Liverpool Heart and Chest Hospital NHS
NHS Foundation Trust

When the Dying Process is Protracted Or Unexpectedly Fast

e-LfH e-Learning for Healthcare

NHS Health Education England

Inspected and rated Outstanding ☆ CareQuality Commission

Learning Objectives

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

- Describe the key issues which you could expect in two contrasting end of life care situations: where the dying process has been particularly protracted or where it has been unexpectedly fast
- Apply the five priorities of care for the dying person to the situations
- Discuss how to support families and those close to the patient in these situations
- Describe the impact that such situations may have on other patients nearby, staff and volunteers, and how to manage this

Introduction

Although death may be expected, the rapidity with which somebody deteriorates and dies can have a significant impact on the adjustment to loss that their family experiences.

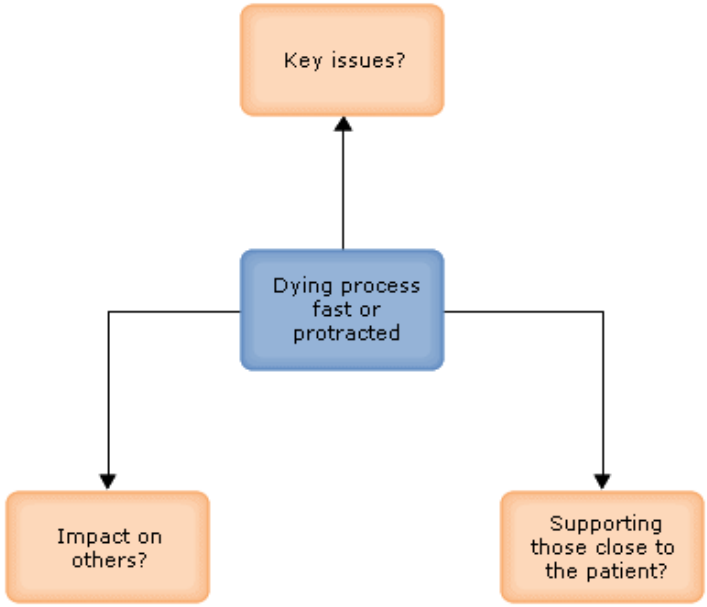
Similarly, when dying is particularly protracted, it can become unbearably difficult for relatives who become exhausted. Staff need to be able to manage patients and support families adequately in both situations, and also manage their own responses to these situations.

This session is aimed at all health and social care professionals who work with patients at the end of life. It looks at two contrasting scenarios:

1. Where the dying process is protracted
2. Where the dying process is unexpectedly fast

You will address the following key questions:

- What are the key issues facing each scenario?
- What should be done to support those close to the patient in these situations?
- What is the impact of such situations on other patients nearby, staff and volunteers, and how should this be managed?



Introduction Priorities for Care

A patient who is dying needs a care plan tailored to their individual needs. This should include attention to physical, spiritual, social and needs that are identified by a holistic assessment.

Five priorities for care of the dying person are identified in the report One Chance to Get it Right [1]. This sets out the approach to caring for dying people that health and care organisations and staf caring for dying people in England should adopt. The approach was developed by the Leadership Alliance for the Care of Dying People (LacDP), a coalition of 21 national organisations concerned tc ensure high quality, consistent care for people in the last few days and hours of life.

Introduction Priorities for Care

Priority 1

The possibility that a person may die within the next few days or hours 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.

Priority 2

Sensitive communication takes place between staff and the dying person, and those identified as important to them.

Priority 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.

Priority 4

The needs of families and others identified as important to the dying person are actively explored, respected and met as far as possible.

Priority 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.

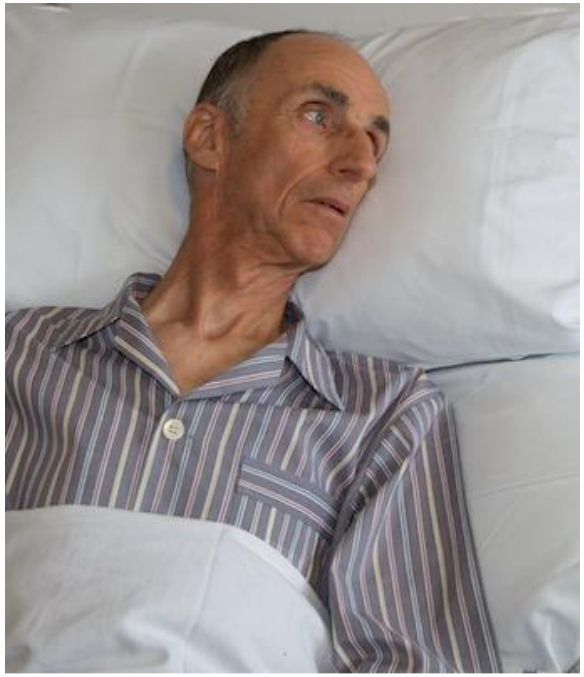
Scenario 1: Dying is Protracted
Overview

Alan, aged 78, has end-stage dementia. He was diagnosed with dementia four years ago and for the past two months has been living in a nursing home.

Alan is married to Edith and has a son, James, and a daughter, Suzie. Edith had always wanted to care for Alan at home. Very reluctantly, she agreed for him to have a period of respite in the nursing home to give her a break as she was exhausted and struggling to cope.

Over the past four weeks, Alan has deteriorated significantly and his psychiatric team, in consultation with the GP, feel that his condition is progressive and irreversible. Alan and Edith's children do not feel their mother can cope at home with caring for him. She spends all day with him at the nursing home.

Alan is now bed bound, no longer eating, drinking very little and has a productive cough. He appears weak, cachectic and is unable to take any oral medication. He appears distressed and in pain and his prognosis is thought to be very poor. James and Suzie feel Alan should be treated acutely in hospital and have a feeding tube.



Scenario 1: Dying is Protracted
Key Issues

Question: What are the key issues so far for Alan and his family: Edith, Suzie and James?

Answer:

Alan

For Alan the following are the key issues:

- He has advanced progressive end-stage dementia
- He is:
- Physically and mentally vulnerable
- Currently in physical and mental distress
- Bed bound
- Not eating, and drinking very little
- Unable to take oral medication
- His prognosis is thought to be very poor
- He lacks capacity to make decisions

Alan's family

The following are the key issues for Edith, Suzie and James:

Edith has been her husband's carer for over a year, and has wanted to be so. However, she is exhausted

As a family, their understanding of Alan's illness - the challenge of accepting the current clinical situation and adjusting to losing Alan

There is potential conflict between:

Edith and her children - they have differing views on where Alan should be cared for now

The family and the nursing home team - over where Alan's needs could be best met

The children and nursing home team - regarding the appropriate nutritional support for Alan

Scenario 1: Dying is Protracted
Further Details

Alan is unable to swallow his anti-psychotic medication or the regular co-codamol that he takes for his long-standing back pain. The team assess that his distress and agitation are due to physical pain.

The team discuss whether nasogastric feeding will add to Alan's overall quality of life (QOL), but they agree that this will not add to Alan's comfort or QOL and is therefore inappropriate.

A subcutaneous 24 hour syringe driver is started with a combination of low dose morphine, haloperidol and midazolam.

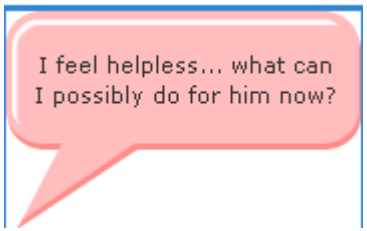
Over the following 10 days, Alan deteriorates, appearing more frail and weak. He no longer verbally communicates and is even unable to sip water.

The nursing team carry out all care including personal care and mouth care.

Scenario 1: Dying is Protracted
Supporting Edith

Alan's wife, Edith, stays with him every day and appears distraught and exhausted. She expresses her thoughts and feelings as shown in the images below.

Question: How would you manage each of these feelings?

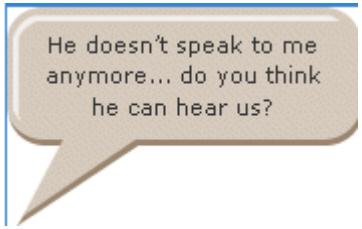


Acknowledge Edith's concerns and distress by using active listening and empathy skills.

Consider ways that Edith could still be part of Alan's care, for example could Edith help with Alan's personal care and mouth care?

Ensure Edith knows how important her presence is. 'Being there' alongside her husband may help calm him by offering a familiar voice and presence for Alan. Suggest to Edith that she behave as if they were at home, for example, she can sit and read a book, watch the TV in Alan's room or sew.

Scenario 1: Dying is Protracted
Supporting Edith



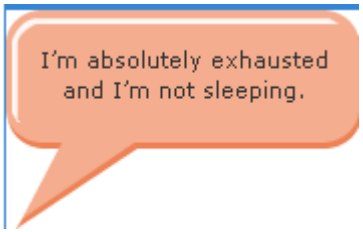
Advise Edith not to be discouraged if Alan gives little response. Explain that this may be due to weakness, rather than not wishing to engage with her.

Discuss with Edith the importance of non-verbal communication. You can pick up non-verbal cues from Alan by close observation. Look at facial expressions, eye contact and observe Alan's general behaviour.

Edith can use 'touch' to let Alan know she is there by his side, for example holding his hand or giving a gentle hand massage.

Remind Edith that although Alan may be unable to speak, he may be able to hear her voice and will be comforted by familiar tones and phrases.

Scenario 1: Dying is Protracted
Supporting Edith



Listen, empathise and acknowledge Edith's distress. Ask open ended questions regarding the causes of her insomnia, in order to explore the specifics of her distress. For example, she may be fearful that Alan may die overnight and that no-one will know how to contact her. This can be managed by clarifying the best contact details with Edith, and reassuring her that the nurses will phone her overnight if there are any changes in Alan's condition.

Offer her advice on non-medical strategies to help sleep, for example a relaxing bath or using aromatherapy such as lavender.

Edith may be feeling guilty if she takes any time away from Alan in these last days, or worried that he might die alone. Acknowledge her feelings. Offer general support; advise Edith to take regular breaks and rest and encourage her to have regular drinks and meals.

Encourage Edith to visit her own GP. This will help with support now and in the long term as her GP will be aware of the key challenges facing Edith.

Re-estimate prognosis to help Edith with her resilience.

Scenario 1: Dying is Protracted
Supporting James and Suzie

Alan is slowly deteriorating, but appears very peaceful and comfortable. The family continue to be distressed and the nursing home team is exhausted with trying to support them.

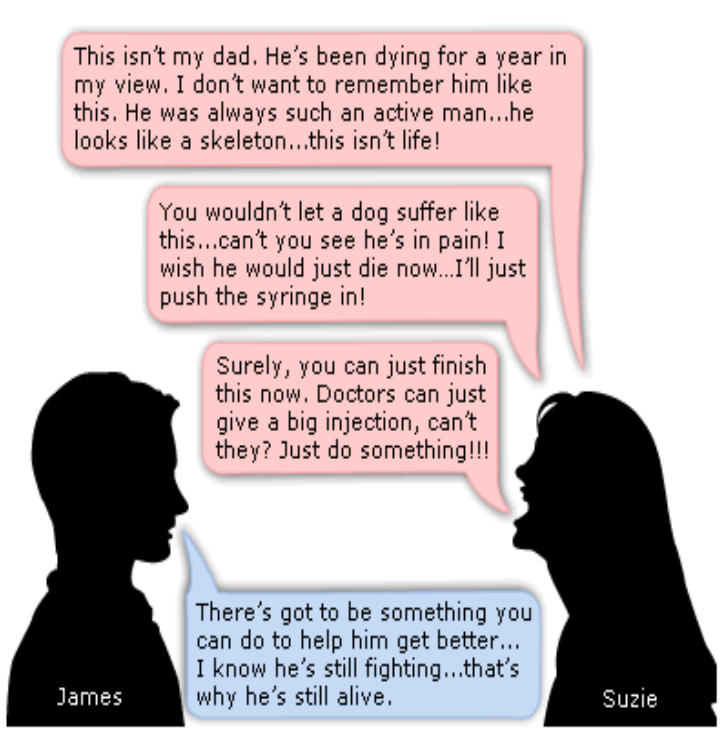
Suzie visits every other day but finds this very difficult. James visits at weekends and still finds it difficult to accept there is no active treatment available.

Their feelings about their dad's situation are shown in the image opposite.

Question: How would you support James and Suzie?

Suggestions:

- Listen to them both, as they trying to cope with the situation in their different ways. In families, it is not uncommon for individuals to find different parts of the clinical situation challenging. James expresses a hopefulness that his father may improve, a frustration with the team and a reluctance to accept that his father is dying
- The nursing home team can help adjustment by active listening, empathy and recognising that James and Suzie may both need their own time to express their distress to accept the clinical situation
- For Suzie, it is the difficulty of actually seeing and visiting her father now, as he deteriorates. She appears to have spiritual distress, trying to find meaning in a very difficult distressing situation. The degree of her distress is leading her to request euthanasia for her father. Listening and exploring the root of her distress is key. Involvement of a chaplain or spiritual advisor may be helpful to support this family



Scenario 1: Dying is Protracted
Supporting the Team

The team is also worn out in caring for Alan and supporting the family.

Question: What can the team do to maintain their resilience in this situation?

Suggestions: To maintain their resilience in this situation the team needs to:

Work together as a team to share the care of Alan and his family so that it is not just one person dealing with their distress every day

Hold regular team debrief meetings so that all the team is up to date with the situation

Maintain a good work/life balance; all staff need to actively consider their own personal coping strategies

Scenario 1: Dying is Protracted Upon Alan's Death

Alan died very peacefully five days later with his wife and daughter present. Edith, Suzie and James were exhausted and devastated but were very thankful that Alan was cared for by a team who had got to know him and who had been so willing to support them too.

The team recognised Alan's death would have an impact on other residents and their families and with Alan's family's agreement, the nursing home team gently told those residents who had known Alan, that he had died. The team had asked for chaplaincy support to help with supporting Alan's family before he died, but also to help with the support for other residents.

The nursing home team had also asked for help from the community palliative care team with both family and staff support and the clinical nurse specialist (CNS) had met Alan and his family before he died. The CNS agreed to access specialist bereavement support for Edith, Suzie and James.

The nursing home staff recognised the challenges of caring for Alan and his family. They organised a team debrief where they could reflect and learn from the situation.

Reflection

Before continuing with the session, spend some time thinking about what has been covered so far.

- What have you learnt from participating in this case scenario?
- Has anything surprised you so far?
- Consider how you may have felt as a professional in this situation and what coping strategies you may have used to help you with these feelings?
- How have the five priorities of care for the dying patient been applied to this case scenario?

Scenario 2: Dying is Unexpectedly Fast Overview

The next section focuses on a different scenario. It looks at issues around when dying is sudden and unexpected. In this scenario, the patient is Alison.

For details about Alison, her illness and what happened on the morning handover please read below

About Alison

Alison, aged 43, has been married to Dave for 20 years. She has two children, Lily, aged 12 and George, aged 8.

Alison's illness

Alison has metastatic breast cancer with extensive bone, lung and liver metastases. She has several difficult symptoms that have been challenging to manage, including pain and abdominal bloating.

Alison is due to start a new chemotherapy to try and control her disease. The oncology team and Alison are hopeful that the treatment will have a positive impact, both on helping her to feel better, and to live longer. Her prognosis is thought to be several months. Alison's children are unaware of the full details of her illness. She has also chosen to keep some information from Dave as he struggles to cope with all this.

Alison is an inpatient in a four-bedded bay on the oncology ward for symptom assessment/management and to start chemotherapy.

At the morning handover

The night staff explain that Alison has had a terrible night with a dropping blood pressure and excruciating abdominal pain that the nursing team have not been able to control, despite repeated parenteral morphine injections.

T

he senior oncology doctor has just assessed Alison and believes she has had a large acute hepatic bleed. The team estimate that Alison is likely to die very shortly, within the next hour or two, and agree that cardiopulmonary resuscitation would not be in her best interests. They complete a DNAR (Do Not Actively Resuscitate) form.

Alison looks grey and appears to be in pain, confused and very agitated. She is restless and calling out for Dave and her children. Other patients in the bay are visibly upset, as are the nursing team. Dave has arrived and is very shocked and tearful. He says:

She'll be alright, won't she?...she sorts everything out normally...pays the bills...and she just made us both do a will but I don't know where anything is. I've just dropped the kids off at school...what do I do?

Scenario 2: Dying is Unexpectedly Fast
Key Issues

Alison
- She has advanced metastatic cancer
- She has multiple symptoms that are not currently controlled
- The prognosis was thought to be several months, but now is very short
- She has coped by not telling her family the details of her illness

Dave
- Is shocked by overall situation and distressed with seeing his wife in high distress
- Does not know all the clinical information
- There is also worry about whether Alison's 'affairs' are in order

The children
- Lily and George currently have limited understanding of what is going on. Alison's coping strategy has always been to keep information to herself and not telling the family, particularly the children

In addition to the above issues, they are all facing a rapidly changing situation.

Scenario 2: Dying is Unexpectedly Fast
Managing Distress

The patients in Alison's bay are visibly distressed.

What can the team do to help the other patients' distress and manage their own distress?

To help the other patients' distress, the team could:

- Be honest about the situation, within the bounds of patient confidentiality
- Offer individual patients time to express their feelings and acknowledge those feelings
- Explore specific causes of distress using active listening skills and empathy

To manage their own distress, the team should:

- Use the understanding that they have about Alison's condition to help with assessment and management of symptoms
- Seek advice and help on how to manage Alison's symptom distress if needed, using resources such as an experienced senior colleague, chaplain or palliative care team
- Seek advice and help on how to manage Dave and the children's distress, if needed
- Be aware of their own personal stress and acknowledge their own boundaries – including where and when to ask for help and seek support

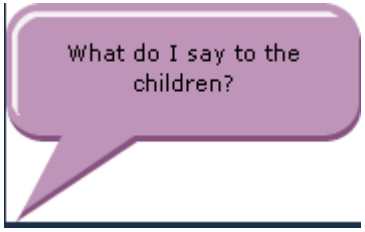
After managing the current situation, following Alison's death, staff could:

- Reflect later on the scenario and it's impact on them
- Conduct a ward debrief with colleagues
- Actively consider their own coping strategies

Scenario 2: Dying is Unexpectedly Fast Supporting Dave

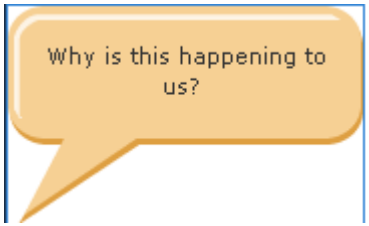
The ward doctors speak to Dave and tell him that Alison is sadly deteriorating rapidly and will die very shortly. Dave has asked Alison's sister to go to Lily and George's school to pick up the children and bring them into the hospital. They will be arriving in the next few minutes. Dave approaches you appearing very tearful. He asks the questions shown below.

Question: How could you manage this situation and his questions?

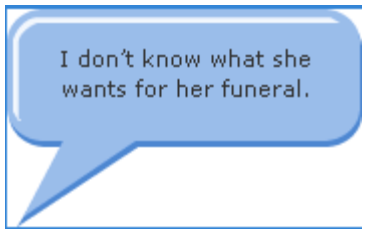


- Offer support to Dave when he talks to George and Lily. Suggest there is no right or wrong way to talk to children about dying. Children who are there when a person dies may find it helps them in the future - it can make it easier to understand what has happened
- Encourage Dave to let George and Lily know that he feels very sad, and may cry, but he will be there with his family to continue to care and be there for them
- Make Dave aware of resources available e.g. books on talking with children about dying and child bereavement services. (See Further Reading and Activities for useful resources)
- As this has been a rapidly changing situation that is highly distressing and shocking, expect Dave not to be able to take in all this information. He may need further opportunity for repetition of questions and reiteration of information. He also needs comfort. Written information that Dave and/or George and Lily can look at a later time will be helpful

Scenario 2: Dying is Unexpectedly Fast
Supporting Dave



- Show empathy by listening and acknowledging how difficult, unfair and distressing this feels for Dave and his family
- Seek support and advice to help you manage this situation. Support may come from chaplaincy, specialist palliative care team, other ward team colleagues
- See if it is possible to move Alison to a side room. Let other patients know you are moving Alison so she can have more privacy with her family
- Ask Dave if he wants other family members to come in for his support and to see Alison



Reassure Dave that he will have support and time to organise Alison's funeral. Other family members and friends will be able to help him. Also reassure Dave that he is not on his own.

Scenario 2: Dying is Unexpectedly Fast Signs of Death

Alison is more comfortable following repeated PRN drugs and a 24 hour syringe driver has been set up. It is clear she is rapidly deteriorating and will die very shortly.

Question: What signs might you expect to see near death?

Answer: In acute clinical scenarios the clinical situation will appear 'fragile' with a rapid speed of deterioration and potentially distressing, intractable symptoms as you have seen in Alison's case scenario. You may see the following:

- Confusion about time, place and person, a general restlessness or agitation
- Loss of bowel and bladder control
- Dark urine or decreased amount of urine
- Skin appearance: skin can appear pale, moist and cool
- Breathing pattern may change; it may appear laboured or the rate changes where there may be longer gaps between breaths
- There can be a noisy rattle in the breathing sound which may be due to excessive secretions in the upper airways or floppy muscles due to excessive weakness
- The person may be mouth breathing so lips and mouth can become dry
- The person usually becomes unresponsive and may have their eyes open or semi-open, but are not seeing their surroundings

Scenario 2: Dying is Unexpectedly Fast Signs of Death

Question: What can you do to help this family at this time?

Answer: Sensitive communication with the family is key to helping them understand what the above signs signify; acknowledging that they can be upsetting to carers, but will not necessarily be distressing to the dying person.

The last moments of a person's life can have a lasting effect on family members, friends, and caregivers.

Where possible, the person should be in an area that is peaceful, quiet and physically comfortable. Ensure family know where and how to obtain nurse support if needed, e.g. know how to use the call bell.

Ensure they have information on how to access specialist bereavement support services to provide ongoing support after death. This can be done through the local hospice, GP or Cruse Bereavement Care.

Differences Between the Two Scenarios

Question: What are the similarities and differences in the two scenarios for each of the following areas?

Symptom management

In both scenarios there was a need for individual symptom assessment and management, which needed ongoing review. There needs to be constant review in acute situations and, at least a daily review, in more prolonged circumstances. In both situations, it is important to know if the patients had advance care planning documents. This could have helped to guide decision-making as neither patient had capacity to participate in decision-making near the end of their life.

Family support

Family support can be very intense and requires an assessment of the individual family's needs. A family in a protracted situation has an increased potential for family or carer exhaustion, but intensity is very high in acute situations with the need to help families 'move forward' very quickly and adjust to devastating change and loss .

Other patients

In both scenarios, it was important to recognise the impact of patients seeing suffering in a fellow patient. It is a reminder of their own illness, vulnerability and mortality. It is important to ensure that time is given to listen and support patients and families affected.

The staff

In both scenarios there was a need for team work, self-awareness of own stress and individual professional need for support. Both require good communication skills. The intensity of managing the unexpectedly fast death can be extremely stressful. However, a protracted death can also lead to high staff pressure as staff need to sustain a level of resilience to be able to care and support over a long period of time.

Five priorities for care of the Dying Person

In both these scenarios the clinical team recognised that the patient was dying and communicated this to the family. The person's needs and wishes were discussed and the families were involved in decisions and care. The team worked together to support the families. The detailed plan of care was quite different for the two patients but each required consideration of the same elements. Were there any elements that in your view were missing from the scenario and the plan of care?

Session Key Points

- It can be difficult to effectively manage dying patients and their relatives, particularly in those situations where families are facing the acute loss in an unexpectedly swift dying phase, or who may be exhausted through longer term caring or protracted last weeks of life
- Every person you care for is an individual and each clinical situation is likely to bring different challenges for you
- However, you can learn from each situation you encounter by reflecting, talking with colleagues, learning from the patients and families you care for and using other resources
- Thorough symptom assessment and management, team work, using your communication skills and reflection all help to optimise care in complex clinical situations