Answer Guidance

# Chapter 33: Care about death

## Activity answer guidance

### Activity 33.1

Think how different illnesses may have a different trajectory toward death.

Check out the Gold Standards Proactive Identification Guide (2016) for further reading.

<https://www.goldstandardsframework.org.uk/cd-content/uploads/files/PIG/NEW%20PIG%20-%20%20%20Updated%2015.5.2018%20vs18.pdf>

#### Answer guidance:

*Think how different illnesses may have a different trajectory toward death.*

*Recognising the deteriorating patient at end of life is complex, this needs to be a multi-disciplinary approach. Palliation and good end-of-life care are appropriate for all patients, with malignant and non-malignant long-term conditions. However, each illness can have very different trajectories, therefore making decisions regarding when an illness reaches its endpoint is complex. We need to understand and acknowledge the differences to provide that important person-centred care. Recognising that a patient is deteriorating allows greater planning of their individual needs and allows wishes to be met. Think of the general indications of decline you may see in a patient, NICE (2017) gives a comprehensive picture of general signs and symptoms and reminds us that care must be individualised. They suggest that identifying people in the final weeks and months of life, is crucial, to instigate Advance Care Planning, choice, and their needs being met. They highlight that it includes people with:*

 *advanced, progressive, incurable conditions*

 *general frailty and co-existing conditions mean they are at increased risk of dying within the next 12 months.*

 *existing conditions if they are at risk of dying from a sudden acute crisis in their condition.*

 *life-threatening acute conditions caused by sudden catastrophic events.*

*To recognise deterioration in these differing groups we need to look at the disease-specific indicators. These are crucial alongside the general clinical indicators seen. These are discussed in detail in the Gold Standards Proactive Identification Guide (2016).*

### Activity 33.2

What is the local policy for Care after Death in your local area?

Find a copy of the policy and discuss how care is delivered with your practice supervisor.

#### Answer guidance:

*You have been asked to find out what is the local policy for care after death in your local area and to find a copy of the policy and discuss how care is delivered with your practice supervisor.*

*Here is an example of a policy from a local NHS trust:* [*NHS end of life brochure copy (sth.nhs.uk)*](https://www.sth.nhs.uk/clientfiles/File/EndOfLifeCareStrategy.pdf)

*This particular trust has six ambitions in relation to the end of life care:*

 *Each person is seen as an individual.*

 *Each person gets fair access to care.*

 *Maximising comfort and wellbeing.*

 *Care is coordinated.*

 *All staff members are prepared to care.*

 *Each community is prepared to help.*

### Activity 33.4

How may your own attitudes, and values impact your involvement in care after death?

How may you manage the emotions that you could experience at the point of death/while performing personal care after death?

#### Answer guidance:

*Culture and religion play a key role in how we think about death. This may involve different ceremonies, different rites of passage, and different beliefs about what happens after we die e.g. reincarnation or an afterlife.*

*Philosophers have had differing perspectives about death for centuries (summarised in this short video here:* [*https://youtu.be/mjQwedC1WzI*](https://youtu.be/mjQwedC1WzI)*)*

*Our social attitudes also shape our attitudes and values towards death, for example, some societies talk very openly about death and have open caskets where friends and family visit to pay their respects, while others do not speak about death and the subject is very taboo.*

*It may also depend on your own age or your own experiences of death personally. For example your experiences of a loved one’s death or how much you know about death.*

How may you manage the emotions that you could experience at the point of death/while performing personal care after death?

*Many students believe that it could be seen as unprofessional to be upset when a patient dies. This is absolutely not true. If you have cared for someone and been with them at death, then it is natural to be upset and display feelings of grief. You need to ensure you speak to your practice supervisor or another member of staff to reflect on the experience and ensure any questions you have are answered. It’s important to discuss your feelings with someone. You may also want to take some time out to go and have a break and reflect quietly by yourself, especially if this is your first experience of the death of a patient. Most importantly, just be kind to yourself.*

### Activity 33.5

You were present when the family of a young woman who has died unexpectedly in the emergency department was told that her death would be referred to the coroner and that a post-mortem would be required. Although clearly devastated, the family understood the need for this course of action.

While you are helping a newly qualified nurse undertakes Last Offices, she insists that you remove all the cannulae, drains, etc. from the body of the deceased. You remind her that this is to be a coroner’s case but she continues to insist. What should you do?

#### Answer guidance:

*You are correct, if a death is to be referred to the coroner, cannulae drains, etc. should be left in place. If the newly qualified nurse will not listen to what you are telling her you to need to explain to her that you are certain what you are saying is correct and suggest that you both consult another member of the healthcare team to check.*

## Case study answer guidance

### Case study 33.1: Bill, Ella, and Harriet

Ella is a final-year nursing student who has always felt it a privilege to perform Last Offices for those who die in her care.

Bill, an elderly gentleman, has died and Ella is aware that Harriet, a student on her first placement, has been involved in caring for him. She watches Harriet and her mentor go into Bill’s room to undertake Last Offices. Shortly after, she sees the mentor leave the room, leaving Harriet alone with Bill. Ella becomes aware that the mentor has got caught up with another patient while Harriet is still alone and goes in to check that she is OK.

Harriet is sitting by the bed of the patient looking very pale and close to tears. She tells Ella that the only other dead body she had seen was that of her grandfather, who died when she was 12 years old.

Ella suggests that they both take some time out and take Harriet to the ward office, informing the mentor and the HCA with whom she is working (to ensure her own patients are cared for) that they are there. She then allows Harriet to talk about how she is feeling about caring for a patient who has died and what she is worried about with regard to Last Offices. The mentor, seeing the rapport between the two students and knowing that Ella has done Last Offices on a number of occasions, suggests that they might undertake the procedure together.

How might this opportunity to do Last Offices together be beneficial for both Ella and Harriet?

Often, one of the best sources of support for nursing students is other students. How might you either support another student or seek support from another student if you were in a similar situation?

#### Answer guidance:

*Often, when you perform Last Offices for a patient you have been caring for, while it might make you sad that the patient has died, it provides you with time to reflect upon the good care that you have given to the patient, and to ensure that the patient is treated with the respect and dignity they deserve. Performing last offices for the first time is usually something most nurses remember, and for Harriet, performing this procedure with another student, who understands how she is feeling, makes the process less daunting. Once you are more experienced, like Ella, it is very positive to be able to support a less experienced colleague, and share with them how you coped with a similar situation.*

*Other students are excellent sources of support during placement. Make sure that you take the time to ask them about their experiences and how they have coped with situations they found challenging. If you see another student struggling when you are on placement, make sure that you offer them the support you would like if you were the one struggling. As students you have a wealth of knowledge to offer each other, and can often understand exactly how each other are feeling.*

### Case study 33.2: Jake and Zoe

Jake was 6 years old. He had been in and out of the children’s ward for the past 21/2 years, having been diagnosed with a brain tumour at the age of 4. Initially it was thought that the tumour was benign and surgeons believed they had successfully removed it, but it came back in a malignant form. Despite further surgery, the tumour could not be removed and Jake had been receiving palliative care for the past 6 months.

Jake’s mother, Terri, and his father, Max, had cared for Jake at home for much of the time he was sick, but he had wanted to die in hospital ‘with his favourite nurses around him’ so, when it became apparent that the end was near the family came into hospital for the final time. They took over Jake’s usual cubicle and Terri, Max and Jake’s 12 year old brother James, all stayed there with him. There were pictures of other family members, the family’s dog and cat and cards all around the room and it didn’t really feel like a hospital cubicle.

After a bad night, Jake deteriorated and died in his mother’s arms around 10am and he did, indeed, have his favourite nurses around him. Terri, Max and James sat with Jake for over an hour after he died until it was time to perform Last Offices. Zoe, the nurse tried gently, but firmly to ask the family to leave, but they were insistent that, having cared for Jake in life, they wanted to perform the final caring acts for him. Although she felt very uncomfortable, the nurse reluctantly allowed Terri and Max to stay, but was adamant that James was too young and should leave.

James’ response was to take Jake’s towel and gently dry the areas that his parents had just washed—talking to Jake all the time, telling him what a special brother he had been and that he (James) would look after their mum and dad. He helped Terri and Max to dress Jake in his Manchester United kit and when the time came to put identity labels on Jake’s body, James took them out of the nurse’s hand and carefully placed them around his brother’s wrist and ankle. He then went to the pile of toys that Jake had accumulated while in hospital and picked out his favourite cuddly bunny which he placed in Jake’s hands before the body was prepared for transfer to the mortuary.

As the family left the cubicle Terri simply said “Thank you,” but James turned and ran back to Zoe to give her a big hug.

Why might Zoe have been reluctant to allow Jake’s family, and particularly his brother James, to participate in performing Last Offices?

#### Answer guidance:

*There are several possibilities here:*

 *Some nurses believe that this procedure should be undertaken by nurses and that family members should not be involved. It is possible that Zoe was trying to protect the family from something she felt they should not see and therefore she asked them to leave the room.*

 *Another option is that Zoe is herself lacking in confidence in undertaking this procedure and therefore would have felt uncomfortable having the family present*

 *Zoe might be worried that she would become upset in front of the family and possibly believes that this would be wrong. Many children’s nurses do cry in front of parents and this is often greatly appreciated by the families concerned*

 *With regard to James, the protectionist approach identified above is the most likely reason why Zoe was so reluctant to involve him. There is a misconception that death is something that only adults should manage and that children should be excluded, but recent research suggests that doing this might be detrimental to a child, particularly those involved in their sibling’s care throughout their illness.*

How could being involved in this procedure have assisted family members in managing their grief both in the period immediately after Jake’s death and in the following months?

*The most important reason for allowing Terri, Max, and James to be involved in performing Last Offices is that it gave them the opportunity to continue in their role as his carers and undertake the final act of caring for Jake. They have all been actively involved in Jake’s care over the past 6 months and have undoubtedly discussed this moment on a number of occasions.*

*By enabling them to be involved they can genuinely say that they did everything they could for him. Their grieving process is likely to be full of mixed emotions—relief because Jake is no longer suffering alongside the sadness that only the death of a child can bring—and giving them these precious last minutes with Jake would bring tremendous relief.*