Care in the last hours to days of life

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Abstract

Care of the dying is a fundamental part of a clinician's role. When somebody is dying, rather than there being 'nothing more that can be done', there is a lot is consider and explore to support and facilitate a 'good death'. Key aspects of end-of-life care should incorporate the following (TERMINAL): a Team diagnosis of dying; Exploring the dying person's priorities and preferences (~~of the dying person~~ e.g. what is important to them, religious or spiritual wishes or beliefs); Resuscitation (and the role of a DNAR form); Medicines and monitoring (rational~~isi~~izing oral medication, use of a ~~a~~ subcutaneous infusion for essential medication, rational~~isa~~ization of observations and blood tests); Involving those important to the person (and exploring their needs and concerns); Nutrition and hydration; Anticipatory prescribing (the 'four~~4~~ A's': analgesic, anxiolytic, anti-secretory, antiemetic)~~,~~; and~~,~~ Location (how high a priority is place of death for this person?). Communication, and communication skills~~,~~ are critically important in end~~-~~-of-~~-~~life care, and the uncertainty around diagnosing dying can be conveyed by explaining that you are concerned that the person is now "~~"~~sick enough to die~~"~~" in the next hours to days.

Keywords

Cardiopulmonary resuscitation; communication; dying; palliative care; terminal care

Key points

- Care in the last hours to days of life is an important aspect of clinical practice; there is only one chance to get it right
- The TERMINAL mnemonic encapsulates key aspects of ~~end of life~~end-of-life care: ~~(~~Team diagnosis; Explore priorities/preferences; Resuscitation; Medicines/monitoring; Involve family/carers; Nutrition/hydration; Anticipatory prescribing; Location~~)~~
- Anticipatory prescribing commonly comprises ~~of~~ the '~~4~~four A's': analgesic; anti~~-~~emetic; anti~~-~~secretory; anxiolytic~~.~~
- When communicating with patients and families, the uncertainty around diagnosing dying can be conveyed by explaining that you are concerned that the person is "~~"~~sick enough to die~~"~~" in the next "~~"~~hours to days~~"~~.~~.~~

Introduction

Care of the dying person is a challenging but also rewarding part of a clinician's role. Around half of people in the UK die in hospital~~s~~, and ~~patients~~ individuals in the last year of life are admitted to hospital an average of 3.5 times in that last year.[1,2] Knowledge, understanding~~,~~ and holistic application of the key principles of ~~end-of-life~~end-of-life care in the last hours to days of life is therefore fundamental for clinicians in any specialty.

The Leadership Alliance for the Care of Dying People identifies five priorities for care of the dying person in their report *One Chance to Get in Right*:[3]

1. This possibility (that the person may have a prognosis of only hours to days) is recognised and communicated clearly, decisions made and actions taken in accordance with the person's needs and wishes, and these are regularly reviewed and decisions revised accordingly.
2. Sensitive communication takes place between staff and the dying person, and those identified as important to them.
3. The dying person, and those identified as important to them, are involved in decisions about treatment and care to the extent that the dying person wants.
4. The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.
5. An individual plan of care, which includes food and drink, symptom control and psychological, social and spiritual support, is agreed, co-ordinated and delivered with compassion.

~~End-of-life~~End-of-life care should be individual~~ise~~ized to the dying person and those important to them, and~~,~~ recorded in an 'individual~~ise~~ized care plan'~~) (.[3]).~~ When someone is dying, rather than there being ~~"~~"nothing more that can be done~~"~~", there is therefore a lot to consider and explore to achieve the aim of a ~~"~~"good death~~"~~': we only have once chance to get it right. Communication (and communication skills) is central to multiple important facets of good ~~end-of-life~~end-of-life care. The mnemonic TERMINAL can be useful as an aide memoir to ensure a holistic and comprehensive individual~~ise~~ized approach to the care of the dying person (~~Figure~~ Table 1).

Recogn~~isi~~izing dying – team diagnosis~~:~~

Recogni~~si~~izing that someone could be dying is the fundamental to achieving high standards of ~~end-of-life~~end-of-life care, yet 'diagnosing dying' can be difficult and there is no 'diagnostic test'. A number of clinical tools to predict death have been developed, but overall none of these ~~are~~ is consistently more accurate than the clinical judgement of experienced healthcare professionals. There is no consistent evidence that one health~~-~~care professional group is any more accurate than any others in predicting dying; however, ~~but~~ there is some evidence that the accuracy of predicting death is better when the prognosis is made by a multidisciplinary team rather than ~~by~~ an individual healthcare professional (see Further reading)~~-~~.

The possibility that a person is dying can be explored by asking three questions:

~~a)~~ ~~•~~Are there clinical features that are compatible with indicating a person is dying? (~~for example~~e.g.~~,~~ the person has become bedbound, reduced consciousness, difficulty physically taking oral medication, reduced oral intake and only managing sips of fluid)~~; and,~~

~~b)~~ ~~•~~Have reversible causes of the~~ir~~ person's deterioration been considered? (~~this~~ includ~~es~~ing where potentially reversible factors have been treated but the person has continued to deteriorate despite this, e.g. continued deterioration despite treatment of malignant hypercalcaemia in someone with advanced cancer, or~~,~~ continued deterioration despite treatment of aspiration pneumonia in someone with advanced dementia)~~; and,~~

~~c)~~ ~~•~~Does the person have an underlying diagnosis that already suggested they had a limited overall prognosis? (e.g. an advanced progressive life~~-~~limiting illness such as advanced heart failure, chronic obstructive pulmonary disease~~COPD~~, dementia, frailty).

~~-~~When communicating with families and those important to the dying person, the uncertainty around diagnosing dying can be conveyed by explaining you are concerned that the person is now 'sick enough to die' within the next hours to days.[1,2] Vague euphemisms cause confusion in communication to patients and those important to them (e.g. ~~"~~"we need to make them comfortable now~~"~~", ~~or~~ ~~"~~"the prognosis is guarded~~"~~"), as does avoiding using the word~~s~~ ~~"~~"dying~~"~~". An initial

conversation is not sufficient; there should be regular and effective communication with those important to the dying person.

Talking about dying – exploring the person's priorities and preferences and involving those important to them

Honest, informed and timely conversations are critical, but these conversations can feel challenging for the patients, family and health care professionals involved. Poor, or lack of, communication underlies a significant proportion of complaints around end of life end-of-life care.[3] There are a number of recognised barriers to these conversations, for example seeing death as a medical failure. Yet if these conversations are not broached, opportunities are missed for the person to express their wishes at the end of life and for those close to them to be prepared that death may might be imminent. Not everybody will wants to have these discussions, yet unless clinicians create the opportunity for these discussions within their conversations with patients, what, and in how much detail, the person wishes to know will remain unknown. A number of frameworks and toolkits exist to support clinicians with these conversations, for example *Talking About Dying: How To Begin Honest Conversations About what Lies Ahead*.[2]

Resuscitation

Decisions around resuscitation are ultimately a clinical one, followingafter informed conversations with patients and family. (54). The presumption is always to explore whether the patient individuals wishes to discuss resuscitation, unless it is felt that the conversation in itself will cause 'psychological harm'. (54).

For patients engaging with discussions around this subject, the conversation should centre around the explanation that cardiorespiratory arrest is the final stage of dying, and that cardiopulmonary resuscitation (CPR) is unlikely to be successful when someone is dying from an advanced and irreversible or incurable illness. (2). For example, the success of cardiopulmonary resuscitationCPR is <1% for people with end stage advanced cancer. (2). Discussions around resuscitation may be best placed in the context of overall conversations about the person's illness and deteriorating condition.[1]

Medicines and monitoring

When the healthcare team have identified that a person is "sick enough to die", it is important to consider the need and appropriateness for ongoingcontinuing monitoring (e.g. regular observations, the use of the NEWS (National Early Warning Score), MUST (Malnutrition Universal Screening Tool) and further blood tests or other investigations). This should be made clear in a treatment escalation plan (TEP) or the equivalent. It is also important to review all existing medication, and identify medicines that are no longer appropriate (e.g. statins) and an alternative route of giving oral medication that remains essential if the patient is no longer able to swallow medication consistently (e.g. medication for pain, breathlessness, nausea and other symptoms).

A continuous subcutaneous infusion ('syringe driver') provides an alternative to the oral route in this context; and different medicines for different symptoms can be combined in one subcutaneous infusion, which can be given in the community or in the inpatient setting. Conversions commonly used to change from oral to subcutaneous opioids are shown in Table 12. If the person has An existing transdermal opioid patch (e.g. fentanyl, buprenorphine), this should generally be continued rather than being 'converted' it into a syringe driver dose, unless there is a concern that the person is not absorbing the patch.[5] (6).

Most antiemetics can be given via a syringe driver, with the dose used often being the same as the total oral dose (e.g. metoclopramide 10 mg three times a day orally given as metoclopramide 30 mg over 24 hours in a syringe driver). In theory haloperidol and levomepromazine require a lower dose when converted to a continuous subcutaneous infusion (although in practice a 1:1 conversion may can be used).[5] (6).

If the patient is taking an oral anti-convulsant, it may be possible to give this via a syringe driver depending on which one drug is being used (e.g. sodium valproate and levetiracetam can be given via a syringe driver); however, or midazolam to replace another anti-convulsants which can't cannot be given via this route. It is important to clarify the indication (e.g. sodium valproate can also be used as a mood stabiliseizer or neuropathic adjuvant analgesic) and strength of indication (e.g.

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how often have seizures occurred, how definite was the original seizure diagnosis, what type of seizures has the person had?) to be able to clinically assess how imperative it is to continue this medication at this point.

Local specialist palliative care advice can be sought for support around converting medication into a syringe driver~~,~~ and for combinations of medicines that are or are n~~i~~ot compatible in a syringe driver.

Anticipatory prescribing

Common symptoms ~~which may~~that can occur in the last hours to days of life (pain~~;~~, breathlessness~~;~~, nausea/vomiting~~;~~, delirium~~;~~, agitation~~;~~, respiratory secretions) can be pre-empted by ensuring the person has medication prescribed in anticipation should these symptoms occur.~~:~~ These are described as the 'four 'A's'. ~~There are:~~ an analgesic, anxiolytic, anti-secretory and anti-emetic agents.~~(6).~~[5]

~~-~~ **Analgesics**, for example ~~e.g.~~ morphine 2.5 mg as required subcutaneously (the dose and choice of opioid may depend on whether the patient is already on oral opioids, and other factors such as renal impairment, where oxycodone or fentanyl may be preferable). Seek advice from ~~your~~ the local palliative care team when needed. The opioid should be prescribed for ~~"~~pain or breathlessness~~"~~' as the indication so that nursing staff can give it for either or both symptoms.

~~-~~

Anxiolytics, for example ~~e.g.~~ midazolam 2.5 mg as required subcutaneously (for severe agitation/distress; it~~,~~ ~~may~~ can also be used as a muscle relaxant for certain types of pain~~,~~ and/or for breathlessness associated with severe anxiety). An anti-psychotic agent such as haloperidol 1.5 mg or levomepromazine 12.5 mg ~~may~~ can also be used, especially where there is agitation associated with delirium. Always consider potential causes of agitation ~~which~~ that could~~may~~ respond to an alternative measure, for example ~~e.g.~~ urinary retention, faecal impaction, pain~~-~~, thirst~~,~~ or poor positioning.

~~-~~

Anti-secretory agents, for example ~~e.g.~~ hyoscine hydrobromide 400 micrograms~~mgc~~ as required (maximum 2.4 mg in 24 hours). This is for retained upper airway secretions ('~~"~~death rattle~~"~~'), which can occur in around half of dying patients.[5] ~~(6).~~ Other drugs such as glycopyr**r**on~~n~~ium or hyoscine butylbromide can also be used. Note that whichever is used, they predominately reduce the development of further secretions ~~developing~~ and should therefore be introduced sooner rather than later when indicated. Repositioning ~~in itself may~~can help, and suctioning should generally avoided unless it is evident that the secretions are causing the person distress. An explanation to the family, particularly if the patient appears comfortable despite the '~~"~~rattle~~"~~', is key.

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Anti-emetics~~-~~, for example ~~e.g.~~ levomepromazine 6.25 mg as required subcutaneously.

Nutrition and hydration

There is currently insufficient evidence to draw firm conclusions on the impact of clinically assisted hydration in the last days of life. ~~(5).~~[4] ~~The~~ General Medical Council guidance recogn~~ise~~ize**s** that the benefit, burdens and risks associated with artificial hydration and nutrition are not clear cut, acknowledging that patients ~~may~~ can experience distressing symptoms because of inadequate hydration (or nutrition), but also that attempts to meet the perceived need for hydration (and nutrition) ~~may~~ can in itself cause avoidable suffering. ~~(5).~~[4] An assessment for each patient is therefore required. In either case it is not likely to be appropriate to make a patient 'nil by mouth', and small amounts of food and fluid should continue to be offered if the person continues to have periods when they are more awake/alert and ~~is~~ asking to eat or drink.

~~-~~Attention to detail with regular mouth care (to keep the mouth moist and clean) is important, and the family can be empowered to support the healthcare team with this (e.g. using a soft toothbrush for the person to suck small amounts of fluid from or assisting them with a straw if they ~~able and~~are asking to drink and are able to do so).

Location

Commented [CW2]: AQ: to keep the order of letters in the acronym, can Anticipatory prescribing go after 'Nutriton'?

There is sometimes an over-emphasis on the place of death, and an assumption that patients do not want to die in hospital. Research has shown that the place of death per se, is often not the highest priority for the dying person. (2). However, there will be some people who will have a strong preference to be at home at the end of life, and the practicalities of this should be explored.

Some practical aspects such as syringe drivers, a hospital bed, and anticipatory medication can be relatively straightforward to implement within a patient's own home. However, in most places it will is not be possible to replicate the 24-hour hands-on care of an inpatient setting within a person's own home; thus, and there may need to be a discussion with the person and those important to them about what their priorities are, and what the practicalities may be for if dying at home.

KEY REFERENCES

1. Royal College of Physicians. Acute care resource: end-of-life care in the acute care setting. Royal College of Physicians; 2021. [accessed 27 Apr 2022] Available from: https://www.rcplondon.ac.uk/projects/outputs/acute-care-resource-end-life-care-acute-care-setting (accessed 27 Apr 2022).
2. Royal College of Physicians. Talking about dying: how to begin honest conversations about what lies ahead. Royal College of Physicians; 2018. [accessed 27 Apr 2022] Available from: https://www.rcplondon.ac.uk/projects/outputs/talking-about-dying-how-begin-honest-conversations-about-what-lies-ahead (accessed 27 Apr 2022).
3. Leadership Alliance for the Care of Dying People. One chance to get it right. Leadership Alliance for the Care of Dying People; 2014. Available from: https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/323188/One_chance_to_get_it_right.pdf
4. General Medical Council. Treatment and care towards the end of life: good practice in decision making. General Medical Council; 2010. [accessed 27 Apr 2022] Available from: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life (accessed 27 Apr 2022).
5. Harris D. Safe and effective prescribing for symptom management in palliative care. *Br J Hosp Med (Lond).* 2019 Dec 2; **80(12):** C184–9. doi: 10.12968/hmed.2019.80.12.C184

ADDITIONAL FURTHER READING

Byw Nawr/NHS Wales. Talk CPR – discuss DNA CPR. Available at http://talkcpr.wales/.

Mannix K. With the end in mind. London: HarperCollins Publishers;, 2019.

Watson M, Armstrong P, Gannon C, et al. Palliative care adult network guidelines. Available at www.book.pallcare.info.

4. White N, Reid F, Vickerstaff V, Harries P, Tomlinson C, Stone P. Imminent death: clinician certainty and accuracy of prognostic predictions. BMJ Supportive & Palliative Care. 10 May 2019 May 10; [accessed 27 Apr 2022] Available from: https://spcare.bmj.com/content/early/2019/05/10/bmjspcare-2018-001761 (accessed 27 Apr 2022).

Commented [CW3]: AQ: please add a date of access for reference 3.

~~Figure~~ Table 1.

Key considerations in holistic ~~end of life~~end-of-life care	
T	**Team diagnosis of dying** Do the healthcare team agree the person is likely to be in the last hours to days of life? Have reversible cause of the deterioration ~~been considered~~, e.g. hypercalcaemia, been considered?
E	**Explore priorities and preferences** What is the person's understanding of their current condition; how much information would they wish to have? Are there opportunities to explore their priorities, wishes and preferences, e.g. tissue donation, religious and spiritual beliefs; what is important to them? Have they previously expressed these wishes formally, e.g. in an advance care plan?
R	**Resuscitation** Has a discussion taken place with the person and those important to them about allowing natural death to occur? Has a ~~DNAR~~ 'Do Not Attempt Resuscitation' form been completed?
M	**Medicines and monitoring** Has oral medication been reviewed and rational~~ise~~ized? ~~Is there~~Does any medication, e.g. opioids, ~~that~~ require~~s~~ conversion into a syringe driver ~~e.g. opioids~~? Is regular recording of vital signs and/or investigations still appropriate?
I	**Involve the family and those important to the person** What is their current understanding? Has someone explained that the team feel the person is "~~-~~dying~~"~~, or "~~-~~sick enough to die~~"~~? What are their needs and concerns?
N	**Nutrition and hydration** Consider on an individual basis as~~:~~ current evidence relating to benefit, harm and burden or artificial hydration/nutrition is not clear cut. Continue to offer oral fluids and diet in small amounts i~~f~~s the patient has periods when they are awake enough and are asking to eat or drink~~.~~
A	**Anticipatory prescribing** Prescribe anticipatory, as required, subcutaneous medication to support prompt management of common symptoms that may occur in the last hours to days of life: the ~~4~~ 'four A's ~~–);~~ Analgesic, Antiemetic, Anti~~-~~secretory, Anxiolytic
L	**Location** How high a priority is place of death for this person and what are their considerations about where they would wish to be cared for?

Table 1:2

Opioid conversion ratios			
From	**To**	**Ratio**	**Example**
Oral morphine	Subcutaneous morphine	Divide by 2	Modified-release oral morphine 40 mg twice daily: convert to morphine 40 mg/24 hours CSCI**
Oral morphine	Subcutaneous diamorphine	Divide by 3	Modified-release oral morphine 30 mg twice daily: convert to diamorphine 20 mg/24 hours CSCI**
Oral oxycodone	Subcutaneous oxycodone[a]*	Divide by 1.5	Modified-release oxycodone 30 mg twice daily: convert to oxycodone 40 mg/24 hours CSCI**

*[a]The recommended conversion ratios vary; and the ratios used in the Palliative Care Adult Network Guidelines opioid calculator (www.book.pallcare.info) are given here.
**CSCI, continuous subcutaneous infusion.

TEST YOURSELF

To test your knowledge based on the article you have just read, please complete the questions below. The answers can be found at the end of the issue or online here.

Question 1

A 71-year-old man with metastatic pancreatic cancer hads deteriorated despite treating recurrent malignant hypercalcaemia. The clinical team feltel he mightay now have a prognosis of hours to days. He wais bed bound, semi-conscious and no longer able to manage oral medication. He was usually tookakinges modified-release oral morphine tablets 40 mg 12-hourlytwice daily.

What dose of morphine should now be prescribed in a 24- hour continuous subcutaneous infusion (syringe driver)?

A. 5 mg
B. 25 mg
C. 40 mg
D. 80 mg
E. 120 mg

Correct answer: C.

The conversion from oral morphine to subcutaneous morphine is 0.5 of the total 24-hour oral dose (i.e. 40 mg + 40 mg / 2 = 40 mg). If diamorphine was being used, it would be a third of the total dose. The breakthrough subcutaneous morphine dose for as-required use is usually prescribed as around 1/6th-1/10thone-sixth to one-tenth of the background dose.

Question 2

An 82-year-old woman presented lady with metastatic ovarian cancer has malignant bowel obstruction from metastatic ovarian cancer . The possibility of Ssurgery and other interventions hadve been explored but it had been concluded tothat they were not be feasible. Despite medical management, she wasis continuing to deteriorate rapidly and the clinical team hadve therefore identified that it would be appropriate to prescribe 'just in case' anticipatory symptom control medication (on the 'as-required' part of the prescription chart). A member of the team has prescribed subcutaneous 'as required' injections of morphine, cyclizine, and glycopyronnium but got called away to another patient before they had finished.

What fourth drug, in addition to morphine, cyclizine and glycopyrronnium, should be prescribed? other drug where they also intending to prescribe?

A. Diamorphine
B. Hyoscine hydrobromide
C. Midazolam
D. Levetiracetam
E. Oxycodone

Correct answer: C.midazolam

Anticipatory prescribing for symptom control in end of lifeend-of-life care should include the 'four4 A's': an analgesic (morphine prescribed in this case), an anti-emetic (cyclizine prescribed in this casehere), an anti-secretory agent (for secretions, with glycopyrronnium prescribed in this case), and, and anxiolytic. Midazolam should therefore also be prescribed anticipatorily also.

Question 3

A 68-year-old woman lady with advanced chronic obstructive pulmonary disease (COPD) hads had recurrent admissions in to hospital in the previouslast 6 months and had continueds to progressively deteriorate. The subject of resuscitation has had been broached with her, and she has had indicated she would not wish to be resuscitated; however, but her family feel felt that having a 'Do Not Attempt Resuscitation' (DNAR) form would be 'giving up' on her.

Commented [CW4]: AQ: should this be 'felt that not having'? The meaning isn't quite clear.

Medicoal-legally, whose decision ultimately is the DNAR form in this situation?

A. An independent mental capacity advocate
B. The clinical team
C. The patient
D. The patient or whoever is listed as their next of kin
E. The patient's Lasting Power of Attorney

Correct answer: B.
Ultimately, medicgal-legally, the decision itself as tof whether it is appropriate to offer cardiopulmonary resuscitation is a clinical one. However, the patient's views and wishes of the patient should always be taken into consideration, and the decision should be discussed with them unless it is deemed that the discussion itself could cause psychological harm. In this situation discussion with the family should include clarification about the reasons for the 'Do Not Attempt Resuscitation' (DNAR) form (e.g. unlikelihood of success, and risk of long-term sequelae even if the resuscitation is successful) and, importantly, clarification for them that the DNAR form only applies only to resuscitation and does n'ot necessarily preclude any other medical treatment (e.g. active management of a pneumonia with intravenous antibiotics for example).