

Assessment of the Dying Phase and After Death

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Health Education England

Inspected and rated

Outstanding ☆



LIVERPOOL HEART AND CHEST HOSPITAL
ENTRANCE

By the end of this session you will be able to:

Recognise the clues which signal the start of the dying phase

Describe the critical aspects of assessment of a dying person, including the patient's family and carers

Outline how to assess and meet the immediate needs of the deceased patient and bereaved people after death

Recognise the potential impact of the death on professional carers



Recognising that a patient has entered the dying phase is one of the biggest challenges in end of life care. Their needs should be re-evaluated as well as the needs of their families and friends.

Holistic assessments allow the team to deliver individualised care taking into account patient's wishes and avoiding inappropriate active management.

You also need to be able to recognise when death has occurred. See session – Symptom Management / Recognising the Dying Phase, Last Days of Life and Verifying Death, which is about recognising the onset of dying and when death occurs.

Following any death the immediate needs of the deceased person and the bereaved have to be recognised and met. An accurate and rapid assessment of the overall situation will help to identify fraught and extreme emotions which require particularly sensitive handling.



To improve care for dying people and meet the needs of their relatives and carers, the Leadership Alliance for the Care of Dying People - a coalition of organisations – has set clear expectations for standards of care for dying.

The Alliance has agreed five priorities that all health and care staff should focus on when caring for dying patients.



Fig 1 Five priorities for the care of dying people

The first step in delivering good end of life care is recognising that a patient has entered the dying phase. There are no precise ways of telling accurately when a patient is in the last days of life and it can sometimes be difficult to diagnose dying. For this reason, it is important to take into consideration as much information as possible about the patient's background and current situation.

Question: What factors may indicate a patient is entering the last few weeks to days of life?

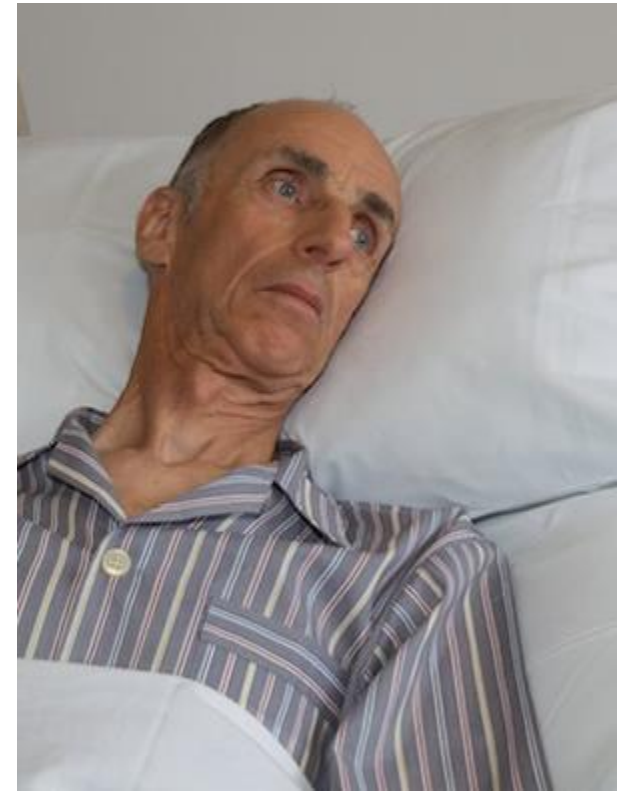
Answer: In the context of advanced disease and if there is no identifiable reversible cause for deterioration, indicators that signal the last few weeks to days of life include:

- Increasing weakness and fatigue
- Deteriorating functional ability
- Bedridden or only able to get out of bed with great difficulty
- Reduction in food and fluid intake
- Difficulty swallowing
- Changes in cognition

Question: What signs may indicate a patient is entering the last few days to hours of life?

Answer: In the final days to hours of life the following signs will probably be present:

- Reduced level of consciousness
- Noisy rattling breathing
- Irregular respiration (Cheyne-Stokes pattern)
- Respiration with mandibular movement
- Cyanosis and mottling of upper extremities
- Relaxation of the facial muscles with the nose often becoming more prominent
- Decreased urine output



Holistic Assessment in the Dying Phase

Introduction

Patients in the dying phase require careful symptom assessment and management. Symptoms in the dying phase must be reviewed regularly in what can be a rapidly changing clinical picture.

Unrelieved symptoms can cause distress to:

The patient

Relatives and carers

Professionals in the multidisciplinary team

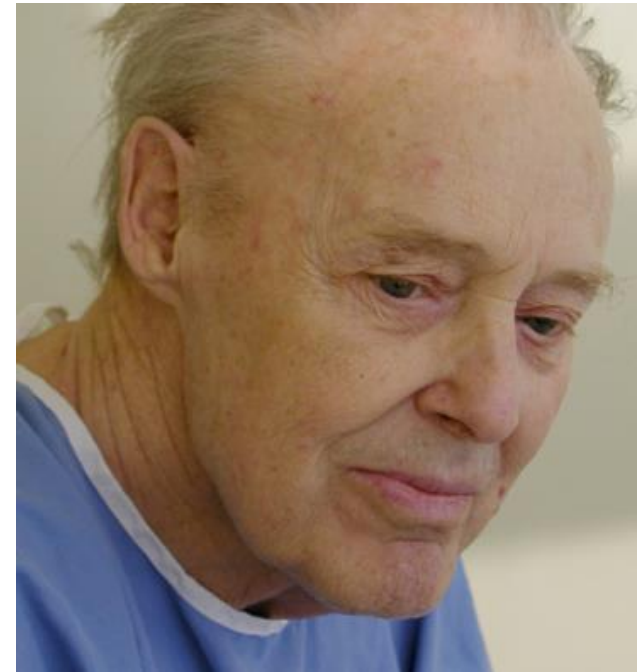
In the last few weeks and days of life, increasing weakness, progressive disease and changes in cognition mean that the process of assessment can be more challenging.

The appropriate timing, duration and content of initial and ongoing assessments need to be negotiated with the patient and their family. Whilst it is important not to subject patients to unnecessary lengthy assessments in these precious last moments, it is also important to ensure that the patient is comfortable and that all the key issues have been considered.

Question: What should be the first step in any assessment?

Answer: The first step in any assessment is to establish the ability of the patient and family to communicate effectively.

As far as possible, you should put in place whatever is required to overcome any barriers to communication – for example, an interpreter, communication aids or carer input.



Holistic Assessment in the Dying Phase

Areas to be Assessed

The next step is to assess the patient's needs and preferences by carrying out a multidisciplinary holistic assessment.

What key areas need to be assessed in the dying phase?



Physical

Assessment of needs in the physical area should focus on physical symptoms and physical functioning and the effect they have on an individual's life. The assessment is also a time to begin to weigh up the risks and benefits of fluids and nutritional support for the patient.

The following are examples of symptoms experienced in the dying phase:

- Pain
- Dyspnoea (shortness of breath)
- Nausea, vomiting or weakness
- Retained secretions
- Agitation
- Dry mouth

Social

Social and occupational well-being include areas such as:

- Managing at home and in the community
- Housing or home needs
- Work and finance (including planning for the future)
- Family and close social relationships
- Social and recreational needs

Psychological

The assessment of psychological well-being includes:

- The patient's mood and interest
- Any symptoms of depression, hopelessness or anxiety
- How they are adjusting to their illness

Spiritual

An assessment of spiritual well-being is a sensitive but important area of holistic care, particularly when someone is facing a life-limiting illness or approaching the end of their life.

At this time their spiritual and/or religious needs may become clear or be heightened. Spiritual well-being may include:

- Faith
- Beliefs (religious or non-religious)
- Worries and challenges related to the impact of the illness and diagnosis or prognosis
- Life, personal and future goals

Question: How can we establish a patient's care preferences?

Answer: A patient's care preferences can be established by asking the patient.

If the patient is increasingly weak or has fluctuating cognitive impairment it may still be possible to discuss key issues by choosing the right time of day to review.

If it is not possible to complete an assessment with the patient themselves, refer to previous assessments to review prior needs and wishes and identify suitable proxies e.g. family/friends.

You should talk to the family/carers to establish their views on what is important to the patient and what they feel their wishes would be. You should also ask if the patient has:

Appointed a Lasting Power of Attorney for health and welfare

Either an advance care plan or an advance decision to refuse treatment in place.

Question: Where it is established that the dying person lacks capacity to make a particular decision, the decision made or action taken on their behalf must be in their best interests, and they should still be involved as far as possible in that decision. Who else should be consulted in this situation?

Answer: In accordance with the Mental Capacity Act 2005, the person making the decision must, if it is practicable and appropriate to do so, consult:

- Anybody named by the person as someone to be consulted on either the decision in question or similar issues
- Anyone engaged in caring for the person, close relatives, friends or others who take an interest in the person's welfare
- Any holder of a lasting power of attorney or enduring power of attorney
- Any deputy appointed by the court to make decisions for the person

It is also important to respect valid and applicable advance decisions.

Consider the normal process for symptom assessment and think about some of the challenges that can be faced when assessing symptoms in the dying phase.

Feedback

Challenges faced when assessing symptoms in the dying phase include:

- Patients are often not able to verbalise what is causing their discomfort
- A rapidly changing clinical picture can make it more difficult to assess the benefits and adverse effects of interventions
- Only a limited examination is appropriate
- Investigations are not always appropriate (e.g. x-ray, scans, blood tests)

Common physical symptoms experienced in the dying phase include:

- Pain
- Breathlessness
- Secretions
- Nausea and vomiting
- Restlessness and terminal agitation
- Dry mouth
- Sessions on all of these symptoms are available in the Symptom Management module.

It is important to proactively seek out physical symptoms in the dying patient. Once identified, symptoms must be regularly reviewed. Ineffective management of physical symptoms causes distress as does ineffective management of non-physical issues, including psycho-spiritual matters. Common end-stage symptoms should also be anticipated and 'as required' medications prescribed and made readily available.

When swallowing becomes difficult, oral medications need to be reviewed and essentials converted to the appropriate parenteral equivalents. Non-essential interventions and medications should be discontinued. Many patients will be able to take small sips of water and the mouth and lips need to be kept moist with frequent mouth care. There is sometimes a need to consider and discuss the risks and benefits of hydration and nutritional support. This can be an area of great concerns to families and must be recognised as an important topic to discuss. The session communication / discussing food and fluids will help you learn more about this.

Pain

Remember that even when unconscious, patients can still experience pain. Assessment can be challenging and often relies on:

- Non verbal clues
- Facial expression
- Body language
- Body movements
- Examination findings
- Knowledge from previous assessments

The cause of pain is often multifactorial and many patients will develop new pains during the dying phase. Consider:

- Pain due to progressive disease e.g. malignant invasion, nerve compression
- Loss of pain control because of change in route of administration: some medication/adjuvants may have been stopped
- Co-morbidities
- Pain related to reduced mobility
- Urinary retention
- Constipation
- Pressure sores

Establishing the pattern of pain will also help to inform the appropriate management plan.

Breathlessness

The main focus in the dying phase will be managing the symptom of breathlessness, as opposed to aggressive investigation of the cause.

Establishing if there is an element of anxiety can help in directing both pharmacological and non pharmacological interventions.

Non essential interventions should be stopped and response to all new interventions must be reassessed regularly.

It may be appropriate to continue treatments such as parenteral antibiotics and/or diuretics as long as access remains viable with the aim of symptom management.

Secretions

Retained secretions in the pharynx and upper respiratory tract can increase during the dying process resulting in the 'death rattle'.

It is important to review interventions, such as parenteral fluids, as these may contribute to excess secretions.

Response to positional changes and pharmacological interventions should be regularly assessed.

The level of distress to both the patient and the family needs to be assessed. Family distress can be greatly reduced if they are made aware that the patient is not suffering.

Nausea and Vomiting

Nausea and vomiting can be difficult to control. Pharmacological management is guided by aetiology, but establishing the cause(s) can be difficult when there is limited history available and where further investigations are inappropriate.

Examination findings and review of previous history may give clues to the aetiology. Consider:

- Gastric stasis and irritation
- Bowel obstruction
- Chemical/metabolic:
 - Drugs
 - Hypercalcaemia
 - Uraemia
- Raised intracranial pressure

Restlessness and Terminal Agitation

Terminal restlessness is a term that is used to describe various forms of patient distress and agitation occurring during the dying phase.

Causes of agitation include:

- **Physical:** uncontrolled pain, retention of urine, constipation, breathlessness, nausea, cerebral metastases, altered consciousness and fitting
- **Existential:** psychological, fear of dying, unresolved concerns about death, fear of losing control
- **Biochemical:** hypoxia, electrolyte imbalance, dehydration, hypercalcaemia, liver failure, renal failure, hyponatraemia
- **Iatrogenic:** response to medication, opiate toxicity, withdrawal of medication e.g. benzodiazepines, nicotine and alcohol withdrawal

The main focus of the examination should be to identify reversible components such as pain, urinary retention and constipation.

Dry Mouth

Dry mouth is common in the last few days of life. The cause of a dry mouth is likely to be multifactorial, including:

- Medication
- Oxygen
- Mouth breathing
- Reduced hydration
- Previous radiotherapy to salivary glands
- Co-morbidities
- Oral thrush

Assessment of the response to effective, regular mouth care and discussion with the family may reduce requests for artificial hydration

Jane, aged 45, has metastatic breast carcinoma. She is married with two children aged 12 and 15 years old.

She was originally diagnosed four years ago and has been under the care of an oncologist. Four weeks ago her oncologist told her that she now has progressive disease with lung, liver and bone metastases and that no further oncological treatments would be of benefit.

Since then she has steadily deteriorated. Jane was admitted to hospital two days ago with increased shortness of breath.

No reversible cause has been identified and she has continued to deteriorate with increased weakness. She is now struggling to mobilise and is sleeping more in the day.

On assessment she is very distressed and appears very anxious and breathless.



Assessing Psychological Well-being

Does the Patient Know They Are Dying?

Question: How would you assess whether patients know they are dying?

Answer: Establishing whether someone knows they are dying requires skilled and sensitive communication.


The first step is establishing what they know and what they want to know.

Exploring what they were told at diagnosis and at subsequent reviews, as well as discussing their clinical deterioration, usually raises opportunities to directly discuss prognosis.

Once you have established that discussion around prognosis is appropriate for that individual, euphemisms must be avoided to ensure there is no confusion. A patient may tell you that he/she knows 'nothing can be done' but may think this means he/she still has months or even years to live.

Establishing a patient's insight will help to direct the conversation to a more detailed assessment of psychological issues.

Exploring what patients know and what they want to know can be challenging and requires skilled communication. If you do not feel confident in this aspect of end of life care you might want to review sessions in the Communication Skills module, discuss your learning needs with your team and look for further education and training opportunities.



Would it be Ok with you to talk a little about how things are changing for you? How do you see things?

Assessing Psychological Well-being

Does the Patient Know They Are Dying?

How is the patient coping?

Denial is a coping mechanism for some patients and may be the only way they can live without being overwhelmed.

How is the patient feeling?

Emotional responses vary and include fear, grief, depression, anger and guilt.

Consider the impact of multiple losses including independence, activities, roles, relationships.

Screen and review if further management is needed for anxiety, depression or delirium.

Are there any unresolved issues?

Discuss issues around:

Relationships

Preparing for an uncertain future, for example:

- Managing finances
- The welfare of children
- Funeral and burial arrangements

What are their fears and concerns?

Go to the next page for Fears and Concerns.

Think about some of the common fears and concerns for patients in the dying phase.

Feedback

In the dying phase, patients may have a fear of:

- Suffering
- Loss of dignity
- Loss of mental awareness
- Being a burden
- When they will die
- How they will die
- The unknown
- Being forgotten

Jane is asking to go home but her husband feels she needs to get a bit stronger before she will be able to manage at home.

Question: What are the potential problems if Jane and her husband are not aware that she is dying?

Answer: If Jane and her husband are not aware that she is dying, this could result in:

Raised anxiety, as she continues to deteriorate inexplicably

Conflicting messages from different professionals and a loss of trust in the team

Symptoms not being managed appropriately and further active interventions being inappropriately pursued

No opportunity to undertake any advance care planning, leading to management decisions not in keeping with patient preferences

The children not visiting as frequently as they would if they were fully aware of their mother's condition

The family not being given the opportunity to say the things they want to say and to say their goodbyes

Cultural, spiritual and religious needs not being addressed

Preferred place of care and death not being achieved

Cardiopulmonary resuscitation (CPR) being inappropriately initiated



Jane's Story: Part 2

Exploring Her Psychological Well-being

During a conversation with Jane, she says that she is frightened of suffocating:

Jane: I just can't seem to get my breath. I feel like I am going to suffocate.

Professional: What brings that feeling on?

Jane: When I do anything my breathing gets worse and then I just can't get my breath.

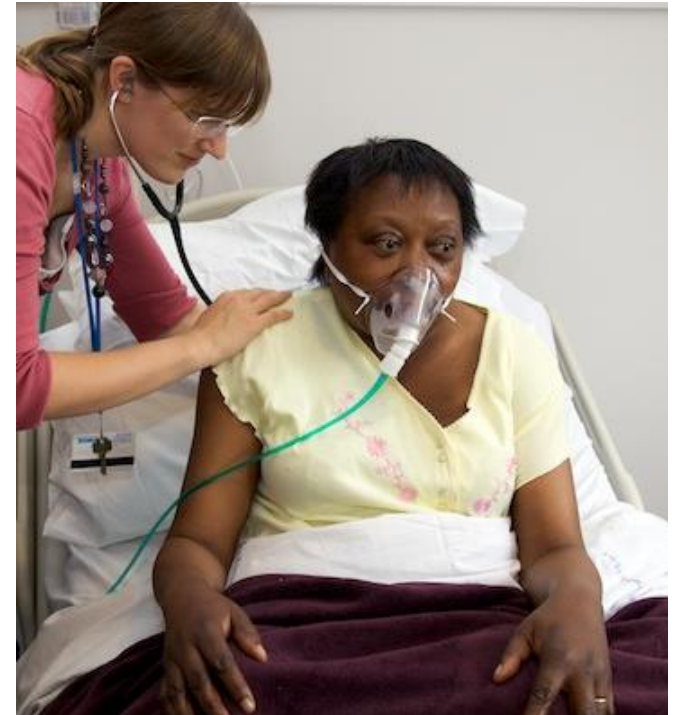
Professional: Do you feel frightened when that happens?

Jane: I am terrified that I am going to suffocate and die.

Question: How would you take this conversation forward and what are the key things you need to clarify?

Answer: There are different ways to pursue the assessment. You may wish to ask Jane if she is frightened of dying. This question and her response to it will allow you to explore her insight: does she know she is dying?

Once you have established that she knows she is dying you can explore her psychological well-being in more detail.



Jane's Story: Part 2

Exploring Her Psychological Well-being

Look at the example questions below and think about the following:

What are the patient's fears, concerns

How is the patient feeling?

How is the patient coping?

Are you frightened of dying?

What frightens you about dying?

Are you frightened about how you are going to die?

In what way has this illness affected you emotionally?

How have you been managing with all of this?

Is there anything you would like to do before you get less well?

Many people have things they need to do before they die. Is there anything you would like to do before you get less well?

Spirituality relates to the search to find meaning and the need to be connected with something. It may or may not involve formal religion.

Spiritual needs are often overlooked or superficially assessed. Spiritual questions can also be avoided as health and social care professionals can feel uncomfortable with questions they cannot answer.

Spiritual assessment is especially important, however, at the end of life as the prospect of imminent death often triggers spiritual questions. If left unexplored these can lead to significant distress.

It is important to establish if a patient follows a formal religion and if they do what role that plays in their life. Each faith traditionally has its own rituals and religious practices, but these will vary for each person, and individual needs and preferences now, at, or after death must be assessed. It is important to ensure that patients with a religious belief are enabled to practise according to their faith.

Question: Can you think of some appropriate questions to assess spiritual well-being?

Answer: The following questions may help in the assessment of a patient's spiritual well-being:

Do you consider yourself spiritual or religious?

When you have had difficult times in your life what has helped you to cope?

What gives your life meaning and purpose?

If you have not already done so, you should familiarise yourself with how to access support for spiritual and religious needs at the end of life in your work setting, for example the chaplaincy or spiritual care team and local community faith leaders.

You can also refer to session – Assessment / Assessment of Spiritual Well-being for further information on this important area of holistic assessment.



Social Assessment in the Dying Phase

Key Elements

It is important to revisit social issues when a patient enters the dying phase.

Unresolved issues in personal matters and especially relationships are a common source of distress to patients at the end of life.

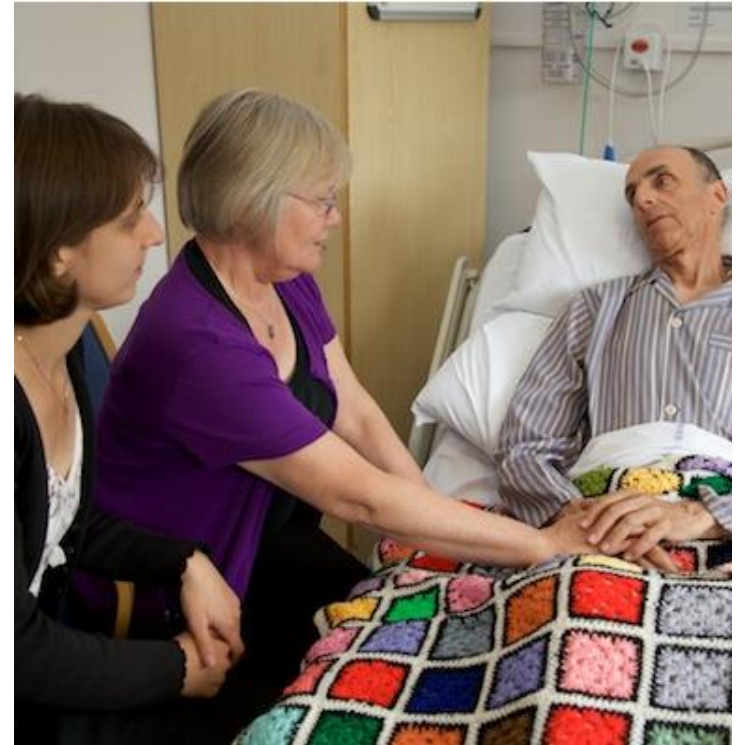
The focus of the assessment for each individual will depend on the patient and their goals.

Question: What are the key elements of social assessment in the dying phase?

Answer: The key elements of social assessment include:

- Family and relationships
- Caregivers
- The home environment
- Financial and legal issues

Illness impacts on social issues and social circumstances impact on illness.



Carers provide invaluable support for people approaching the end of life, but the role is demanding, involving both emotional and physical challenges. Family relationships can be put under huge pressure, especially when family members are the patient's main carers.

Family and carers should be supported, listened to and kept fully informed.

What issues relating to relatives and carers should be assessed when a patient enters the dying phase?

See if you can think of five of them

Feedback on next page

What will I do in the middle of the night when he wakes up with severe pain?

How will I get him to the toilet?

How will I know when he has died?

I don't want him to die in the house

I am just too exhausted

Feedback

It is important to assess carer's and family members' realisation that the patient is dying (including the understanding of children and those not present).

Also, check their understanding of:

- The changing goals of care
- The rationale for discontinuation of non-essential investigations and medications
- The measures that are being taken to maintain the patient's comfort
- The possibility of physical symptoms e.g. restlessness and agitation
- The fact that there is a reduced need for food and drink as part of the dying process (discuss mouth care)
- The physical signs of dying – what to expect
- The fact that the duration of the dying phase is hard to predict

You need to assess:

- How carers/family members are coping physically, emotionally and spiritually
- Are they at high risk of a complicated bereavement?
- Do they need any further support?
- If there are vulnerable family members
- The patient is at the centre of the assessment but don't forget the needs of those who care

Jane's Story: Part 4

Social Assessment

You are able to discuss with Jane and her husband that she is dying. She tells you that she wants to die at home.

Question: What are the key things in the social assessment that need to be reviewed in order to facilitate Jane going home?

Answer: The main issues to clarify are:

- What care is needed
- Who will provide that care to the patient
- The home environment

Professional caregivers will:

- Complete the fast track paperwork
- Assess care needs and arrange a package of care
- Inform the GP of details of the patient's discharge

If family and/or friends are to provide care, it is important to assess their needs.

In terms of the home environment:

- Where will Jane be cared for?
- What equipment will she need?



Jane and her husband decide that they will go home.

A hospital bed and a commode are organised so Jane can be cared for downstairs. A full care package and night sitters are also put in place.

Question: What information would you give to Jane and her husband before she goes home?

Answer:

Information to give to Jane and her husband should include what to expect with regard to the dying process:

- Explain the physical symptoms that might be experienced (e.g. restlessness and agitation) and discuss how they could be managed
- Explain that the duration of the dying phase is hard to predict
- Provide information on how to contact different professionals

You should also explain what to do when Jane dies – the GP surgery should be contacted, rather than dialling 999.

You should also ensure that Jane and her husband have the information they need to pass on to professionals involved in her care. For example:

- Hand over forms
- Out of hours services (OOH)
- Do not Resuscitate status (DNR)



Question: What additional medications would you like to ensure are available for Jane at home?

Answer: Jane has now entered the dying phase and it is important, therefore, to anticipate her future needs. These are likely to include subcutaneous alternatives for administration of essential medications as she becomes less able to swallow.

It is important to become familiar with local policies regarding anticipatory prescribing at the end of life, as recommended first line anticipatory medications will vary in different regions.

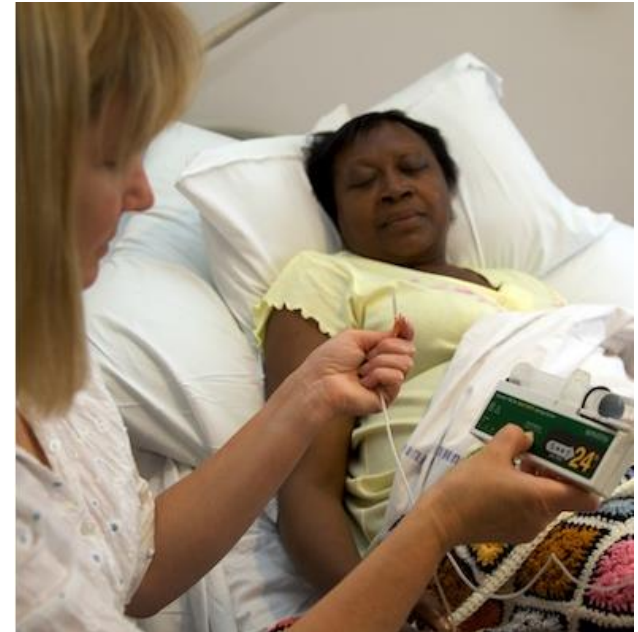
Jane's Story: Part 4

Ongoing Assessment

Assessment must be ongoing as the dying phase can present a rapidly changing clinical picture.

Although Jane and her family wanted their privacy, they were also keen to have regular reviews. The frequency and timing of these assessments were negotiated together to minimise intrusion.

Jane gradually became bed bound, then lost consciousness over the next ten days. She died at home 2 weeks after she was discharged.



Diagnosing Death Verification and Certification of Death

A key element of a 'good death' is timely verification and certification of death.

Question: What needs to be carried out before the undertaker is allowed to remove the body?

Verification of death

Verification and certification of death

Answer: Option 1

Delay in verification of death leads to delays in removal of the body which is especially relevant if a patient dies at home. Certification can be completed after transfer to the undertakers.

On the other hand, the family need to know that there is no hurry, if they wish to spend a little more time with the patient before the body is removed.

Question: Who is allowed to verify a patient's death?

Answer: In the case of an expected death, death can be confirmed by a doctor or a nurse who has received appropriate training. Ambulance staff may also have received training that allows them to confirm death if supported by a local protocol.

An expected death is a death following on from a period of illness and where no active intervention to prolong life is ongoing. Death is recognised as the expected outcome by:

- the patient's family or close friends
- the professional team
- the patient

If the death is not expected then only a doctor is allowed to confirm the death.

Question: Who is required to complete the death certificate?

Answer: The death certificate has to be completed by a doctor who has seen the patient within the 14 days preceding death.

The doctor can only issue a certificate if he or she knows the cause of death.



Diagnosing Death

Reporting a Death to the Coroner

There are a number of specific situations which require a patient's death to be reported to a coroner.

See if you can think of 5

Feedback

A patient's death needs reporting to a coroner in the following situations:

- The cause of death appears unknown
- The death was sudden or unexpected
- The death occurred after an accident or injury
- The death occurred at work or was due to industrial disease or poisoning; e.g. mesothelioma
- The death occurred during a surgical operation
- The death occurred before recovery from an anaesthetic
- The death was violent or unnatural. For example, suicide, accident or a drug or alcohol overdose
- The death occurred in prison or in custody
- The deceased was not seen either within fourteen days before death nor after death

This list is not exhaustive. If you are unsure of the cause of death, you should consult the Coroner's Office.



Question: Who can verify Jane's death?

Answer: Jane's death was expected, so a doctor, a nurse or a paramedic who has received the appropriate training can confirm (verify) Jane's death.

Question: What are the signs that need to be checked to confirm death?

Answer:

Correct procedure for confirming death

1. Confirm the absence of breathing for 1 minute
2. Confirm the absence of heart sounds for 1 minute
3. Confirm that the carotid pulse is absent for 1 minute
4. Confirm that the pupils are fixed and dilated



Jane's death now needs to be certified.

Certifying Jane's Death

Jane's GP can certify the death if he or she has seen Jane within the 14 days preceding her death.

If a doctor is not able to issue the death certificate, the case has to be referred on to the coroner.

When a patient is expected to die it is essential to inform the GP at the point of discharge home. This is to allow the delivery of quality end of life care and also to ensure that the GP can then issue the certificate at the time of death.

Question: What are the implications for Jane's family if she is referred to the coroner?

Answer: In some cases, the coroner will need to order a post-mortem. The registrar cannot register the death until the coroner's decision is known.

Relatives will need to know that referral to the coroner may mean that the funeral will be delayed.

Care does not end with the death of the patient. After death, the body must be handled and laid out in a dignified, safe and culturally sensitive way, in keeping with any religious beliefs.

Staff must be familiar with the procedures and processes following death and ensure that there are no unnecessary delays to funeral arrangements.

Question: What are the 'last offices'?

Answer: Last offices and laying out the body mean different things to different people but relates to care of body after death and involves issues relating to:

- Hygiene
- Aesthetics
- Legal issues

More information on the next slide

Question: Can relatives be involved in carrying out the last offices?

Answer: Family members should be given the opportunity to assist in performing the last offices. For some this may be therapeutic and can facilitate grief and give purpose.

The patient's best interests and dignity must be respected after death as they are in life.



Hygiene

After death the body is washed and dressed.

The main risk of infection is via body fluids and standard infection control measures should be followed.

A patient who is potentially infective after death should be placed in a leak proof plastic cadaver bag.

The mortuary or funeral director should be informed of the infectious status of the patient by the healthcare professional who certifies/verifies death, or the member of staff handing over the body. An infection control notification sheet should be completed.

Parenteral devices need to be removed and disposed of. Entrance sites must be covered with a waterproof dressing.

Aesthetics

Eyes should be closed with downward pressure and the jaw closed and supported by a bandage tied around the head or by a pillow.

Where appropriate, dentures should be removed and cleaned, the mouth cleaned and the dentures replaced.

Legal Issues

There should be clear patient identification.

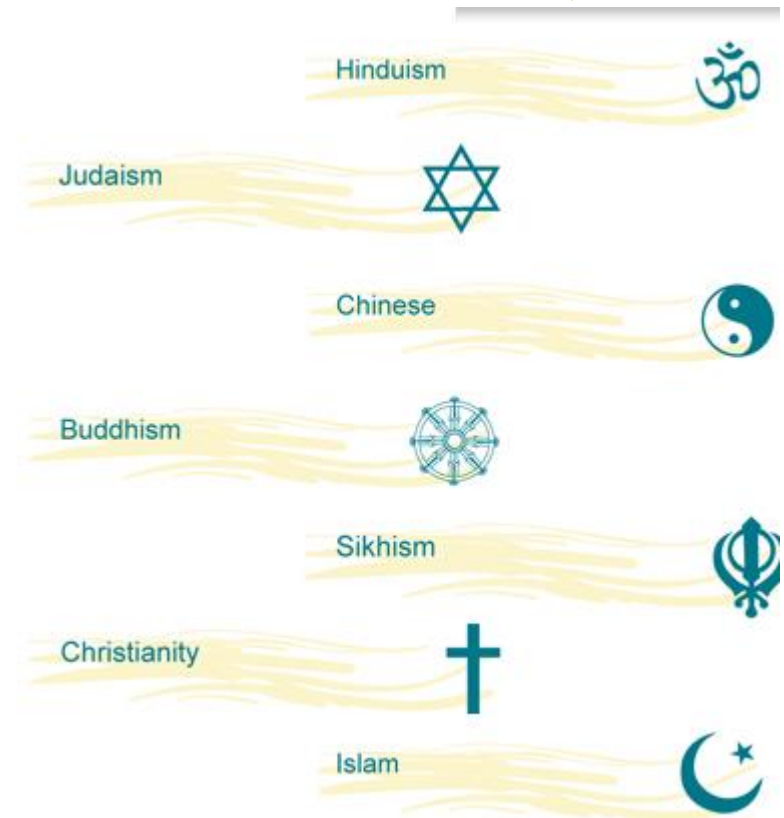
An accurate record of the patient's personal belongings must be taken.

A Notification of Death certificate should be attached to the sheet.

Care After Death Cultural, Spiritual and Religious Needs

Some families will have specific religious/cultural needs around care of the body after death.

Before carrying out the last offices, it is essential to consult relatives and friends about procedures concerning the body and any personal effects, to ensure that they are carried out in accordance with their beliefs.





Judaism

- Health workers should touch the body as little as possible
- The Jewish Burial Society will collect the body and perform a ritual wash before burial
- Burial should take place as soon as possible
- Funerals do not take place on the Sabbath or Holy days



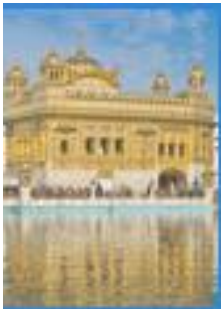
Hinduism

- The family usually wash the body themselves
- If a healthcare worker washes the body, they must wear disposable gloves
- Jewellery or religious objects must not be removed
- Cremation should take place as soon as possible



Islam

- Non-Muslim health workers should ask permission to touch the body. Disposable gloves must be used
- Eyes and mouth should be closed, limbs straightened and the face turned towards Mecca
- The feet of the deceased should not be allowed to face Mecca
- The body must be kept covered
- Ritual washing by same sex Muslims will take place
- Burial should be as soon as possible (often within 3-4 hours in many Muslim countries)
- As a sign of respect, relatives may not eat until burial is complete



Sikhism

- The hair or beard should not be trimmed
- The body should be covered with a plain white cloth
- The 'five Ks' should remain on the body:
 - Kesh (uncut hair)
 - Kara (a steel bracelet)
 - Kanga (a wooden comb)
 - Kaccha (special cotton underwear)
 - Kirpan (steel sword)
- Cremation should take place as soon as possible

When a patient dies, families need to be informed of the procedures following death. These include:

- How to view the body
- Instructions about collecting the death certificate
- Discussion of post mortem and/or referral to the coroner, if relevant
- What they need to do to register the death
- The need to contact an undertaker to transfer the body
- Information regarding bereavement services, especially if there are any concerns about the risk of complex bereavement. You can learn more in session – Assessment/Bereavement Assessment and Support

If cremation is being considered for a patient with a cardiac device, a pacemaker or certain orthopaedic prosthesis, relatives should be advised that these will need to be removed prior to cremation. You must remember to notify the undertakers.

Relatives who may wish to take remains abroad will require documentation from the coroner, to authorise export of the remains. A 'free from infection' certificate will also be completed by a senior doctor.

In some cases organ or tissue donation may be possible and may even have been discussed prior to death.



Organ and Tissue Donation

All bereaved families should be offered the option of organ and/or tissue donation, as long as the patient fulfils the criteria for donation.

Patients and families can feel comforted through the knowledge that they have given hope to others. Donation may be the one positive thing that comes out of a tragic situation.

For further information, refer to session – Communication Skills/Request for Organ and Tissue Donation.

Recognising the Potential Impact of a Death on Professional Carers

Caring for dying patients can be challenging and stressful and may have a significant impact on professional carers.

There is a responsibility among employers to provide staff support. Without support, health and social care staff may develop professional detachment and withdraw, or employ blocking behaviours to distance and protect themselves. This behaviour leads to poor quality of care.

Question: What might be some of the reasons that staff become stressed when caring for dying patients?

Answer: Some of the reasons include:

- Inability to relieve distressing symptoms
- Over involvement with a patient
- Increased awareness of personal losses and fear of one's own death
- Increased workload associated with patients in the dying phase
- Disagreement about goals of care

Question: List two ways that professionals can reduce stress.

Answer: Strategies include:

Formal and informal reflection on caregiving experiences

Effective team working and communication

Patient rotation

If stress is not recognised and managed it can lead to burnout and poor quality of care.



- Recognising that a patient may be entering the dying phase is an important part of meeting end of life care needs
- A multi-dimensional assessment of end of life care needs is required when someone is identified as entering the terminal phase
- Communicating with patient and carers in the dying phase is essential, but can require sensitive handling
- Early recognition of signs of extreme distress in patients and carers is helpful
- Good assessment of needs of the deceased person and their family/carers will ensure person-centred care can be delivered
- Assessment of your needs as a professional when someone is dying, or has died, is important