

Assessing mental capacity

GMC Interactive decision support tool: Case studies

Maximising capacity for a patient with Downs syndrome: Sally Jackson

With additional support, can the patient now make and communicate their decision?

Case study 1

Sally Jackson is 49 and has Downs 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

All paragraph numbers in the vignettes refer to the GMC's guidance *Treatment and care towards the end of life: good practice in decision making* (2010). You can [download the guidance here](#) (486 kb, pdf) for reference.

- 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).

With additional support, can the patient now make and communicate their decision?

Case study 2

Tracey Searle has Down's syndrome and is 25 years old. She lives in a residential home for adults with learning disability and works in a sheltered garden centre placement under supervision.

She attends with a male member of the care home staff, Sam, to see the practice nurse. It transpires that the appointment has been booked in response to a letter inviting Tracey for a cervical screening test. Tracey does not appear to the practice nurse to understand why the appointment has been made. Sam is keen to get the appointment over with as he needs to return to the residential home to take some other residents to a work placement and is impatient with the practice nurse. The practice nurse is concerned that Tracey will be unable to give informed consent for the procedure and asks Dr Mitchell to see her.

Dr Mitchell talks to Tracey on her own to see how much she understands about why the appointment has been made. It is clear that no-one had discussed the appointment and its purpose with Tracey. Dr Mitchell suggests to Tracey that it would be better if she had some time to discuss the purpose of cervical screening tests with a nurse and has more information about how they are carried out. Tracey makes it clear that she would prefer to talk about this with one of the female members of staff with her as well. Dr Mitchell asks Tracey if she is happy for this to be explained to Sam and the manager of the care home and Tracey agrees to this.

Dr Mitchell telephones the care home and speaks to the manager to let them know what is happening. She explains that she wishes to arrange for the specialist learning disability nurse to visit Tracey and discuss cervical screening. She also advises the home of Tracey's preference for a female carer to accompany her to future appointments. Dr Mitchell then contacts the specialist learning disability nurse and explains the situation to her. The learning disability nurse visits Tracey at her home and takes with her some easy read information about cervical screening and a video to explain the procedure.

A further appointment is then booked to see Dr Mitchell, and Tracey attends with a female care worker, June. They have a discussion together and Dr Mitchell feels satisfied that Tracey understands how a smear test is taken and why it is being done. Dr Mitchell documents the discussion in the medical records and the fact that Tracey has capacity to give informed consent for the procedure. She attends for a further appointment with the nurse, supported by June. This time it is clear to the nurse that Tracey knows why she is attending and she is able to have her smear test. Dr Mitchell then sees her again 3 weeks later to discuss the results face to face and ensure that they are explained properly.

GMC guidance

All paragraph numbers in the vignettes refer to the GMC guidance *Consent: patients and doctors making decisions together* (2008).

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

You must work on the presumption that every adult patient has the capacity to make decisions about their care

Case study 3

Mr Lang is 83-year-old with a known diagnosis of vascular dementia. His wife died three years ago and he was unable to cope alone at home. The couple had no other close family. He had consented to admission to the care home at that time. There is little doubt that his dementia has worsened. In particular, it affects his speech: he has expressive dysphasia with obvious word-finding problems. Nevertheless, it is felt that he can understand most things said to him.

In addition, a choroidal melanoma was diagnosed four years ago. But before he came into the care home he made an advance decision to refuse treatment (ADRT) for the eye tumour. He said he was too old and preferred to take his chances. He was aware that this might eventually lead to his death. The ADRT was properly signed and witnessed and is still considered to be both valid and applicable.

There are now two issues for the home. First, the staff have noticed that his affected eye is bulging, which it was not doing previously. Secondly, he has been coughing up green phlegm and has spent yesterday in bed not eating.

Dr Tuke is a new GP in the practice and he has not previously met Mr Lang. Mr Lang can be difficult to understand but some of the staff in the home can communicate effectively with him. Dr Tuke sees him with a member of staff. Mr Lang looks unwell: he is thin, has a fever, is somewhat unkempt having spent a day in bed and his room is malodorous. In addition, his face looks quite odd because there is no doubt that his eye is bulging from its socket. Mr Lang is quite apathetic but complies with an examination and Dr Tuke confirms that he has a chest infection. Otherwise, apart from the appearance of the eye, he can find no further evidence of pathology. He is still able to swallow and has been compliant with taking his medication.

Although he is clearly quite poorly, Dr Tuke explains that he thinks he has an infection in his lungs. He does not respond, but when he suggests that it might be treated with an antibiotic he nods and says "yes". Dr Tuke feels comfortable to assume that he has capacity to give consent to the antibiotic treatment.

He then asks him about his eye and whether it is giving him any problems. He grimaces a little and says "problem". He asks if it is causing any pain and he says "yes, problem". He is not on regular analgesia, so Dr Tuke offers this and again assumes he has capacity to consent to this treatment. He then asks Mr Lang if, perhaps, he ought to be seen in the eye hospital because his eye seems bigger than it ought to be. At this, he becomes agitated and says some words Dr Tuke cannot make sense of, although he seems to be repeating the word "problem". Dr Tuke is not sure if he is simply perseverating. But he asks for help from

the care assistant who is with him. He explains again to Mr Lang that the doctor is wondering if he should go to hospital for his eye. Mr Lang still seems upset, but the carer calms him and Mr Lang then very clearly says “No hospital”. The carer confirms that Mr Lang has never liked hospitals and he states emphatically “Never”. Dr Tuke also confirms that he is aware of his previously written statement (her ADRT), which says that even if it were to worsen and be a threat to his life he would not wish to have further treatment. He agrees. Dr Tuke says he will record this for him, for which she seems grateful.

GMC guidance

All paragraph numbers in the vignettes refer to the GMC’s guidance *Consent: patients and doctors making decisions together* (GMC 2008).

- Dr Tuke presumes that Mr Lang has the capacity to consent both to examination and to treatment for his chest infection and to regular analgesia for his pain, despite his communication difficulties. (Paragraph 64)
- Dr Tuke does not assume that he lacks capacity simply because he is old, is unkempt, has a diagnosis of dementia and has expressive dysphasia. (Paragraph 65)
- Some of the decisions are fairly simple, e.g. he wishes to have antibiotics for an infection and he wishes to have pain relief, so it is easier for him to retain the ability to make a decision for himself. (Paragraph 66)
- In order to be sure that he understands what he is trying to communicate in connection with the more complex decision about going to hospital about his eye tumour, Dr Tuke asks for help from the carer from the care home, which facilitates Mr Lang’s ability to communicate. (Paragraph 68)
- Dr Tuke keeps a written record of the consultation and of the decisions that were made. (Paragraph 70)

Has the patient made a valid advance decision to refuse treatment (ADRT) that is applicable to the circumstances?

Case study 4

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 she is aware of the law relating to medical treatment of patients who lack capacity. She 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 she 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 herself that she is acting reasonably, Dr Philips also speaks to her 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 she 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

All paragraph numbers in the vignettes refer to the GMC's guidance *Treatment and care towards the end of life: good practice in decision making* (2010). You can [download the guidance here](#) (486 kb, pdf) for reference.

- 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).

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

Case Study 5

Mr Foster, 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, Julie, and their adult children. Mr Foster 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 Foster 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 Foster'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 Foster'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 Foster at home, at his GP's request. Mr Foster asked frankly how long he had left to live and Dr Reagan explained it was probably a matter of days to weeks. With Mr Foster'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 Foster 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 Foster called the out of hours (OOH) service who suggested calling an ambulance, but on Mrs Foster's insistence, agreed that Dr Singh the OOH GP would visit. Dr Singh found Mr Foster to be distressed by breathlessness and unable to communicate.

He measured Mr Foster's oxygen saturation and concluded that he needed to be admitted to hospital. Mrs Foster 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 Foster's file saying he had a strong preference to die at home.

Dr Singh discussed the options with Mrs Foster. 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 Foster'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 Foster to die at home.

He explained that since Mr Foster 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 Foster at home. Mr Foster'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

All paragraph numbers in the vignettes refer to the GMC's guidance *Treatment and care towards the end of life: good practice in decision making* (2010). You can [download the guidance here](#) (486 kb, pdf) for reference.

- Starting with the presumption that Mr Foster 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 Foster 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 Foster's wishes and preferences to others involved in his care.
(Paragraphs 61, 75-76)
- Involving and supporting Mrs Foster; 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 Foster.
(Paragraphs 17-21, 22-23, 75-77)
- When Mr Foster 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 Foster.
(Paragraphs 12 13, 15-16, 24-26, 40-43)

Powers of Attorney

Case study 6

Mrs Clarke 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 Clarke'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 Clarke would remain dependent on ventilation and other intensive care support, and would be at risk of developing other organ systems failure.

Mrs Clarke 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 Clarke. At the meeting, Mr Clarke 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 Clarke has specified that her husband can make decisions about life-sustaining treatments. She reminds Mr Clarke that he must make decisions that are of overall benefit to Mrs Clarke. 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 Clarke invites other family members too.

At the meeting Mr Clarke and his sons listen to the assessments of Mrs Clarke'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 Clarke is tolerating treatment and whether her breathing and circulation support are causing her any distress.

The family, particularly Mrs Clarke's sons, are distressed and overwhelmed by the situation and Mr Clarke is hesitant about making a decision. Dr Arya reminds Mr Clarke 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 Clarke asks Dr Arya whether he can take some time to consider all the information and they agree to meet the following afternoon. Mr Clarke discusses the issues with the family, including Mrs Clarke'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 Clarke 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.

GMC guidance

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

Footnotes

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.

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

- **the patient's records**
- **those close to the patient (family, close 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

Case study 7

Mrs Julia Young is 70yrs 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 Mrs Young was admitted to hospital after her 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

All paragraph numbers in the vignettes refer to the GMC's guidance *Treatment and care towards the end of life: good practice in decision making* (2010). You can [download the guidance here](#) (486 kb, pdf) for reference.

- 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).

Please Note

The vignettes attached to the flow chart are fictional and for illustration purposes only.

They provide examples of how the decision-making model in the guidance might work in practice.

They do not 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 *Consent: patients and doctors making decisions together* (2008).

All paragraph numbers refer to the GMC's guidance [Treatment and care towards the end of life: good practice in decision making](#) (2010) (468 kb, pdf) and [Consent: patients and doctors making decisions together](#) (2008) (386.24kb, pdf).

