

***Treatment and care towards the end of life:
good practice in decision making***

Supporting materials

May 2010

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Introduction

1. The General Medical Council's (GMC's) guidance, *Treatment and care towards the end of life: good practice in decision making (2010)* sets out the ethical principles underpinning good end of life care, and provides advice to support doctors in approaching these often complex and difficult situations.
2. The vignettes and case studies included in these supporting materials highlight some of the key issues and principles covered in the guidance. We hope that they will help doctors and others to understand how the principles in the guidance apply in practice.
3. The supporting materials consist of:
 - a flow chart that sets out the decision making process where questions arise about a patient's capacity to make their own decisions;
 - five short vignettes illustrating key points in the flowchart;
 - two longer case studies exploring issues arising from decisions about cardiopulmonary resuscitation (CPR) and clinically assisted nutrition and hydration (CANH), which we know can be particularly difficult for doctors, members of the healthcare team, patients and those close to them.
4. All paragraph numbers in the flowchart, vignettes and case studies refer to the GMC's guidance *Treatment and care towards the end of life: good practice in decision making (2010)*. The full guidance is available online at www.gmc-uk.org or call 0161 923 6602 for a hard copy.
5. An interactive version of these supporting materials is also available on the GMC's website at http://www.gmc-uk.org/end_of_life_care/learning

Please note

The vignettes and case studies are fictional and for illustration purposes only. They provide examples of how the decision-making model in the guidance might work in practice. Neither the flow chart nor associated material represent GMC guidance or policy in themselves, nor are they intended to replace *Treatment and care towards the end of life: good practice in decision making (2010)* or any other GMC guidance'.

End of life care: Decision making flowchart

The doctor considers what options for treatment and care and might be clinically appropriate.
(Paras. [24-27](#), [31-32](#), [38](#))

The patient has a condition or disability that may impair their capacity to make decisions about treatment and care.

(Vignette 1)

Can the patient understand, retain, use and weigh up the information needed to make the decision in question, and communicate their wishes?

Yes

No

Not sure

Patient makes the decision
(Para. [14](#))

Provide or arrange additional help and support.
(Paras. [12](#), [28-30](#), [35-36](#))

Arrange a formal assessment of the patient's capacity to make the decision.
(Paras. [11-12](#))

Not sure

(Vignette 2)

Can the patient now make and communicate their decision?

Yes

No

(Vignette 3)

Has the patient made a valid and applicable advance refusal of any of the treatments that you consider clinically appropriate?

Yes

No

Not sure

You must respect a valid and applicable advance refusal of treatment. You must not override a legally binding advance refusal.
(Paras. [16 \(c\)](#), [68-69](#))

Check the patient's records; make inquiries with those close to them, and the team providing care.
(Para. [15](#))
If an advance refusal exists and you are uncertain whether it is binding, seek advice.
(Paras. [70-74](#))

(Vignette 4)

Does someone else hold legal authority to make the decision about the patient's treatment and care?

Yes

No

Not sure

Legal proxy makes the decision.
(Paras. [16 \(d\)-\(e\)](#), [34-35](#), [43](#))

Make inquiries with those close to the patient; establish what decisions the legal proxy is authorised to make.
(Para. [15 \(c\)](#), [16 \(d\)-\(e\)](#))

(Vignette 5)

Seek information about the patient's wishes, preferences, feelings, beliefs and values, consulting:

- o the patient's record, advance care plan, written statements (Paras. [61](#), [75-77](#))
- o those close to the patient (partner, family, carers etc)(Paras. [17-21](#))
- o members of the team providing care (Paras. [22-23](#))
- o an independent mental capacity advocate, when required (Para. [16 \(g\)](#))

Make the decision, taking account of the law where you practise.
(Paras. [13](#), [16\(a\)-\(c\)](#), [\(f\)-\(h\)](#) [40-46](#))

Vignette 1

Can the patient understand, retain, weigh up and use the information to make a decision and can they communicate their wishes?

Mr Wu, who is 73 years old, was diagnosed 18 months ago with pulmonary fibrosis, after developing a dry cough and breathlessness. He had previously been quite active, playing golf regularly with his wife, Lee, and their adult children. Mr Wu understood that his condition might deteriorate over the next 2-3 years and was keen to spend as much time as possible with his grandchildren while he was still relatively well.

After a recent admission to hospital with breathing difficulties, Mr Wu expressed concern about his future health to the nursing staff, but was reluctant to discuss this when approached by Dr Reagan, the Respiratory Consultant.

Mr Wu's symptoms worsened and tests showed his lung function had deteriorated. He was started on medications that stabilised his lung function, but left him with significant breathlessness requiring short burst oxygen to manage his symptoms. Despite the treatment, Mr Wu's condition continued to deteriorate and over subsequent months he required 3 hospital admissions. He told Dr Reagan that he was tired of going back and forth from hospital, and preferred to be at home with his family, but knew that his wife found it very distressing when he couldn't breathe, and his care was taking its toll on her.

At home, he required oxygen 24-hours a day. His bed had been brought downstairs and with the help of his GP, a care package had been put in place which helped with his washing and dressing. The GP and community matron visited regularly and the community palliative care team were helping to ensure that his breathlessness and pain were effectively managed.

Dr Reagan visited Mr Wu at home, at his GP's request. Mr Wu asked frankly how long he had left to live and Dr Reagan explained it was probably a matter of days to

weeks. With Mr Wu's agreement, the community team placed his name on their end of life care register, recording his strong wish to die at home surrounded by his family, if that was at all possible.

Days later, at 8pm on a Sunday evening, Mr Wu became quite distressed. He took large doses of medication for his breathlessness and pain, but continued to call for help. As a result of the drugs and hypoxia he became quite confused. Mrs Wu called the out of hours (OOH) service who suggested calling an ambulance, but on Mrs Wu's insistence, agreed that Dr Singh the OOH GP would visit. Dr Singh found Mr Wu to be distressed by breathlessness and unable to communicate. He measured Mr Wu's oxygen saturation and concluded that he needed to be admitted to hospital. Mrs Wu explained that if her husband was going to die, she knew he would prefer to be at home with her. She was clearly upset and the OOH service advised Dr Singh that there was a note on Mr Wu's file saying he had a strong preference to die at home.

Dr Singh discussed the options with Mrs Wu. He explained that in hospital, they would be likely to be able control his symptoms more quickly and it might be possible to stabilise his condition and allow him to return home. However he understood Mr Wu's preference to be at home and he could seek advice and support from the palliative care team about how to manage the pain and breathlessness and allow Mr Wu to die at home. He explained that since Mr Wu couldn't communicate his present wishes, he needed to make a decision and felt that, on balance, it would be best to try and care for Mr Wu at home. Mr Wu's daughter arrived to support her family and Dr Singh phoned the out of hours palliative care team for further advice and to arrange for the team to attend.

GMC guidance

- Starting with the presumption that Mr Wu has capacity to make the decision in question; helping him to understand his prognosis and options for treatment and care (Paragraphs 11, 14).
- Advance care planning to encourage and support Mr Wu in thinking about what he might want to happen as his condition progresses, including his preferred place of care (Paragraphs 52-57).
- Recording and communicating Mr Wu's wishes and preferences to others involved in his care (Paragraphs 61, 75-76).
- Involving and supporting Mrs Wu; sharing relevant information (using local systems) and working in partnership with the health and social care teams to provide effective care at home for Mr Wu (Paragraphs 17-21, 22-23, 75-77).
- When Mr Wu lacks capacity to communicate his current wishes, taking account of the views of his wife and other information about his wishes and preferences, to make a decision about what treatment and care would be of overall benefit to Mr Wu (Paragraphs 12-13, 15-16, 24-26, 40-43).

Vignette 2

With additional support, can they now make a decision?

Sally Jackson is 49 and has Down's Syndrome. Twelve months ago she was diagnosed with breast cancer. She has been having chemotherapy and although she found the side-effects unpleasant and distressing, she continued with it because she thought it would cure her illness. However, recent tests have shown that the cancer has spread to other parts of her body and her condition is now terminal.

Dr Michaels is a Specialist Registrar in Oncology and has an appointment with Ms Jackson to discuss with her the options for her future treatment and care. Ms Jackson, who lives in supported accommodation, is accompanied to the appointment at the hospital by her support worker, Kim.

Dr Michaels explains the diagnosis to Ms Jackson, and tells her that there are two things they can do. She can have a round of radiotherapy which may shrink the tumour and extend her life but unfortunately will not cure her. It may also cause soreness and swelling, and will make her feel very tired. Or if she decides that she does not want radiotherapy, he can arrange for her to have specialist palliative care to control her pain and other symptoms, possibly at the local hospice. Dr Michaels tries to explain in straightforward terms what the radiotherapy will involve and what palliative care can do for her, but Ms Jackson does not seem to understand. She becomes confused and upset.

Dr Michaels asks Kim to explain the options to Ms Jackson in her own words. He then asks Ms Jackson what is upsetting her. Ms Jackson says she does not understand why he wants to give her treatment that will not make her better, and she does not want to leave her home. Kim tells Dr Michaels that Ms Jackson is usually very determined about doing things for herself but can take a while to grasp complicated situations, and hates being rushed.

As the decision does not have to be made immediately, Dr Michaels suggests that he give Ms Jackson and Kim some written information to take away, for Ms Jackson

to read when she is less distressed. He gives them an easy-read leaflet which explains what a patient can expect when they have radiotherapy, together with some information about the local hospice. He also undertakes to contact Ms Jackson's Macmillan nurse and ask her to visit and talk to Ms Jackson at home, when she has had time to digest the diagnosis and may feel less pressured than she does in the hospital environment.

The following week, the Macmillan nurse reports that Ms Jackson has decided that she does not want any more active treatment, and would prefer to go into a hospice when the time comes, but wants to stay at home for as long as she can.

GMC guidance

- Starting with the presumption that Ms Jackson has capacity to make the decision in question (Paragraph 11).
- Helping Ms Jackson to understand her options and make a decision (Paragraph 12).
- Involving Kim and Ms Jackson's Macmillan nurse in the discussion to help support Ms Jackson (Paragraphs 17-21, 22).
- Not allowing assumptions about Ms Jackson's learning disability to affect the treatment she is offered (Paragraphs 44 – 46).

Vignette 3

Do they have a valid ADRT that is applicable to the circumstances?

Matthew Cohen is 53 and was diagnosed with Motor Neurone Disease (MND) 12 months ago. Six months after diagnosis he made a written advance decision to refuse certain treatments, including antibiotics in the event that he had a severe chest infection that might threaten his life. Mr Cohen had signed the statement and it was witnessed. He had given a copy of the statement to his GP and Respiratory Consultant to place on his medical records and also to his wife.

Mr Cohen collapses and is brought into the Emergency Department late one night. He is confused, feverish and mildly dehydrated. He is not able to communicate with the ambulance team or the Emergency Department team.

Dr Philips, a Senior Registrar in the Respiratory team, is on duty and is asked to see Mr Cohen. Dr Philips diagnoses the cause of Mr Cohen's collapse as a severe chest infection that could be successfully treated by antibiotics and fluids but is uncertain whether to proceed because of Mr Cohen's advance refusal.

Mr Cohen's wife, Sharon, is at the hospital and explains that while her husband was initially adamant that he didn't want to live with MND, he has in recent months been coming to terms with his illness and is looking forward to the birth of their first grandchild in 4 months time. They have also booked a holiday to visit friends in France at the end of the year. While his symptoms are getting worse, she is adamant that he would want to receive treatment for a reversible chest infection at this time.

This is the first time Dr Philips has treated a patient with an advance decision to refuse treatment but he is aware of the law relating to medical treatment of patients who lack capacity. He believes that Mr Cohen's advance refusal is not valid because of the information from his wife that suggests a change of mind in recent months. Dr Philips checks the relevant sections of the Act's Code of Practice on the Office of the Public Guardian's website to make sure he has taken into account all of

the relevant criteria in deciding if Mr Cohen's advance refusal is valid and applicable to the circumstances.

In order to reassure himself that he is acting reasonably, Dr Philips also speaks to his on call Consultant, Dr Sharma by telephone. Dr Sharma discusses the steps Dr Philips has taken to assess the validity and applicability of the written advance refusal and the factors he has taken into account. She agrees that, on the basis of what Dr Philips has said, it would be reasonable to conclude that Mr Cohen's views had changed and that, as a result, his advance refusal of antibiotics for a chest infection was not valid.

Dr Philips provides fluids and antibiotics to Mr Cohen who responds well over night. Dr Philips' reasons for not acting on Mr Cohen's written refusal are recorded in Mr Cohen's records. Two days later Dr Philips has a discussion with Mr Cohen and his wife and Mr Cohen agrees that he feels differently now and will make an appointment with his GP to revise his advance care plan and reconsider his advance refusal which he still wants to apply when he is much closer to the end of his life.

GMC guidance

- The benefits of advance care planning (Paragraphs 50-55).
- Supporting patients to formalise their advance wishes (Paragraph 60).
- The importance of advance care plans being recorded and shared with those providing care and across different services (Paragraphs 61-62).
- The reasons why patients like Mr Cohen may choose to make an advance decision to refuse treatment in particular circumstances (Paragraph 67).
- What Dr Philips should do to decide whether Mr Cohen's advance refusal is valid and applicable (Paragraphs 68, 70-71).

- The importance of Dr Philips documenting the reasons for not following Mr Cohen's advance refusal (Paragraph 74).
- The need to review and update advance care plans as the patient's situation or views change (Paragraph 62).

Vignette 4

Does someone else hold legal authority to make the decision about the patient's treatment and care?

Mrs Kadiri is 58 and a retired nurse. A week ago she unexpectedly suffered a serious stroke during heart-bypass surgery. She remains in an intensive care unit on mechanical ventilatory support with a breathing tube still in place.

Tests, including several electrocardiograms (ECGs) and an Echocardiogram (ultrasound) suggest that some further surgery might help improve her heart function. The surgery carries significant risks because of Mrs Kadiri's condition and it is unclear, if the operation is successful, whether she will recover sufficiently to be able to leave intensive care. However, without surgery, Mrs Kadiri would remain dependent on ventilation and other intensive care support, and would be at risk of developing other organ systems failure.

Mrs Kadiri has a large family who are constant visitors. The consultant, Dr Arya, asks to talk to the family about the next steps in treating Mrs Kadiri. At the meeting, Mr Kadiri explains that his wife has given him 'a power of attorney'¹, in case anything should happen to leave her unable to decide for herself after the operation.

Dr Arya asks whether she can see the documents, and notes that Mrs Kadiri has specified that her husband can make decisions about life-sustaining treatments.

She reminds Mr Kadiri that he must make decisions that are of overall benefit to Mrs Kadiri. She suggests a meeting where the options can be explored and the benefits, burdens and risks explained – by herself, another physician who specialises in treatment of stroke, and two of the nurses who have been providing care. She suggests Mr Kadiri invites other family members too.

At the meeting Mr Kadiri and his sons listen to the assessments of Mrs Kadiri's conditions and prognosis, why she is unlikely to currently understand the situation and whether she is likely to recover functions, including speech, and the levels of pain and other discomforts arising from her treatment. The potential risks of surgery are also explained, and the probable consequences if the operation is not done. They ask questions about clinical matters, and also ask the nurses their views on how well Mrs Kadiri is tolerating treatment and whether her breathing and circulation support are causing her any distress.

The family, particularly Mrs Kadiri's sons, are distressed and overwhelmed by the situation and Mr Kadiri is hesitant about making a decision. Dr Arya reminds Mr Kadiri that he must consider what would be of overall benefit to his wife, bearing in mind his wife's values and approach to life and how they would have affected her decision in these circumstances.

Mr Kadiri asks Dr Arya whether he can take some time to consider all the information and they agree to meet the following afternoon. Mr Kadiri discusses the issues with the family, including Mrs Kadiri's mother, and with the minister from his church. He reaches the conclusion that in the circumstances further surgery would not be of overall benefit to his wife.

Mr Kadiri is reassured by the team's explanation of the steps they would take to ensure his wife's comfort and dignity and to manage any pain or distressing symptoms, including removing any active intensive care interventions and removing any devices that were not of benefit and avoiding anything that might cause her distress. It was also explained that if she remained relatively stable for many days, or even weeks, there would be support for him and the family to care for her at home, or in a hospice.

¹ In England and Wales this is a Lasting Power of Attorney; in Scotland a Welfare Attorney. There is no equivalent in Northern Ireland. Decisions must be made, in consultation with those close to the patient, on the basis of what is of overall benefit to the patient.

GMC guidance

- Understanding the scope of Mr Kadiri's legal authority to make decisions in relation to his wife's treatment and care (Paragraph 15 (c)).
- Explaining the options to Mr Kadiri, setting out the benefits burdens and risks of each option; offering support to Mr Kadiri in making a decision but being careful to not pressurise him to make a particular decision (Paragraph 16 (d)).
- The information Mrs Kadiri's sons and others close to her can contribute to help Mr Kadiri make a decision (Paragraph 16(e)).
- Recognising the emotional difficulties Mr Kadiri and his family are facing and supporting them in understanding Mrs Kadiri's condition; helping Mr Kadiri to make a decision about his wife's treatment and care (Paragraphs 33-36).
- Supporting Mr Kadiri to weigh up the benefits, burdens and risks of the treatment options for his wife and to reach a decision about what course of action would be of overall benefit (Paragraphs 40-43).

Vignette 5

Seek information about the patient's wishes, preferences, feelings, beliefs and values from

- *those close to them (family, friends, carers)*
- *members of the team providing care*

Take the views of those consulted into account in making a decision about what would be of overall benefit for the patient

Mrs Julia Young is 80yrs old and living in a care home. She is quite frail but has no underlying chronic medical conditions.

Mrs Young recently became poorly and seemed to lose her appetite. On Saturday morning she was complaining of a sore throat, high temperature and nausea. The care home manager Mrs Field called the out of hours (OOH) GP and they decided to visit. On examination, Mrs Young had an inflamed, swollen throat; she was very weak and confused and probably was dehydrated. When the OOH GP Dr Morgan said he wanted to admit her to hospital for further assessment and treatment, Mrs Young became quite agitated but wasn't able to speak.

Mrs Young's daughter Anna had arrived and she told the GP that her mother feared being admitted to hospital. Some months ago, her husband was admitted after a fall and died in hospital after getting an infection. Her mother had been very distressed because it had happened so quickly and unexpectedly. Anna would prefer it if her mother could be treated at the home. The care home manager agreed that Mrs Young was fearful of going into hospital; adding that she had been a bit depressed since a friend of hers in the home had died.

Dr Morgan asked Anna about what had happened when Mr Young was admitted to hospital after his fall. Mrs Field checked the information in the care records about Mrs Young's recent general health. Between them, it was agreed that while Mrs Young's fears were understandable, it would be of overall benefit for her to be admitted to hospital for treatment. Dr Morgan believed her condition was reversible with antibiotics and fluids which the hospital could provide by using a drip or tube.

This was highly unlikely to involve a long stay in hospital, as was necessary to treat her husband after his fall. They explained this to Mrs Young, assuring her that Dr Morgan would ask the GP practice to visit once she was settled back at the care home, so she could have a chance to discuss any worries that she had about her future care. She seemed to become more settled and Dr Morgan arranged her admission to hospital.

GMC guidance

- Assessing Mrs Young's capacity to make a decision about whether to go to hospital and maximising her ability to make a decision (Paragraphs 11-12).
- What steps should the doctor and other members of the team take to make a decision if Mrs Young is not able to make the decision for herself (Paragraphs 15-16).
- How to take account of the information from Mrs Young's daughter and the nursing home manager (Paragraphs 15-16, in particular 16 (f), 17-21).
- Making a decision about what action would provide overall benefit to Mrs Young (Paragraphs 41 and 43).
- How to deal with Mrs Young's general fears about dying in hospital (Paragraphs 33-36).
- Helping Mrs Young to talk about her fears and her wishes and preferences for treatment and care at the end of her life (Paragraphs 50-55).

Case Studies

Case study 1: Decisions about future cardiopulmonary resuscitation

Part 1

Mr Alan Bruce is 42 and a self employed electrician. He has a partner, Donna, and two teenage children. He has recently been diagnosed with prostate cancer with bone metastases following investigations for back pain. His disease initially responded to hormone therapy but a repeat bone scan shows clear disease progression. He accepts the offer of palliative (non-curative) chemotherapy to be given in three cycles to improve his symptoms, because he wants to keep going as long as possible. After the first cycle, the chemotherapy is put on hold as he experiences severe nausea and vomiting.

Just as the nausea and vomiting is starting to settle, Mr Bruce develops a chest infection. His GP visits and starts oral antibiotics. Mr Bruce has sudden onset chest pain after a bout of prolonged coughing and takes several doses of his usual pain medication. But then his partner discovers him slumped in a chair barely breathing. Donna phones the ambulance. In the Emergency Department they conclude that his breathing difficulties result from the sensitivity he has developed to his pain medication - he is given treatment to reverse this effect - and he is admitted to the intensive care unit (ITU) with severe pneumonia.

After 24 hours of ventilation and IV antibiotics Mr Bruce is improving; he's waiting for a bed on the medical ward. His ITU consultant, Dr Douglas, reviews his medical history and investigations which show that he has a rib fracture and cancer deposits in several other ribs. She discusses with the ITU nursing and medical team that there is a significant risk that Mr Bruce could suffer a cardiac or respiratory arrest; this might be reversible if it were due to the effect of his pain medication on his breathing; however the new information about the cancer deposits in his ribs meant that CPR carried a clear risk of significant harm to Mr Bruce. If his heart stopped for

any reason attempting CPR would be likely to have significant and severe side effects. They agree there's a need to consider making a DNACPR decision.

Mr Bruce is improving – how should the ITU team decide if this is a decision that they need to discuss with him?

- What are the likely benefits, burdens and risks of CPR for Mr Bruce? (Paragraphs 24-25, 40-42, 128-131, 133 of the guidance)
- What is Mr Bruce's understanding and expectations about his condition and the likely course of his disease? (Paragraphs 28, 132-133)

The team agree that it is uncertain whether CPR would work, but the likelihood is that CPR, if successful, would result in rib fractures and would possibly result in a flail chest, punctured lung, ruptured spleen or liver and therefore significant morbidity for Mr Bruce. It would be helpful to know Mr Bruce's views, but they are also concerned about raising the issues with him at this stage.

What factors do the team need to consider?

- Might he be willing to discuss, in general terms, his wishes about end of life care? (Paragraphs 52-55, 137-138)
- Can there be realistic discussion about the physical nature of CPR treatment and the likely clinical and other outcomes in his case, or would this need to be approached gradually? (Paragraphs 55-58, 138-139)

Part 2

Mr Bruce understands that his disease is progressing. He is adamant that he wants every effort to be made to keep him alive; he has only just started palliative chemotherapy and believes that if he has the chance to continue with that, he may

get several more months with his family. He is willing to accept the significant risk of pain and morbidity from CPR, for the small chance that it would keep him alive. He is distressed that there is any consideration that a DNACPR order might be appropriate for him and accuses Dr Douglas of giving up on him. Donna asks to see Dr Douglas on her own. She is very upset that the issue of CPR has been raised with her partner when he is struggling to recover. Donna insists that any further discussions about it should be with her, not her partner.

- How should Dr Douglas respond to Donna's concerns and her wish to make decisions on behalf of her partner? (Paragraphs 17-21, 28, 30, 59).
- How should Dr Douglas take account of Mr Bruce's views? (Paragraphs 14, 40-42, 63-64, 139).

Dr Douglas and the ITU team feel that the benefits, burdens and risks of CPR are finely balanced for Mr Bruce. So, given Mr Bruce's clearly expressed wish that CPR should be attempted, Dr Douglas concludes that a DNACPR order should not be made. She records the decision in the clinical notes.

Part 3

Four months later Mr Bruce is readmitted to the Oncology Unit with severe shoulder pain and he is noted to be jaundiced on admission. Investigations confirm that he has extensive liver metastases and is anaemic with signs of bone marrow infiltration. Dr Jensen the oncologist discusses the results with Mr Bruce and his partner and explains that there are no further chemotherapy options. Mr Bruce's prognosis is very limited and the aim now is to provide treatment that manages his symptoms and keeps him as comfortable as possible, and to get him home if that is where he wants to be. He asks whether Mr Bruce feels able to discuss his situation and future care.

Mr Bruce is devastated. He perceives the consultant's question about future care as a way of raising CPR again and insists that he has already made it clear that he

wants it to be attempted. Dr Jensen makes some further attempts to explore Mr Bruce's situation with him and his family. But Mr Bruce is clear he wants to get home; he doesn't want to discuss his prognosis and what may happen at home.

- As Dr Jensen judges that CPR will not be successful in Mr Bruce's circumstances, what would he need to consider before making a DNACPR decision? (Paragraphs 56-58, 134-135).
- Could Dr Jensen discuss his decision that a DNACPR order should be made with Donna, who will be Mr Bruce's main carer at home, or with the GP? (Paragraphs 19, 22, 28, 34-35, 75-77, 143-144).

Part 4

Mr Bruce agrees that Dr Jensen can discuss and agree arrangements for his care at home with his wife and inform his GP about his current condition. The GP is advised that Mr Bruce is at risk of cardiac or respiratory arrest; that Dr Jensen considers that CPR will not work in Mr Bruce's current circumstances; Mr Bruce is unwilling to accept this at present; no DNACPR order has been made, but his prognosis has been discussed with his partner Donna.

The GP visits Mr Bruce shortly after discharge. Mr Bruce has been in bed since discharge and says he feels too tired and unwell to talk about anything. The GP asks if its okay to talk about the details of his care with Donna and Mr Bruce agrees. It emerges that Mr Bruce has admitted to Donna that he was terrified of dying in hospital. He has made her promise that he will be able to stay at home and has been making arrangements to take care of his will. They discuss what needs to happen to meet Mr Bruce's wishes and a DNACPR form is completed by the GP in discussion with Donna. He provides her with information about who to contact out of hours and local support services if she is finding it difficult to cope. Mr Bruce continues to deteriorate and dies peacefully at home 8 days after discharge from hospital.

Case Study 2: Decisions about clinically assisted nutrition and hydration (CANH)

Part 1

Mr Singh is 82 and the head of a large Sikh family. He had a haemorrhagic stroke two months ago which left him with a reduced consciousness level and unable to communicate in any meaningful way. He did, however, retain the ability to swallow soft food. His family, including his daughters and granddaughters, have cared for him at home and have been feeding him by mouth for the duration of his illness.

During the last week his consciousness level has declined a little more and he is now having difficulties swallowing. Dr Dawson, Mr Singh's GP for the past six years, suspects that he has had further cerebral bleeding. She is concerned that Mr Singh may choke on food or aspirate, causing a chest infection, and discusses her concerns with Mr Singh's daughters. They want to continue caring for their father at home including feeding him by mouth if this is at all possible. It is an important part of their culture and the care they provide, and they feel strongly that it is what Mr Singh would want.

What factors should Dr Dawson be taking into account to decide what to do next?

- Approaching decisions when patients lack capacity (Paragraphs 15-16 of the guidance).
- Making sound clinical judgements (Paragraphs 24-27, including seeking advice or a second opinion).
- Assessing whether Mr Singh is receiving nutrition and hydration to meet his needs by oral feeding, including assessing any underlying causes for his swallowing difficulties (Paragraphs 109-111).

Dr Dawson feels that Mr Singh's swallowing difficulties need specialist assessment and she needs some further advice about how to best manage his care at home given what she knows about Mr Singh's wishes. She asks Dr Garcia, a Palliative Care consultant, and her team to assess Mr Singh at home.

The team do not find any reversible cause, such as mouth ulcers, which might be causing Mr Singh's swallowing difficulties. They recognise that Mr Singh has been very well cared for by his family and that, up until now, his nutrition and hydration needs have been met by the food and fluids that they have been providing. However, Dr Garcia is concerned that Mr Singh's swallowing difficulties mean that he may not get sufficient nutrition and hydration by mouth and there are some indications that he is dehydrated.

What factors should the palliative care team be taking into account to decide whether to provide nutrition and hydration using a drip or a nasogastric or surgically inserted tube (clinically assisted nutrition or hydration)?

- Considering what options for clinically assisted nutrition and hydration might be clinically appropriate for Mr Singh (paragraphs 112-115).
- Assessing his nutrition and hydration needs separately (paragraph 118).
- Their approach to decisions about an adult patient who lacks capacity to decide and who is expected to live for many more weeks/days (Paragraphs 119-122).

Part 2

Dr Garcia and her team conclude that to meet Mr Singh's hydration needs, the use of a drip would be clinically appropriate in the short term and it might be possible, though difficult and risky, to continue to meet his nutrition and hydration needs at home by careful oral feeding.

Mr Singh's family clearly wish to continue to care for him at home, and reaffirm that he also expressed this wish when he was still able to communicate. They are very concerned that if he goes into hospital he will not be able to come back home. They stress to Dr Garcia that despite their father's difficulties swallowing, he can still take some soft food and fluids and they believe they could manage the risks at home with advice and support from the palliative care nurses.

How should Mr Singh's wishes and the family's request be taken into account?

- Recognising the family's role in helping the healthcare team to understand Mr Singh's wishes, preferences, feelings, beliefs and values (paragraph 16 (f))
- Taking account of the family's role in providing care to Mr Singh and their need for information and support (Paragraphs 17-21).

Part 3

Dr Dawson knows that Mr Singh and his family consider it important for him to be at home, surrounded by his family and community and to be cared for in accordance with his cultural beliefs. In discussion with Dr Garcia and her team they agree it should be possible to manage Mr Singh's nutrition and hydration needs at home, with support from the palliative care team, but this would need careful monitoring.

How should Dr Garcia and her team approach the discussions with the family and what should these include?

- Explaining the clinical issues in a way that the family can understand, being sensitive to their concerns and anxieties (Paragraphs 28-30, 34-35).
- Planning ahead to address any changes in Mr Singh's condition (paragraphs 50-51, 75-78).

The risks of Mr Singh choking or aspirating food into his lungs are discussed and it is agreed that the family will offer thickened fluids and only small amounts of soft food to Mr Singh. Dr Dawson explains that Mr Singh's nutrition and hydration status will have to be monitored and the decision to continue with oral feeding will be reviewed if Mr Singh's circumstances change or if it appears that he is not getting sufficient nutrition or hydration. The family will need to carefully record Mr Singh's intake of food and fluids. Dr Garcia also explains that If Mr Singh's condition stabilises but he continues to have difficulty swallowing, or those difficulties increase, other measures for meeting Mr Singh's nutrition and hydration needs might need to be considered, for example by a PEG tube surgically inserted into his stomach.

After extensive discussions between Dr Garcia, Dr Dawson, the nursing team and Mr Singh's family, it is agreed that a drip will be put up to provide hydration and that Mr Singh does not need to go to hospital at this stage. It is agreed that the community palliative care team will visit regularly to review Mr Singh's condition and ensure the family have the support they need to provide care safely at home.

Part 4

Two weeks later, Mr Singh is admitted to hospital with a chest infection caused by aspiration of food into his lungs. He is treated with IV antibiotics and a drip is inserted to provide hydration while further assessment of his condition is made. A CT head scan shows that Mr Singh has suffered progressive cerebral bleeding. It is clear that Mr Singh is no longer able to take nutrition or hydration by mouth.

What factors do the healthcare team need to consider in deciding what action would be of overall benefit to Mr Singh?

- Assessing the overall benefit of treatment options for Mr Singh (Paragraphs 40-46).
- Making decisions about clinically assisted nutrition and hydration for an adult patient who lacks capacity and is expected to die within days (Paragraph 123).

Dr Garcia and her team consider that it might be clinically appropriate to insert a PEG but they judge that Mr Singh only has a few days to live; clinically assisted nutrition would not extend his life; and any benefits are outweighed by the burdens of the procedure. The team explain to Mr Singh's family the factors they have weighed up in reaching a view that clinically assisted nutrition would not be of overall benefit for Mr Singh at this stage. They believe that the goals of care should be focused on palliation - managing any pain and other symptoms and keeping him comfortable in the remaining few days. They explain that this would mean Mr Singh could be transferred home if that was what he would want to happen.

The family are struggling to come to terms with their father's situation. They are anxious to meet his wishes to die at home but do not really understand what it will involve and are worried about him not receiving nutrition or hydration.

What support might the family need at this time?

- Supporting the family to understand the options for treatment and care at this stage in Mr Singh's condition, and to cope with the emotional distress they are feeling (Paragraphs 24-26, 28-30, 33-36).

Part 5

As requested by one of Mr Singh's daughters, Dr Garcia arranges for the hospital's multi faith chaplaincy service to speak with the family, and for the discharge nurse to help explain what they can expect to happen if Mr Singh goes home.

The family are reassured that they will receive support from the palliative care team to help them care for Mr Singh. They agree that clinically assisted nutrition would not be of overall benefit at this stage and that the goals of care should focus on managing any pain and other symptoms and ensuring their father's dignity and comfort will be maintained. It is agreed that a drip will be continued to provide hydration. Dr Garcia explains to the family that it will need to be closely monitored and may need to be withdrawn if it is causing harm (for example secretions of fluid into Mr Singh's lungs).

Mrs Garcia sensitively raises the possibility that Mr Singh might develop another chest infection or might have a cardiac arrest. The family agree that a Do not attempt resuscitation form should be completed to try and ensure that Mr Singh's wishes to die at home are respected, and that antibiotic treatment for a chest infection would not be of overall benefit in these circumstances. A DNA CPR form is completed and sent to the local ambulance service and the family take a copy home with them.

Mr Singh is transferred home where he dies peacefully five days later.