority; another group may want a balance of the two. Their goals may include elements of any of the domains of end of life care, such as communication, psychological, spiritual, cultural (including dignity), practical (pets, young family members) and social needs. Specific examples might be along the lines of "control my pain" or perhaps "get home as soon as practical" and can be nuanced: while one patient may want maximal pain medication, even if it causes significant drowsiness, another might value staying alert even if it comes at the price of tolerable pain.

Our focus is often on medical treatment care goals, but it is important that we hear, document and help to fulfil where possible, other goals of care which a patient feels are more important, while avoiding harmful overtreatment. Phrasing the discussion around what treatments might work, which ones won't work, and which might actually cause harm can be helpful.

If we feel that the patient is dying or is likely to die during this current hospital attendance, we should document this clearly.

If a patient has previously completed a ReSPECT form (from the Resuscitation Council UK), or similar, which contains personalised but not legally binding recommendations for a person's clinical care in the event of an emergency, it can help guide this discussion. However, a patient may have changed their mind or altered their priorities since the form was completed, so its content should be explored again.

## Escalation of treatment

A decision regarding an appropriate escalation of treatment may also be necessary; this should take into account the proposed benefits and be balanced against potential burdens of treatment, the patient's capacity to recover and the patient's values and wishes **[22]**.

For this to take place, an understanding of the patient's pre-existing conditions, baseline health and an assessment for the presence and degree of frailty is necessary. The Clinical Frailty Score is a useful tool as part of building up this picture, however a frailty score number by itself cannot determine whether escalation of treatment is appropriate, and an individualised assessment of frailty is required **[23]**. It should not be used in patients with stable long-term conditions (for example cerebral palsy), learning disabilities or autism.

If it would be inappropriate to admit the patient to the Intensive Care Unit then this should be documented. In some cases, transfer to a High Dependency Unit may also be inappropriate, particularly if this meant being subjected to treatments which were unlikely to be of benefit to the patient, and in fact cause distress.

Making and documenting these decisions in the ED means that the patient is less likely to come to harm on the wards due to inappropriate escalation.

Excellent communication skills are required. Instead of focusing the conversation on the various treatments a patient will **not** be getting, focus on the interventions that you **will** put your energy into, for example symptom control and dignity. Instead of "there is nothing more we can do", try:

> *"I am sorry to tell you that your wife is deteriorating despite our treatment.*
>
> *She is dying.*
>
> *[Pause]*
>
> *I think it is time we change our focus of care and now concentrate on ensuring she is comfortable and is not distressed or in pain."*

## CPR Decisions

If a patient is deteriorating rapidly, time may not allow for a wide-ranging conversation around goals of care, or for a patient's primary treating team to attend for individualised discussions around treatment and cardiopulmonary resuscitation (CPR) risk-benefit, which would be ideal. Instead, time pressures mean we, as emergency physicians, must often focus exclusively on whether CPR will be performed in the event of a (potentially imminent) cardiac arrest. We occasionally resort to graphic language around broken ribs or injuries caused by CPR to truncate a resuscitation discussion with family members if we feel it would offer no realistic prospect of success.

Instead, it is more effective to frame this CPR discussion within an abbreviated overview of a patient's prognosis and our opinion on realistic treatment goals and escalation limits. Again, using positive language to outline what treatments we ***will*** do and what ***will*** work, as well as phrases such as "allowing a natural death" if these treatments fail, can be easier to understand for patients and families.

You could phrase the conversation along these lines:

> *"Your dad's body is already struggling from his heart failure, kidney problems and dementia. This infection is so severe that it has damaged his organs even more. Time is very short, so let's focus all our energy into what we know will help him – antibiotics, some intravenous fluids and pain relief as he's very uncomfortable.*
>
> *If his heart stops though, it would be the final blow. CPR will not work, and we must protect him from any treatment that we know won't help him."*

If patients or families want more detailed information around CPR, explaining that it is just a first aid treatment to buy time, rather than a cure in itself, can be helpful. As with any treatment, it has risks that include committing a patient to uncomfortable investigations and treatments or dependence on a ventilator, without achieving meaningful recovery. In fact, it may prolong and remove dignity from dying.

We should not use time pressures or risk of causing distress as excuses to avoid having this conversation (though they might slightly delay it). Engaging patients and/or family members on this topic is a legal requirement, and failure to do so has been described as maladministration leading to a breach of patient rights [19]. However ultimately, while it is important that a patient's and family members' views are heard and taken into account, the final **decision** about whether to initiate CPR in the event of a cardiac arrest is a **clinical one**. Patients cannot insist that CPR is performed if a clinician feels it wouldn't work. Neither can family members insist that CPR is performed. If there is significant disagreement with a clinician's view that CPR should not be performed, it can be helpful to get a second opinion from another senior clinician.

Try also to avoid giving the unintentional impression that you are asking the family's permission, or need them to decide, not to resuscitate their loved one. The decision on whether to perform CPR is not theirs to make. Even when they are in complete agreement that CPR would be inappropriate, it can leave them with the feeling that they were somehow *responsible* for their loved one's death – no matter how peaceful, inevitable or appropriate that death may have been.

Using the terms "futile" and "ceilings of care" in these discussions can also be counterproductive as they may inadvertently convey a sense of abandonment, withdrawal of care or giving up, rather than the clinician's intention to energetically redirect efforts towards treatments and interventions that are likely to be effective and appropriate. A DNACPR order has come to symbolise for the public a general "ceiling of care" rather than a documented discussion about a very focused first aid treatment, eroding public trust in DNACPR conversations generally [19]. It is important we don't reinforce this impression in the language we use.

Note also that a "Do Not Resuscitate" or DNACPR order only relates specifically to CPR in the event of cardiac arrest. It does not proscribe / limit any other procedure or intervention, so on its own fails to address other important end of life issues and care needs.

## Preferred place of care

Someone's preferred place of care should also be considered. Very few people want to die in hospital and in certain circumstances, albeit a minority of cases for our ED population, we may be able to fulfil their wishes. Every ED should know how to access their local hospice and community palliative care team for those few patients that may be stable enough to transfer out of the hospital environment.

## Patients who lack capacity

*"If your mum could talk to me now, what would she tell me she wanted?"*

If the patient is unable to communicate their wishes, or lacks capacity, we should try and establish if any formal advance care planning (also known as future care planning in Scotland) has taken place. This can include a variety of documents:

- Advance statement / statement of wishes: general preferences around treatment and care, or nomination of a named spokesperson. While it can provide a useful guide, it is *not* legally binding.
- Advance directive / advance decision to refuse treatment / "living will": lists specific treatment which a patient does not wish to receive in the event of losing capacity. This *is* legally binding.
- Lasting Power of Attorney for Health and Welfare: an individual nominated by the patient while they had capacity, to make legally binding treatment decisions on their behalf after they lose capacity. The exact wording of the document determines what treatment decisions the attorney can make (but could include decisions on life sustaining treatment).
- Context-specific treatment recommendations: may include emergency care or treatment plans, treatment escalation plans and decisions about CPR. A variety of forms can be used to record this information, such as the ReSPECT form, or other documentation held by the patient's GP / care home or the Electronic Palliative Care Coordination System (EPaCCS).

If a patient is deemed to have lost capacity to make a decision about medical treatment, and none of these documents have been completed, we must make decisions in their ***best interests.*** This is underpinned by appropriate legal frameworks across the UK: in England and Wales, the Mental Capacity Act (2005, and amended in 2019), in Scotland, the Adults With Incapacity Act (2000), and in Northern Ireland, the Mental Capacity Act (2016). To do this, we will need to speak to family members where possible to understand who the patient is as a person and what their priorities and preferences would be. However, the senior clinician responsible for the patient's care must ultimately make treatment decisions following the best interests principle.

## Organ and Tissue Donation

One "end of life wish" that many of us have considered, discussed, and hopefully formally recorded, is whether we would want to be an organ/tissue donor after we have died. Consideration of organ/tissue donation should be a routine part of end of life care in the ED, not simply to help those outside of our care awaiting vital organs, but as a way of honouring the end of life wishes of the patient in front of us.

Organ donation legislation varies across the UK. In England, Wales, Scotland, Northern Ireland, Guernsey and Jersey, there is a system of deemed consent/authorisation for organ donation. This means there is an understanding that all adults agree to become organ donors when they die, unless they have made it known that they do not wish to donate. In the Isle of Man there is an opt-in system through the NHS Organ Donor Register and patients sharing their decision with their family **[24]**.

The opportunity to donate organs directly from the ED is uncommon, as most donors die on an Intensive Care Unit. For any patient with an advanced airway in situ (endotracheal tube or supraglottic device) for whom a decision has been made to withdraw life-sustaining treatment, a discussion should be held with the Specialist Nurse in Organ Donation (SNOD). They will consider suitability for donation and see if they have recorded their wishes on the NHS Organ Donor Register. If the patient would be an appropriate candidate, a joint approach with a SNOD should be made to the loved ones. This discussion should not normally be held without their expertise on hand to support.

Unlike organ donation, almost everyone can donate tissues after death. Tissues such as tendons, skin, corneas and heart valves can be life transforming to recipients. They can be retrieved up to 24-48 hours after death. Discussing and providing information about tissue donation should be a normal part of post bereavement care. The National Referral Centre (0800 432 0559) can offer guidance about individual referrals and support departments with relevant resources.

- Treatment Escalation Plan – NHS Lanarkshire (*see Appendix A*)
- Respect Form
- Organ Donation: identification and referral guide
- GMC guidance on DNACPR Decision making
- BMA Guidance on Best Interests Decision Making
- RCEM Learning: DNA CPR in the ED

# Symptom Management

At the end of life there can be troubling and distressing symptoms, 90% of which we are able to alleviate with simple measures and treatments [25].

Patients with cognitive impairment may not be able to describe their symptoms. Utilising insights from those who know the person best, documents such as hospital passports, pain assessment tools (such as the Abbey Pain Scale), and of course our own clinical examination will help us identify and act on distressing symptoms.

## Non-pharmacological techniques

### Breathlessness

- Airflow: The feeling of air moving over the face can provide great relief, so opening a window or introducing a fan to blow air towards the patient's face can be refreshing. Fans, however, should be avoided in certain infectious diseases because of the risk of dispersing infectious droplets.
- Bedside breathing exercises: with pursed lips, exhaling from the mouth for twice as long as inhaling [26].

> *"Breathe in through your nose and count 1-2. Purse your lips, breathe out through the mouth and count 1-2-3-4."*

- Positioning: sitting up makes breathing easier as it avoids pushing against abdominal contents. If lying down is preferred, position so the "good" lung is up to improve ventilation.

### Acute Haemorrhage

Using dark coloured towels to absorb blood can reduce the visual and psychological impact on the patient and any family present. The presence of a calm and reassuring healthcare professional should not be underestimated, so a member of staff should stay with the patient [27]. In the event of severe distress, there may be a role for "crisis dose midazolam" (*see page 18*) to help rapidly relieve anxiety and agitation. Direct pressure (with dressings soaked in topical agents such as adrenaline or tranexamic acid) and gentle suctioning are options, depending on the site of bleeding.

### Agitation

Nurse in a calm, quiet, low stimulation environment. Look for and address causes of pain or distress, such as a full bladder, full rectum or wet bed. Playing someone's favourite music through a relative's smart phone can have a soothing and calming effect.

### Respiratory Secretions

Repositioning may settle the noise of un-cleared secretions, as can gentle suction to the oropharynx. Secretions are rarely troublesome to the patient themselves; simple reassurance can go a long way in alleviating the family's distress to reassure them that their loved one is not choking.

### Pain

Explanations to facilitate understanding of the nature of the pain and the nature and expectations of treatment often allow patients to cope better [28]. Covering open wounds or sores can provide relief, as does splinting fractures and providing distraction.

### Nausea & vomiting

Assess for likely causes of nausea and vomiting. These might include medication side effects, biochemical disturbances (e.g. hypercalcaemia), raised intracranial pressure, ileus or obstruction. Consider whether these are reversible before commencing pharmacological management with anti-emetics.

## Pharmacological therapies

Most Trusts will have easy to navigate algorithms for common symptoms such as pain, breathlessness and agitation that can be incorporated into ED care. These symptoms should be anticipated, and appropriate prescriptions made early so nursing staff are able to treat symptoms as they arise and not have to wait for a clinician who can prescribe. If more than three PRN doses are needed in a 24-hour period, a subcutaneous infusion via a syringe pump would be beneficial.

**Anticipatory Medication example**

- ➢ **MORPHINE** 2mg s/c, hourly PRN – for pain and / or breathlessness in an opioid naive patient with eGFR >30 ml/min/1.73 $m^2$.
- ➢ **MIDAZOLAM** 2mg s/c, hourly PRN – for anxiety / agitation
- ➢ **HYOSCINE BUTYLBROMIDE** 20mg s/c, maximum of 120mg in 24hrs – for secretions.
- ➢ **LEVOMEPROMAZINE** 2.5mg (two point five) s/c, 12 hourly PRN – for nausea
- ➢ **HALOPERIDOL** 2mg s/c, 12 hourly PRN for agitation / delirium.

### Patients on long term opioids

Alternative anticipatory regimens will be needed in those already on long term opioids as they will have developed drug tolerance. To calculate an appropriate PRN dose for someone already on long term opioids, use 1/6th of their total dose in 24 hours. For example, if a patient is taking morphine modified-release 30mg twice a day - the PRN dose is 60 divided by 6 = 10mg when required. If three or more PRNs are needed per day, a review of pain management is needed with specialist input from the palliative care team to consider up-titration of background analgesia or an alternative regimen.

### Renal and hepatic impairment

Patients known to have renal or hepatic impairment will require individualised anticipatory regimens due to potential accumulation of metabolites and impaired metabolism. Common substitutions for morphine in renal impairment would be oxycodone (eGFR 10-30 ml/min/1.73 $m^2$) and alfentanil (eGFR <10 ml/min/1.73 $m^2$). In these circumstances advice from the local Specialist Palliative Care Team is recommended. An example of a prescribing regimen for renal impairment is included in the links below but should not replace specialist input if available.

### Nausea and Vomiting

Management of nausea and vomiting in palliative care often involves the use of low dose antipsychotic medication, which can feel unfamiliar to standard ED practice. These agents act centrally, have broader coverage of the nausea and vomiting centres and are long acting.

If a definitive cause of this very distressing symptom can be targeted by a specific agent, a more nuanced approach should be taken. For example, if there is raised intracranial pressure, steroids would be appropriate. Vomiting caused by bowel obstruction can be palliated using hyoscine butylbromide or, if symptoms do not improve, octreotide. This should be done under the direction of the specialist palliative care team.

### Crisis dose midazolam

In UK hospices it is common practice to prescribe "crisis dose midazolam" (10mg IM) as an anticipatory medication in case of seizures or to relieve anxiety rapidly in catastrophic haemorrhage. This means nursing teams do not have to wait for an off-site on-call doctor in such emergencies to provide rapid relief of distressing symptoms **[27]**. The appropriateness of this in the ED will depend on the experience of the nursing staff and the availability of prescribing clinicians to attend a patient rapidly in such a situation.

### Prescribing in Parkinson's Disease

Haloperidol, levomepromazine and metoclopramide should be avoided in patients with Parkinson's disease or Lewy body dementia because of the anti-dopaminergic effects exacerbating their parkinsonian symptoms. Alternatives for the management of delirium are benzodiazepines, and for nausea/vomiting domperidone or ondansetron **[21]**. Early input from a Parkinson's specialist nurse or doctor, or from the specialist palliative care team, is advised.

### TTOs

In cases where patients have expressed a wish not to spend their last days in hospital, it may be possible to discharge a patient home (or to a care home) from the emergency department. As well as ensuring that the patient will have the appropriate level of family and community support, departments should consider whether they can dispense any anticipatory medication, with the appropriate safeguards, that might be needed, whether 'in-hours' or 'out of hours'.

- Abbey Pain Scale
- Pain Assessment in Advanced Dementia
- BMA "Just in Case" example prescription
- NENC Palliative and End of Life Care Symptom Control Guidelines
- Uncontrolled blood loss – Northampton General Hospital (*see Appendix B*)
- Dose adjustment of anticipatory medication in renal impairment – Somerset

## Continuing Care Needs

If the patient is identified as near the end of life, stop all non-essential medication, blood tests and physiological observations as they are an unnecessary burden.

Essential medication may need to be adjusted in terms of dose and route of administration, especially for conditions such as diabetes, Parkinson's disease and epilepsy. Early involvement of experts such as the specialist palliative care Team should be sought (*see links below for examples of medication regimens*).

Food and drinks should be offered if a patient is awake enough to swallow, though appetite is normally lost as death approaches. Thirst may be troublesome, so oral fluids can offer relief, and clinically assisted hydration can be considered (intravenous or subcutaneous) if the oral route does not relive their symptoms. Spending time with family members, to explain the loss of appetite and thirst as death approaches, may help to allay anxiety that their loved one is 'dying of thirst'. A dry mouth is a common and distressing problem which is easy to remedy with basic mouth care interventions. The Taste for Pleasure campaign (*see below*) advocates using a patient's favourite drink for mouth-care; a simple intervention that can make care personalised. The ED may not have stocks of the patient's favourite tipple, but the hospital's specialist palliative care team might. Families are often keen to help and feel useful, so may be able to bring something in from home or go to a nearby shop.

Assess bladder and bowel dysfunction, as they can be easily ameliorated causes of distress.

As length of stay in ED increases, attention to skin integrity is ever more important. Pressure sores develop quickly, especially in the frail. They can cause significant pain and therefore should not be neglected even in those who are actively dying. The need for regular turns and the use of appropriate mattresses should be assessed and employed as indicated and tolerated.

Continued care and practical support for loved ones should also be considered. The ED catering team should include them when conducting drinks rounds of the department and offer food and snacks as appropriate. Pre-arranged parking permits can be useful to hand out, as hospital parking is a recognised cause of stress to all visitors, especially when they are likely to be in the hospital for extended periods.

- RCN Mouth Care during end of life care including taste for pleasure
- Diabetes UK End of Life Guidance for Diabetes Care 2021
- Oxford University Hospitals Medicines Information Leaflet: Dying with Parkinson's disease
- Parkinson's Disease medication calculator
- Seizure management: Scottish Palliative Care Guidelines

# Spiritual Care

*"Do you have a faith that helps you at a time like this?"*

*"Are there any spiritual rituals or customs you would like to have performed?"*

*"Are there pieces of jewellery or religious objects that should not be touched or removed?"*

Spirituality is an important part of life for many people, and providing spiritual support in death can be just as important to some people as good symptom control. Asking about spiritual needs using questions such as those above should be a routine part of end of life care in the ED. Detailed knowledge or experience of someone's faith or culture, with its associated rituals or traditional imperatives, is less important than a sensitivity to the fact that their needs may be different to our own **[29]**. We should be careful to avoid cultural stereotypes but remain confident that compassion, care and interest in someone's spiritual needs will transcend all faith groups and cultures.

Members of the hospital chaplaincy team are a valuable resource who can support patients and families with pastoral, spiritual and/or religious care **[30]**. Current NHS standards emphasise that chaplaincy care should be available to everyone, without discrimination, and is inclusive of all religions and beliefs. People who do not hold any particular religious affiliation may also require pastoral support in times of crisis, which the chaplaincy team will provide **[30]**.

The core skill of chaplains is the ability to listen to each person's unique story, respecting what matters and is meaningful to that individual. While relationship building, care of the dying, and attending to spiritual distress are traditionally seen as their role, they can help patients identify their goals of care, assist patients and family members through complex decision making, provide connections to further resources and assist with post-bereavement meetings **[31, 32]**.

Chaplains also provide individual support to NHS staff, students and volunteers involved in these situations and contribute more generally to staff wellbeing and resilience initiatives such as post-incident debriefing sessions, meditation and Schwartz Rounds.

Each Emergency Department should make strong links with their hospital's Chaplaincy Team to ensure their diverse skills in supporting patients, families and staff can be fully utilised. Contact numbers should be available to arrange out-of-hours input as necessary.

- Religion or Belief: a practical guide for the NHS Pages 29-31

# Emotional Care

*No one should die alone*

Proactive management of end of life care is essential for patients and their families. This may involve the use of side-rooms as well as increased frequency of checks. For some with troubling symptoms that are being actively managed, this may involve multiple checks each hour; for those with more stable symptoms, every few hours. Ask about worries or fears, taking time to listen and respond.

Many loved-ones need to feel helpful and to know their contribution is valued; involving them in tasks such as mouth care or hydration can be beneficial to all **[33]**. Others may see this type of task as a burden, so no expectations should be placed on the family; a simple invitation so they know they are welcome to be involved if they and their loved one would like is sufficient.

For those without family present, effort should be made for a member of staff to sit with them so they are not alone. Given the pressures in EM, this may mean seeking help from outside the ED and asking for a member of staff to be released from other less acute areas of the hospital to sit with a dying patient. Resources such as video conferencing can be used to facilitate patients and families seeing and speaking to each other if circumstances prevent them being together in person.

Providing loved ones with keepsakes such as fingerprints, a print-out of the ECG (heart beat in a bottle) or locks of hair, are often well received by families **[34]**. Like all aspects of care, this should be discussed with individuals beforehand, as for some, well intended actions such as providing a lock of hair may not be culturally or spiritually appropriate.

Talking with and supporting children after a death brings its own unique challenges. Without open discussions, children can develop fears and misunderstandings. Using age appropriate language to be clear and direct is important. Children understand words very literally, so euphemisms can cause confusion. They often ask practical questions instead of talking about their feelings as they process what has happened. Children are observed to jump in and out of “puddles of grief” to protect themselves from overwhelming feelings: going from extreme emotions of sadness or anger to playing normally then back again. In sudden deaths, families will often keep youngsters away from the ED and will explain what has happened themselves. Having resources to signpost them to can be most helpful (*see below*). If there is an opportunity for children to visit a loved one who is dying, support from the specialist palliative care team may be sought for their expertise in managing such situations and their practical resources, for example creating a memory box.

When caring for those who are dying and who have died, we need to turn off our “fix-it” mentality and recognise the value in moving from “doing” to “being”. Instead of being task focused, we need to be present and bear witness, giving emotional support and space for the patient and their family to grieve [35]. It has been observed that after commencing a nurse-led care plan for end of life care, families can feel abandoned by clinicians [36]. Regular reviews and check-ins are valued and can be built into shift handovers, so patients and families know who their clinicians are and shows that even if we cannot cure, it does not mean we cannot care.

Displaying humanity and empathy are key behaviours; being able to embrace the patient's experience or walking in another person's shoes is considered vital to good patient experience. These situations often raise challenges to even the most experienced clinicians; having to control their own feelings and recognising the need to 'step back' and reflect [37]. A technique called The PAUSE (Promoting Acknowledgement, Unity and Sympathy at the End of life) can be a useful tool at the end of an unsuccessful resuscitation to show respect for the life lost and help staff transition to their next tasks [38]. It is a short period of silence at the time of a patient's death shared by the team at the bedside:

> *"I would like to take a moment to honour [patient's name] and the staff. For those who would like to stay, we'll take a moment of silence to acknowledge [name], their death, and our care for them.*
>
> *(Moment of silence)*
>
> *May [name] rest in peace.*
>
> *I thank you all for your hard work in this case and for your care."*

The toll of providing care and bearing witness to such events means that emotional support must be available to staff themselves. We must be cognisant that debriefs and time-outs may be beneficial if we and our colleagues find ourselves distressed, especially if there are similarities with our own personal circumstances or history. Staff should know what mechanisms are in place to support them if they find themselves in difficulty. Networks of psychological peer support delivered by staff trained in the Trauma Risk Management (TRiM) model have been found to be helpful in NHS Trusts to support staff who have experienced traumatic events [39]. The cost of training a member of staff as a TRiM practitioner is equivalent to the cost of a life support course, with both face-to-face and remote courses available from a number of providers.

- Sudden: a charity to support those after a sudden death
- Dying matters: talking with children about death (link available to printable leaflet)
- Child bereavement UK: Puddle jumping animation
- Support for Families Bereaved by Suicide (Support after Suicide Partnership)
- Debrief Toolkit: A guide for staff – Royal Derby Hospital. Includes information about The PAUSE.
- Psychological first aid – NHS Scotland

# Legal Responsibilities

In our routine ED practice, we work within the framework of various pieces of legislation applicable to our jurisdiction (*see Respecting the Patient's Wishes above*).

We will also be familiar with assessing capacity for a specific decision and how to make a best interests decision in the absence of an appointed attorney (*see RCEM's Mental Capacity Act in Emergency Medicine Practice Best Practice Guideline – link below*). This is especially relevant for those who are at the end of life.

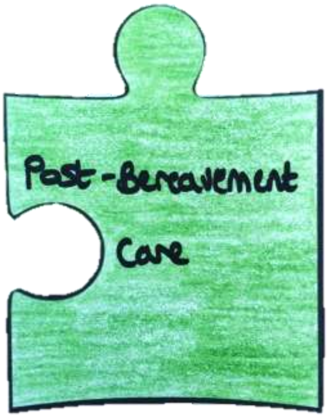
We must seek out and be respectful of wishes that have already been put in place by our patients (for example Advance Decisions to Refuse Treatment).

After a patient has died, we also have specific legal responsibilities pertaining to referrals to the Medical Examiner, the Coroner or Procurator Fiscal.

Finally, in the ED we also face situations less familiar to those working in other palliative care settings, specifically the preservation of evidence in forensic cases. These systems and recommendations will vary depending on local legislation, forensic pathology services and police requirements.

- RCEM: Mental Capacity Act in Emergency Medicine Practice (2017)
- Guidance on Coronial Referrals
- Guidance on completion Medical Certificate Cause of Death (MCCD)
- Reporting Deaths to the Procurator Fiscal

# Post-Bereavement Care



Bereavement meetings are offered by many EDs, where families are invited to return to meet senior clinicians as an opportunity to ask questions or seek clarification on events.

It may be that information was not available on the day their loved one died, or that information was provided but the family were not able to take it in due to the distress of the situation. A number of methods have been adopted to offer this invitation; letters sent to the next-of-kin 4-6 weeks after the death has been shown to be a successful format **[40]**. Whilst there may be a low response rate to these invitations, each one has the potential to make a difference by the expression of care that is conveyed **[29]**.

Reviewing deaths as part of departmental Morbidity and Mortality Meetings is a useful learning opportunity and should be routine for all deaths in the ED. For potential topics, see Audit Standards.

- Bereavement meeting SOP and Condolence Letter template – Northampton General Hospital (see Appendix C)
- Best_Practice_Guideline_Mortality_Reviews_in_the_Emergency_Department_V1.pdf

## Environment

It is well established that the noise and busyness of the ED is a challenge in providing a suitable environment to care for someone at the end of life [41]. Providing a private space to care for the patient and their loved ones, as well as hold sensitive and confidential discussions, has never been more challenging.

The ideal model would be for a dedicated private cubicle, large enough for additional comfortable chairs for loved ones to be at the bedside and decorated in a calming colour to feel less like a clinical space. This would preferably be co-located with a separate relatives' room with toilets and drinks making facilities [42]. Funding for such renovations was provided for the author's ED by the Trust's Charitable Funds.

The reality of the current NHS estate means that for many EDs, such facilities are aspirational. If so, prioritising these patients for a cubicle with a door as opposed to a curtain will help block out excess noise and provide more privacy. Ensuring monitors are either removed or placed into silent/privacy mode will reduce unnecessary noise. Florence Nightingale used music to provide a peaceful environment [43]; we too can introduce music into our clinical spaces, for example by utilising a loved one's smart phone or with the loan of a departmental tablet to play someone's favourite music using free apps such as YouTube.

Having a dedicated trolly stocked with relevant end of life care resources has proved a useful adaptation for those without a dedicated facility in the ED, allowing specialist equipment to be taken to the bedside wherever that might be in the department. Stocking it with relevant documentation, clinical guidelines, consumables for syringe pumps and items for nursing care, allows all the relevant tools to be in one place. This is not only efficient for busy staff, but also reported by users to be a useful visual symbol, reminding all that their focus has changed from lifesaving to comfort care, promoting feelings of compassion and care for the patient and family [44].

## Additional training resources

- RCEM Learning: Multiple learning resources from podcasts to on-line learning modules covering palliative and end of life care topics.
- End of Life Essentials: Australian e-learning modules covering many relevant end of life topics, including a specific module on end of life care in the ED.
- End of Life Care for All: An e-learning library on a variety of end of life care topics hosted by eLfH. This includes modules specifically designed for emergency care and out of hours staff.
- NHS Scotland: Effective Communication for Healthcare workshops.
- Royal College of Nursing: End of Life care and wellbeing for the nursing and midwifery workforce.

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## Endorsements

None.

## Review

First published in May 2025.

Usually within three years or sooner if important information becomes available.

## Declaration of Interests

None.

## Disclaimers

The College recognises that patients, their situations, Emergency Departments and staff all vary. This guideline cannot cover all possible scenarios. The ultimate responsibility for the interpretation and application of this guideline, the use of current information and a patient's overall care and wellbeing resides with the treating clinician.

## Research Recommendations

The Royal College of Emergency Medicine has included the optimal delivery of end of life care amongst its top 10 research priorities **[50]**:

> *"How can excellence be achieved in delivering end of life care in the ED? How can patients, families and staff be best supported with handling bereavement issues?"*

Some specific areas meriting research include:

- The most effective methods of training staff to recognise and appropriately manage patients approaching the end of their lives in the Emergency Department
- The role of, and optimal, criteria-based scores for the recognition of palliative care needs in the Emergency Department
- The role of, and optimal, criteria-based scores for the recognition of the dying patient in the Emergency Department
- The potential for decision support systems or AI to assist clinicians in identifying patients approaching end of life
- How to best design and implement structured, individualised and workable end of life care plans for patients in the ED, including those with communication challenges and cognitive impairment
- The optimal model for delivering palliative in the ED (staff mix, hours of operation, models of joint care, etc.)
- Disparities in the delivery of palliative and end of life care in the ED; race, ethnicity, religion, socio-economic status, underlying disease, cognitive abilities, ED location.
- The impact on ED staff looking after dying patients, including effective wellbeing support for staff

# Audit standards

Various national audits of end of life care have been conducted, such as the National Audit of Care at the End of Life, the National Confidential Enquiry into Patient Outcome and Death and RCEM's Care of Older People in the Emergency Department QIP, which have identified a range of potential quality indicators [45-47]. An emergency department team or trust could incorporate any, or all, of the topics below into local reviews of end of life care provision.

Some of these topics could also be incorporated into routine mortality reviews of emergency department deaths, both to highlight local good practice and ensure care prior to death is of a suitable standard (*see RCEM's Mortality Reviews in the Emergency Department Best Practice Guideline for more details*).

## Individual patient care

- Timely recognition
    - Time from arrival to recognition of dying
    - Time from recognition of dying to death
- Communication
    - Was patient told they were dying?
    - Were family members told patient was dying?
    - Were patient's goals of care discussed and an individualised care plan arranged?
        - If so, was patient's preferred place of care documented?
    - Were needs of those important to the patient discussed with them?
- Coordination
    - Did the patient have a pre-existing advanced care plan?
        - If so, was it available in a timely way, and was this attendance consistent with the wishes documented therein?
        - If a decision had been made previously that the patient was not for transfer to hospital, but were transferred anyway, how did that decision change?
    - Did the patient have a named 'care coordinator' within the hospital (especially if known underlying condition such as dementia, heart failure, cancer or liver disease)?
        - If so, was it possible to contact this individual?
    - Was the patient reviewed by a specialist palliative care team member during their time in the ED?
        - If not, should they have been, and why weren't they?
- Treatment
    - Were patient's current symptoms reviewed and appropriately treated?
    - Were anticipatory medications prescribed?
        - If so, were they individualised as necessary?
    - Was an appropriate treatment escalation plan/DNACPR decision discussed and documented?
- After death
    - Was a referral for organ/tissue donation made?
        - If not, should one have been made and why wasn't it?

## Department-level quality indicators

- Proportion of deaths where it was recognised that the patient was dying out of total departmental deaths (expected and unexpected)
- Proportion of patients recognised as dying that had an individualised care plan

## Organisational

- Staffing
  - Is there a departmental lead for end of life care?
  - Is there a named ED link person within the specialist palliative care team?
  - Is there timely access to:
    - Chaplaincy teams?
    - Specialist palliative care team/resources?
    - Hospice and community palliative care pathways to support discharge of people at end of life to their preferred place of death?
- Infrastructure **[48, 49]**
  - A side room, with a door, to allow a quiet and private space to deliver end of life care to patients
  - A relatives' room that is private, quiet, has comfortable chairs/sofa, a phone, drinks and access to outside space
  - A room for the bereaved to sit with their loved one after death
- Training
  - End of life training for clinical staff in the ED covering, but not limited to:
    - Communication skills
    - Mental Capacity legislation
    - Organ and tissue donation
  - Refresher training delivered on a three-yearly basis
- Post bereavement care
  - Is there a mechanism for family members to ask meet with EM clinician and ask follow-up questions in weeks following patient's death?
  - Are hospital systems in place to notify GP & Medical Records Department of a death within 1 working day?

## Governance

- Is there an ED representative on the Trust's Organ Donation Committee?
- Does your department conduct routine mortality reviews on all deaths to retrospectively look at the quality of care of those who die in the ED?
  - If ED attendance was at variance with documented advanced care plan, were the reasons for this variance explored?
- Are potential harms associated with treatment decision making (or lack thereof) discussed at hospital morbidity & mortality reviews?
  - E.g. reviews of cardiac arrest calls; appropriateness of full escalation decisions

# Key words for search

END OF LIFE CARE, PALLIATIVE CARE, BEREAVEMENT, SUDDEN DEATH, DYING, TREATMENT ESCALATION PLAN, DNACPR, CARE AROUND DYING, FUTURE CARE PLANNING, GOALS OF CARE

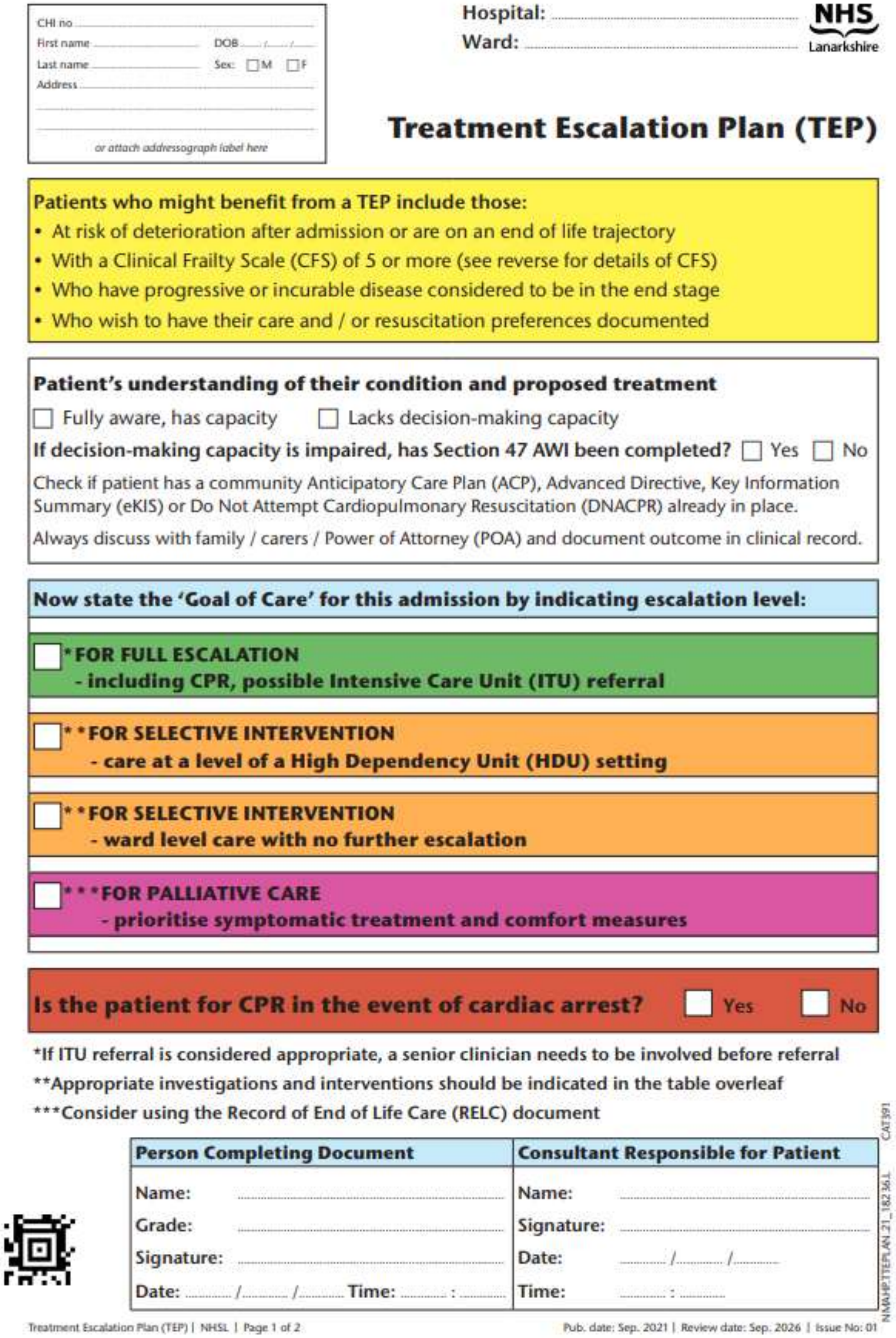
# References

1. Bailey C, Murphy R, Porock D: **Trajectories of end-of-life care in the emergency department**. *Annals of emergency medicine* 2011, **57**(4):362-369.
2. Limehouse WE, Feeser VR, Bookman KJ, Derse A: **A model for emergency department end-of-life communications after acute devastating events--part II: moving from resuscitative to end-of-life or palliative treatment**. *Academic emergency medicine : official journal of the Society for Academic Emergency Medicine* 2012, **19**(11):1300-1308.
3. Barham F, King S, Hawksley J: **133 Palliative care in the emergency department – a scoping review**. *Emergency Medicine Journal* 2020, **37**(12):822-823.
4. Rayner S, Griffiths A, Milward S, Hooper D, Thomas M: **58 Front door palliative care: development of a macmillan specialist palliative care practitioner role in the emergency department of a tertiary hospital in the UK**. *BMJ Supportive & Palliative Care* 2024, **14**(Suppl 2):A29-A30.
5. Murray K, Kerslake S, Specialist Palliative Care Team: **121 Development of a nurse-led Specialist Palliative Care in-reach service to an Emergency Department and assessment areas**. *BMJ Supportive & Palliative Care* 2023, **13**(Suppl 3):A53-A53.
6. Edwards S, Keillor L, Murray K, Kerslake S, Grant J: **112 Specialist palliative and end of life timely intervention project (SPELTIP) on the emergency floor – outcomes from the first 20 weeks**. *BMJ Supportive & Palliative Care* 2021, **11**(Suppl 1):A49-A49.
7. Hall H, Frew K, Armstrong L, Spriggs H, Atkinson K: **P-106 Embedding palliative care in the ED**. *BMJ Supportive & Palliative Care* 2022, **12**(Suppl 2):A48-A49.
8. Shipton S, Purewal G, Ashton Z: **56 Exploring the impact of proactive in-reach by the supportive and palliative care team (SPCT) in the emergency department (ED) of manchester royal infirmary (MRI), a city centre teaching hospital**. *BMJ Supportive & Palliative Care* 2024, **14**(Suppl 2):A29-A29.
9. Cooper E, Sheikh Z, Townend W, Johnson M, Hutchinson A: **Palliative Care in the Emergency Department: A systematic review**. *Emergency Medicine Journal* 2016, **33**(12):919-920.
10. Lightbody CJ, Campbell JN, Herbison GP, Osborne HK, Radley A, Taylor DR: **Impact of a treatment escalation/limitation plan on non-beneficial interventions and harms in patients during their last admission before in-hospital death, using the Structured Judgment Review Method**. *BMJ open* 2018, **8**(10):e024264.
11. Taylor DR, Lightbody CJ, Venn R, Ireland AJ: **Responding to the deteriorating patient: The rationale for treatment escalation plans**. *J R Coll Physicians Edinb* 2022, **52**(2):172-179.
12. Parmar KL, Pearce L, Farrell I, Hewitt J, Moug S: **Influence of frailty in older patients undergoing emergency laparotomy: a UK-based observational study**. *BMJ open* 2017, **7**(10):e017928.
13. Ibitoye SE, Rawlinson S, Cavanagh A, Phillips V, Shipway DJH: **Frailty status predicts futility of cardiopulmonary resuscitation in older adults**. *Age Ageing* 2021, **50**(1):147-152.
14. Mols EM, Haak H, Holland M, Schouten B, Ibsen S, Merten H, Christensen EF, Nanayakkara PWB, Nickel CH, Weichert I *et al*: **Can acutely ill patients predict their outcomes? A scoping review**. *Emergency medicine journal : EMJ* 2024, **41**(6):342-349.
15. Ouchi K, Haimovich A, Bowman J: **Prognostic awareness of seriously ill older adults in the emergency department**. *Emergency medicine journal : EMJ* 2024, **41**(6):350-351.
16. Clark D, Armstrong M, Allan A, Graham F, Carnon A, Isles C: **Imminence of death among hospital inpatients: Prevalent cohort study**. *Palliat Med* 2014, **28**(6):474-479.
17. **Top tips based on NICE guidance care of dying adults in the last days of life (NG31) for GPs and Primary Care Clinicians** [https://www.rcgp.org.uk/getmedia/9716307f-c860-4ebe-a94a-affa3634a28d/Top-tips-LDOL-NICE.pdf]
18. Mannix K: **With the End in Mind: Dying, Death and Wisdom in an Age of Denial**. Glasgow, UK: William Collins; 2017.

19. Parliamentary and Health Service Ombudsman: **End-of-life care: improving ‘do not attempt CPR’ conversations for everyone**. In. Manchester, UK: Parliamentary and Health Service Ombudsman,; 2024.
20. **Delivering high quality end of life care for people who have a learning disability. Resources and tips for commissioners, service providers and health and social care staff.** [https://www.england.nhs.uk/wp-content/uploads/2017/08/delivering-end-of-life-care-for-people-with-learning-disability.pdf]
21. Bell D, Ruttenberg MB, Chai E: **Care of Geriatric Patients with Advanced Illnesses and End-of-Life Needs in the Emergency Department**. *Clin Geriatr Med* 2018, **34**(3):453-467.
22. Bassford C, Griffiths F, Svantesson M, Ryan M, Krucien N, Dale J, Rees S, Rees K, Ignatowicz A, Parsons H *et al*: **Developing an intervention around referral and admissions to intensive care: a mixed-methods study**. In: *Health Services and Delivery Research.* Southampton (UK): National Institute for Health Research; 2019.
23. National Institute for Health and Care Excellence: **COVID-19 rapid guideline: managing COVID-19. NICE guideline [NG191]**. In. London, UK: National Institute for Health and Care Excellence; 2021.
24. **Organ donation laws** [https://www.organdonation.nhs.uk/uk-laws/]
25. Sweeny AL, Alsaba N, Grealish L, May K, Huang YL, Ranse J, Denny KJ, Lukin B, Broadbent A, Burrows E *et al*: **End-of-life care: A retrospective cohort study of older people who died within 48 hours of presentation to the emergency department**. *Emergency medicine Australasia : EMA* 2024, **36**(1):13-23.
26. Prachanukool T, George N, Bowman J, Ito K, Ouchi K: **Best Practices in End of Life and Palliative Care in the Emergency Department**. *Clin Geriatr Med* 2023, **39**(4):575-597.
27. Watson M, Ward S, Vallath N, Wells J, Campbell R: **Catastrophic Bleeds**. In: *Oxford Handbook of Palliative Care 3rd Edition.* Oxford: Oxford University Press; 2019.
28. Bennett M, Forbes K, Faull C: **The principles of pain management**. In: *Handbook of Palliative Care Second edition.* Edited by Faull C, Carte Y, Daniels L. Oxford, UK: Blackwell Publishing; 2005: 116-149.
29. LeBrocq P, Charles A, Chan T, Buchanan M: **Establishing a bereavement program: caring for bereaved families and staff in the emergency department**. *Accid Emerg Nurs* 2003, **11**(2):85-90.
30. **Guidelines for NHS managers on pastoral, spiritual and religious care** [https://www.england.nhs.uk/long-read/nhs-chaplaincy-guidelines-for-nhs-managers-on-pastoral-spiritual-and-religious-care/]
31. Jeuland J, Fitchett G, Schulman-Green D, Kapo J: **Chaplains Working in Palliative Care: Who They Are and What They Do**. *J Palliat Med* 2017, **20**(5):502-508.
32. McCurry I, Jennett P, Oh J, White B, DeLisser HM: **Chaplain Care in the Intensive Care Unit at the End of Life: A Qualitative Analysis**. *Palliat Med Rep* 2021, **2**(1):280-286.
33. Faull C, Nicholson A: **Terminal Care and Dying**. In: *Handbook of Palliative Care 3rd edition.* Edited by Faull C, de Castecker S, Nicholson A, Black F. New Jersey, USA: Wiley-Blackwell; 2012: 295-313.
34. Riegel M, Randall S, Buckley T: **Memory making in end-of-life care in the adult intensive care unit: A scoping review of the research literature**. *Aust Crit Care* 2019, **32**(5):442-447.
35. Bove DG, Rosted E, Prip A, Jellington MO, Timm H, Herling SF: **How to care for the brought in dead and their relatives. A qualitative study protocol based on interpretive description**. *J Adv Nurs* 2020, **76**(7):1794-1802.
36. Davies N, Manthorpe J, Sampson EL, Iliffe S: **After the Liverpool Care Pathway--development of heuristics to guide end of life care for people with dementia: protocol of the ALCP study**. *BMJ open* 2015, **5**(9):e008832.
37. Rawlings D, Devery K, Poole N: **Improving quality in hospital end-of-life care: honest communication, compassion and empathy**. *BMJ Open Qual* 2019, **8**(2):e000669.
38. Welch AA, Esquibel BM, Osterloth KA, Kallies KJ, Fitzsimmons AJ, Waller CJ: **Trauma and Death in the Emergency Department: A Time to PAUSE (Promoting Acknowledgment, Unity, and Sympathy at the End of Life)**. *J Trauma Nurs* 2022, **29**(6):291-297.

39. Flaherty M, O'Neil VE: **Psychological peer support for staff: implementing the Trauma Risk Management model in a hospital setting**. *Nurs Manag (Harrow)* 2022, **29**(1):26-31.
40. Parris RJ, Schlosenberg J, Stanley C, Maurice S, Clarke SF: **Emergency department follow-up of bereaved relatives: an audit of one particular service**. *Emergency medicine journal : EMJ* 2007, **24**(5):339-342.
41. Cooper E, Hutchinson A, Sheikh Z, Taylor P, Townend W, Johnson MJ: **Palliative care in the emergency department: A systematic literature qualitative review and thematic synthesis**. *Palliat Med* 2018, **32**(9):1443-1454.
42. Beckstrand RL, Corbett EM, Macintosh JLB, Luthy KEB, Rasmussen RJ: **Emergency Nurses' Department Design Recommendations for Improved End-of-Life Care**. *Journal of emergency nursing: JEN : official publication of the Emergency Department Nurses Association* 2019, **45**(3):286-294.
43. Zhang Y, Yash Pal R, Tam WSW, Lee A, Ong M, Tiew LH: **Spiritual perspectives of emergency medicine doctors and nurses in caring for end-of-life patients: A mixed-method study**. *Int Emerg Nurs* 2018, **37**:13-22.
44. Robson S, Craswell A: **Experiences of emergency department nurses using palliative care resources and associated tools in the provision of quality care of a dying patient**. *Int J Palliat Nurs* 2022, **28**(10):464-472.
45. **National Audit of Care at the End of Life** [https://www.nacel.nhs.uk/]
46. The National Confidential Enquiry into Patient Outcome and Death: **Planning for the End. A review of the quality of care provided to adult patients towards the end of life.** In. London, UK: Healthcare Quality Improvement Partnership; 2024.
47. **Care of older people in the Emergency Department. National Quality Improvement Programme information pack 2023-2025.** [https://rcem.ac.uk/wp-content/uploads/2024/07/Care_of_Older_People_in_the_ED_QIP_Information_Pack_2023_25_v2.pdf]
48. Design Brief Working Group, NHS Estates: **A place to die with dignity: Creating a supportive environment.** In. London, UK: NHS; 2005.
49. Waller S, Dewar S, Masterson A, Finn H: **Improving Environments for Care at End of Life. Lessons from eight UK pilot programmes.** In. London, UK: The King's Fund; 2008.
50. Cottey L, Shanahan TAG, Gronlund T, Whiting C, Sokunbi M, Carley SD, Smith JE: **Refreshing the emergency medicine research priorities**. *Emergency Medicine Journal* 2023, **40**(9):666-670.

# Appendix 1: Treatment Escalation Plan NHS Lanarkshire



CHI no ............................................
First name ............................ DOB ...... / ...... / ......
Last name ............................ Sex: ☐ M ☐ F
Address ............................................
............................................
............................................
*or attach addressograph label here*

Hospital: ............................................
Ward: ............................................

NHS
Lanarkshire

## Treatment Escalation Plan (TEP)

**Patients who might benefit from a TEP include those:**

- At risk of deterioration after admission or are on an end of life trajectory
- With a Clinical Frailty Scale (CFS) of 5 or more (see reverse for details of CFS)
- Who have progressive or incurable disease considered to be in the end stage
- Who wish to have their care and / or resuscitation preferences documented

**Patient's understanding of their condition and proposed treatment**

☐ Fully aware, has capacity ☐ Lacks decision-making capacity

**If decision-making capacity is impaired, has Section 47 AWI been completed?** ☐ Yes ☐ No

Check if patient has a community Anticipatory Care Plan (ACP), Advanced Directive, Key Information Summary (eKIS) or Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) already in place.

Always discuss with family / carers / Power of Attorney (POA) and document outcome in clinical record.

**Now state the 'Goal of Care' for this admission by indicating escalation level:**

☐ ***FOR FULL ESCALATION**
**- including CPR, possible Intensive Care Unit (ITU) referral**

☐ ****FOR SELECTIVE INTERVENTION**
**- care at a level of a High Dependency Unit (HDU) setting**

☐ ****FOR SELECTIVE INTERVENTION**
**- ward level care with no further escalation**

☐ *****FOR PALLIATIVE CARE**
**- prioritise symptomatic treatment and comfort measures**

**Is the patient for CPR in the event of cardiac arrest?** ☐ Yes ☐ No

*If ITU referral is considered appropriate, a senior clinician needs to be involved before referral

**Appropriate investigations and interventions should be indicated in the table overleaf

***Consider using the Record of End of Life Care (RELC) document

| **Person Completing Document** | **Consultant Responsible for Patient** |
|---|---|
| Name: ............................ | Name: ............................ |
| Grade: ............................ | Signature: ............................ |
| Signature: ............................ | Date: ...... / ...... / ...... |
| Date: ...... / ...... / ...... Time: ...... : ...... | Time: ...... : ...... |

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Treatment Escalation Plan (TEP) | NHSL | Page 1 of 2

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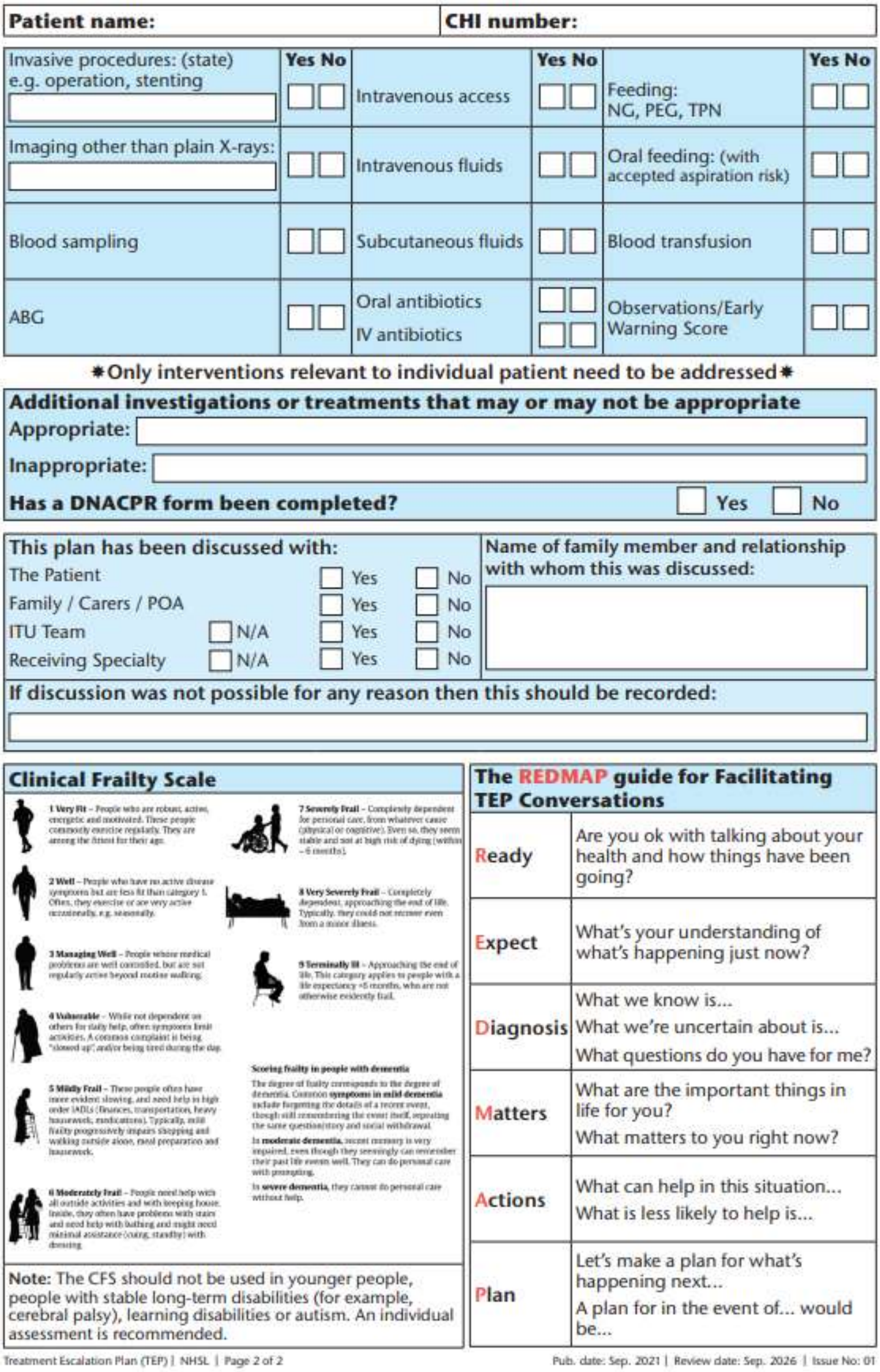

| | |
|---|---|
| **Patient name:** | **CHI number:** |

| | Yes No | | Yes No | | Yes No |
|---|---|---|---|---|---|
| Invasive procedures: (state)<br>e.g. operation, stenting | ☐ ☐ | Intravenous access | ☐ ☐ | Feeding:<br>NG, PEG, TPN | ☐ ☐ |
| Imaging other than plain X-rays: | ☐ ☐ | Intravenous fluids | ☐ ☐ | Oral feeding: (with accepted aspiration risk) | ☐ ☐ |
| Blood sampling | ☐ ☐ | Subcutaneous fluids | ☐ ☐ | Blood transfusion | ☐ ☐ |
| ABG | ☐ ☐ | Oral antibiotics<br>IV antibiotics | ☐ ☐<br>☐ ☐ | Observations/Early Warning Score | ☐ ☐ |

**✱Only interventions relevant to individual patient need to be addressed✱**

**Additional investigations or treatments that may or may not be appropriate**

**Appropriate:**

**Inappropriate:**

**Has a DNACPR form been completed?** ☐ **Yes** ☐ **No**

| **This plan has been discussed with:** | | | |
|---|---|---|---|
| The Patient | | ☐ Yes | ☐ No |
| Family / Carers / POA | | ☐ Yes | ☐ No |
| ITU Team | ☐ N/A | ☐ Yes | ☐ No |
| Receiving Specialty | ☐ N/A | ☐ Yes | ☐ No |

**Name of family member and relationship with whom this was discussed:**

**If discussion was not possible for any reason then this should be recorded:**

## Clinical Frailty Scale

**1 Very Fit** – People who are robust, active, energetic and motivated. These people commonly exercise regularly. They are among the fittest for their age.

**2 Well** – People who have no active disease symptoms but are less fit than category 1. Often, they exercise or are very active occasionally, e.g. seasonally.

**3 Managing Well** – People whose medical problems are well controlled, but are not regularly active beyond routine walking.

**4 Vulnerable** – While not dependent on others for daily help, often symptoms limit activities. A common complaint is being "slowed up", and/or being tired during the day.

**5 Mildly Frail** – These people often have more evident slowing, and need help in high order IADLs (finances, transportation, heavy housework, medications). Typically, mild frailty progressively impairs shopping and walking outside alone, meal preparation and housework.

**6 Moderately Frail** – People need help with all outside activities and with keeping house. Inside, they often have problems with stairs and need help with bathing and might need minimal assistance (cuing, standby) with dressing.

**7 Severely Frail** – Completely dependent for personal care, from whatever cause (physical or cognitive). Even so, they seem stable and not at high risk of dying (within ~6 months).

**8 Very Severely Frail** – Completely dependent, approaching the end of life. Typically, they could not recover even from a minor illness.

**9 Terminally Ill** – Approaching the end of life. This category applies to people with a life expectancy <6 months, who are not otherwise evidently frail.

**Scoring frailty in people with dementia**

The degree of frailty corresponds to the degree of dementia. Common **symptoms in mild dementia** include forgetting the details of a recent event, though still remembering the event itself, repeating the same question/story and social withdrawal.

In **moderate dementia**, recent memory is very impaired, even though they seemingly can remember their past life events well. They can do personal care with prompting.

In **severe dementia**, they cannot do personal care without help.

**Note:** The CFS should not be used in younger people, people with stable long-term disabilities (for example, cerebral palsy), learning disabilities or autism. An individual assessment is recommended.

## The REDMAP guide for Facilitating TEP Conversations

| | |
|---|---|
| **R**eady | Are you ok with talking about your health and how things have been going? |
| **E**xpect | What's your understanding of what's happening just now? |
| **D**iagnosis | What we know is...<br>What we're uncertain about is...<br>What questions do you have for me? |
| **M**atters | What are the important things in life for you?<br>What matters to you right now? |
| **A**ctions | What can help in this situation...<br>What is less likely to help is... |
| **P**lan | Let's make a plan for what's happening next...<br>A plan for in the event of... would be... |

Treatment Escalation Plan (TEP) | NHSL | Page 2 of 2

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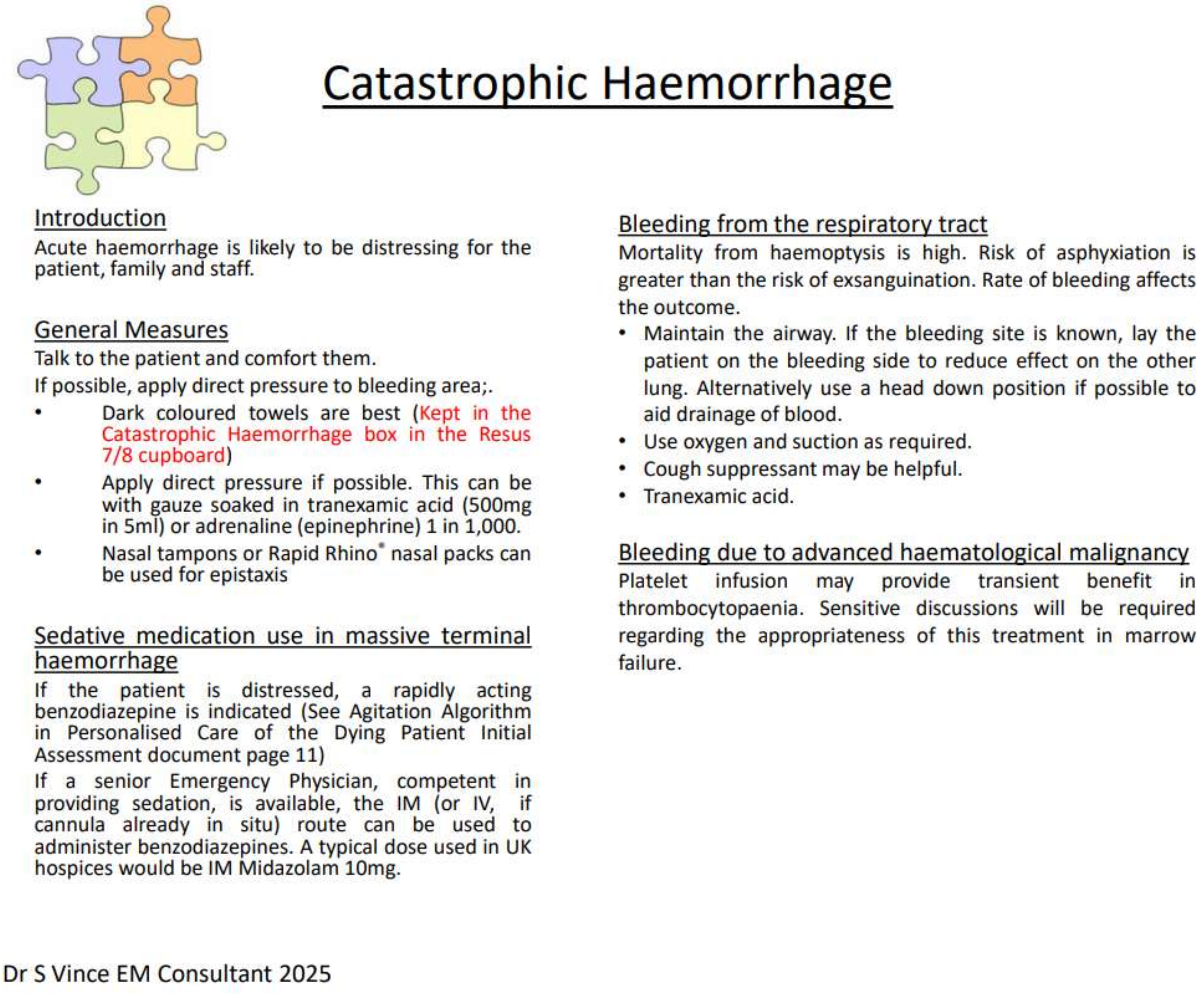
# Appendix 2: Catastrophic Haemorrhage Northampton General Hospital



## Catastrophic Haemorrhage

### Introduction

Acute haemorrhage is likely to be distressing for the patient, family and staff.

### General Measures

Talk to the patient and comfort them.

If possible, apply direct pressure to bleeding area;.

- Dark coloured towels are best (Kept in the Catastrophic Haemorrhage box in the Resus 7/8 cupboard)
- Apply direct pressure if possible. This can be with gauze soaked in tranexamic acid (500mg in 5ml) or adrenaline (epinephrine) 1 in 1,000.
- Nasal tampons or Rapid Rhino® nasal packs can be used for epistaxis

### Sedative medication use in massive terminal haemorrhage

If the patient is distressed, a rapidly acting benzodiazepine is indicated (See Agitation Algorithm in Personalised Care of the Dying Patient Initial Assessment document page 11)

If a senior Emergency Physician, competent in providing sedation, is available, the IM (or IV, if cannula already in situ) route can be used to administer benzodiazepines. A typical dose used in UK hospices would be IM Midazolam 10mg.

### Bleeding from the respiratory tract

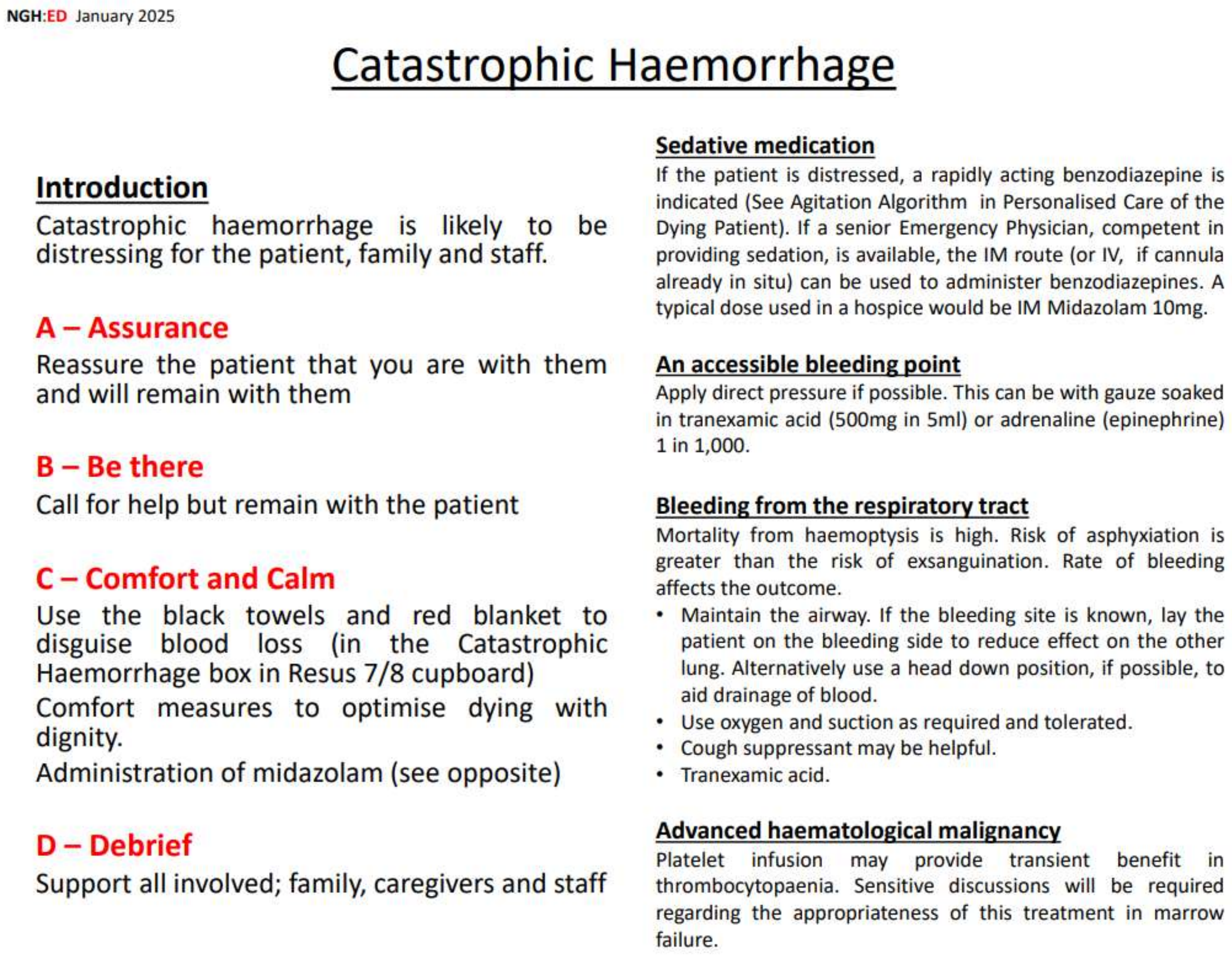
Mortality from haemoptysis is high. Risk of asphyxiation is greater than the risk of exsanguination. Rate of bleeding affects the outcome.

- Maintain the airway. If the bleeding site is known, lay the patient on the bleeding side to reduce effect on the other lung. Alternatively use a head down position if possible to aid drainage of blood.
- Use oxygen and suction as required.
- Cough suppressant may be helpful.
- Tranexamic acid.

### Bleeding due to advanced haematological malignancy

Platelet infusion may provide transient benefit in thrombocytopaenia. Sensitive discussions will be required regarding the appropriateness of this treatment in marrow failure.

Dr S Vince EM Consultant 2025



NGH:ED January 2025

# Catastrophic Haemorrhage

## Introduction

Catastrophic haemorrhage is likely to be distressing for the patient, family and staff.

## A – Assurance

Reassure the patient that you are with them and will remain with them

## B – Be there

Call for help but remain with the patient

## C – Comfort and Calm

Use the black towels and red blanket to disguise blood loss (in the Catastrophic Haemorrhage box in Resus 7/8 cupboard)

Comfort measures to optimise dying with dignity.

Administration of midazolam (see opposite)

## D – Debrief

Support all involved; family, caregivers and staff

### Sedative medication

If the patient is distressed, a rapidly acting benzodiazepine is indicated (See Agitation Algorithm in Personalised Care of the Dying Patient). If a senior Emergency Physician, competent in providing sedation, is available, the IM route (or IV, if cannula already in situ) can be used to administer benzodiazepines. A typical dose used in a hospice would be IM Midazolam 10mg.

### An accessible bleeding point

Apply direct pressure if possible. This can be with gauze soaked in tranexamic acid (500mg in 5ml) or adrenaline (epinephrine) 1 in 1,000.

### Bleeding from the respiratory tract

Mortality from haemoptysis is high. Risk of asphyxiation is greater than the risk of exsanguination. Rate of bleeding affects the outcome.

- Maintain the airway. If the bleeding site is known, lay the patient on the bleeding side to reduce effect on the other lung. Alternatively use a head down position, if possible, to aid drainage of blood.
- Use oxygen and suction as required and tolerated.
- Cough suppressant may be helpful.
- Tranexamic acid.

### Advanced haematological malignancy

Platelet infusion may provide transient benefit in thrombocytopaenia. Sensitive discussions will be required regarding the appropriateness of this treatment in marrow failure.

## Appendix 3: Bereavement meeting Standard Operating Procedure and Condolence Letter template Northampton General Hospital

**NGH:ED**

# SOP for Post Bereavement Meetings

## Admin Team

- Each week obtain the list of ED deaths occurring in the same week in the previous month from Symphony e-audit
- Request Complaints and PALS search their data-bases for any relevant investigations. If there are any relevant investigations this must be discussed with Dr X, as a bereavement meeting may not be appropriate.
- Send out a personalised letter to NOK (getting details from Symphony or Evelyn Centre). If a relative phones in requesting an appointment:
    - Explain appointments are available on Fridays after 11am and ascertain which Friday would suit them best and offer to phone them back with an appointment time and venue.
    - Ask if there is anything specific they wished to discuss with the doctor.
- After receiving a request for a meeting, establish if either X, Y or Z are on duty on the preferred Friday and have non-clinical time they can offer for an appointment.
- Once the date and time is established, book the interview room in the Evelyn Centre.
- Write or phone the relatives with the appointment time and venue.
- Contact the Coroner's Office for the post mortem results.
- Request the hospital notes for the doctor conducting the interview.

## Clinical Team

Prior to the meeting – read the Symphony notes, the Post Mortem results and hospital notes if needed.

Find out from admin team if any specific things were highlighted by the family for discussion.

On the day of the interview, establish if a Band 6 or 7 nurse is free to attend the meeting. If this is impossible, a member of the bereavement team e.g. may be able to attend.

After the meeting complete the database

## Letter Template

I am writing to you on behalf of the Northampton General Hospital Emergency Department (ED) to extend our condolences to you and your family at this difficult time following the death of [name].

We appreciate that deaths occurring in the ED are often sudden or unexpected and that in the weeks following such a loss, families may find they have unanswered questions about the care their loved one received. The ED is an unfamiliar and stressful environment so, given your loss on [date], you may not have had the opportunity to ask questions or felt able to take in the information that was available. We would therefore like to offer you the opportunity to meet with one of our senior doctors in order to discuss [name]'s care here and ask questions. If you would like to make an appointment please contact the ED Secretary on XXXXXX.

May I again offer you our sympathies.

Yours sincerely

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