

STATION 19

Information given to candidates

The appointment has been booked by Raymond Mallory's sister, Stephanie Mallory. She wants to talk to you about Raymond, who has Down's syndrome and is a patient at your practice. Raymond's sister lives 70 miles away and is attending on her own today.

Raymond is 44 years old and lives in supported accommodation for people with mild to moderate learning disabilities.

Raymond suffers from diabetes and heart failure, secondary to an incompetent mitral valve. His current medication is:

Spirolactone	25 mg OD	Bisoprolol	10 mg OD
Furosemide	80 mg OD	Metformin	500 mg TDS
Ramipril	5 mg BD	Gliclazide	80 mg OD

The last letter from the cardiologist from a month ago noted that Raymond's heart failure appeared to be gradually deteriorating despite treatment. His renal function is normal and his diabetes well controlled. The cardiologist is due to see him again in 1 month.

Raymond has had three admissions (all less than 1 week's stay) in the last year as a result of worsening breathlessness secondary to heart failure.

On the last admission Raymond was assessed by one of the psychiatrists who judged that he had the capacity to discharge himself early, against medical advice.

Raymond has not appointed anyone to make medical decisions on his behalf (lasting power of attorney).

As Stephanie Mallory enters the room she says, 'Doctor, I want to talk to you about Raymond. He's been so unwell over the last year, the family doesn't think he should go into hospital again if his breathing gets bad.'

- What do you think this station is testing?
- Make notes or discuss your thoughts with a colleague before you read on.





Plan your approach to this station:



Information given to simulated relative

Basic details – You are Stephanie Mallory, a 50-year-old woman and the older sister of Raymond Mallory, who is a patient at the practice. You are attending on your own today. You live 70 miles away and visit Raymond once a month.

Appearance and behaviour – You are well presented and assertive. If the doctor does not agree to your request to keep Raymond out of hospital then you will initially be a little shocked. However, if the doctor explains carefully why this is the case, and takes your perspective and concerns into account, then you will accept this.

History

Freely divulged to doctor – You want to talk to the doctor about your brother, Raymond, who has Down's syndrome. Raymond had an operation on one of his heart valves when he was a baby and over the last 4 years has been suffering from 'heart failure'. He used to see the local heart specialist once every 6 months, as initially things weren't too bad. But now he's very breathless even if he potters around in the garden and his lips always have a bluish tinge. He now sees the heart doctor every 2–3 months.

Divulged to doctor if specifically asked – Raymond is now taking lots of medication, and the heart failure specialist nurse visits every 2–3 weeks to see how he is doing. His ankle swelling seems to have got worse over the last few months, even though Raymond knows that he needs to be careful with how much he drinks. He still seems generally happy and his keyworker – one of the supported accommodation staff – often takes him out on trips or to various groups. Raymond does not seem to know what the heart doctor said to him when he last saw her 1 month ago. Raymond knows that his heart is not working properly and that he has to take all his tablets to help it. You have not discussed with Raymond what he would like to happen if his breathing gets bad again. You have only discussed this with one of Raymond's three brothers. Raymond does not know that you are coming to see the doctor today.

Ideas, concerns and expectations – You still feel a little guilty about moving so far away when your partner got a new job 4 years ago. Raymond has always disliked going into hospital. But over the last year he has become more and more distressed when he has gone in, so much so that the last time he was admitted he came home early, against medical advice. With his worsening condition, and his dislike of hospitals, you believe he should not have to undergo this trauma again if his breathing deteriorates, and should instead be kept at home. You want the doctor to agree with you today that Raymond will stay at home if his breathing gets bad again rather than going into hospital, and you would like this written in his notes.

First words spoken to doctor – 'Doctor, I want to talk to you about Raymond. He's been so unwell over the last year; the family doesn't think he should go into hospital again if his breathing gets bad.'

Medical history – You are fit and well. Raymond suffers from 'heart failure' and diabetes.

Drug history – You do not take any medication. You know that Raymond is on 'lots of tablets' for his heart failure and diabetes.

Social history – You live 70 miles away with your own family. You work as a primary school teacher.

Family history – Apart from Raymond's problems, there are no other significant medical problems in your immediate family.

- Having read the information given to the simulated relative, what do you now think this station is testing?
- Make notes or discuss your thoughts with a colleague before you turn the page.

Review your approach to this station:

Tested at this station:

1. Addressing a relative's concerns.
2. Data gathering.
3. Respecting patient autonomy.
4. Negotiating with a patient's relative.

Domain 1 – Interpersonal skills

Addressing a relative's concerns

This station is primarily about addressing the concerns of a patient's close relative, while respecting patient autonomy and confidentiality in negotiating a way forward. As such, your ability to relate to Raymond's sister in an empathetic and supportive way is a key skill:

- Raymond's sister is obviously concerned about her brother's well-being. You should acknowledge this and ask her to say more about her worries.
- She mentions him being 'so unwell' over the last year. Can she say more about this?
- Is there any particular reason why she is so worried about him going into hospital again? Did anything happen in the last few admissions which upset or concerned her?
- What sort of impact has Raymond's learning disability had on her life?
- Has it been difficult balancing her own life with helping support Raymond?
- Has Raymond ever mentioned what he would like done if his health deteriorates further?
- Has she discussed this matter with anyone else?

Domain 2 – Data gathering, technical and assessment skills

Data gathering

It would be useful to obtain further details about Raymond's health, to help inform you when negotiating a way forward with his sister:

- How is Raymond doing at the moment?
- What is he able to do, what is he not able to do? Is he getting out?
- How have things changed over the last year?
- Does Raymond understand what is happening with his heart problem?
- Is he taking his medication as prescribed?
- Has Raymond said anything that might make you think his poor health is getting him down?
- Has his behaviour changed in any way recently?

Domain 3 – Clinical management skills

Respecting patient autonomy

All adult patients have a right to respect for autonomy (self-determination):



- Under the Mental Capacity Act 2005 for England and Wales, adult patients are presumed to have capacity to make decisions for themselves unless proven otherwise.
- Stephanie Mallory is asking you to make an advance decision regarding withholding care from Raymond, should his condition deteriorate. You are not in a position to agree to this request without consulting Raymond himself.
- Just because a patient has a learning disability does not mean they are incapable of making decisions regarding their medical care. Indeed, Raymond was judged to have the capacity to agree his own discharge during his last admission.
- Although Stephanie believes she has Raymond's best interests at heart, and is a close relative, she has no legal right to determine Raymond's medical treatment.
- Nonetheless, it is good practice to involve relatives in key decisions, with the patient's consent.
- Given Raymond's gradual deterioration, it would be good practice to discuss with him his wishes should he become very ill.

Negotiating with a patient's relative

Although you are not able to agree to Stephanie's request that you keep Raymond at home if he becomes unwell again, you should focus on positive ways forward, emphasizing the need to involve Raymond at all stages:

- You need to sensitively explain that it is important to involve Raymond in any decisions about his future care.
- You could suggest that Stephanie first discusses the issue with Raymond – what would he want to happen if he became ill again? What did he think about being in hospital?
- You could also suggest that Stephanie speaks with Raymond's brothers – what are their thoughts on the matter?
- Involving his keyworker might also be useful – Stephanie could ask her whether Raymond has ever talked about his wishes if he became ill again.
- You could offer to see Raymond to discuss things further. If Raymond is happy, you could see them both together. And you could ask the heart failure nurse specialist to attend, too, if Raymond is ok with this.
- Raymond and his sister may also find it helpful to discuss the issue with his cardiologist at the next appointment.
- You need to be careful to not breach patient confidentiality when negotiating how best to proceed.

Knowledge base

References: see Further reading below

Common and/or important conditions associated with learning disabilities

- *Epilepsy* – increased incidence and complexity with severity of learning disability.
- *Sensory impairments* – hearing and vision, ear wax.
- *Obesity* – predisposes to other medical problems.

- *Gastrointestinal* – swallowing problems, reflux oesophagitis, *Helicobacter pylori* infection, constipation, gastric carcinoma.
- *Respiratory problems* – chest infections, aspiration pneumonia.
- *Cerebral palsy* – especially with severe learning disability.
- *Orthopaedic problems* – joint contractures, osteoporosis.
- *Dermatological problems*.
- *Psychiatric problems* – emotional and behavioural disorders, bereavement reactions, anxiety and depression, schizophrenia, bipolar affective disorder, Alzheimer's disease, autistic spectrum disorder.

Diagnostic overshadowing

The GP curriculum warns against 'diagnostic overshadowing', which is when the presenting complaint of a patient with a learning disability is put down to their learning disability rather than health professionals looking for another cause.

If a patient with a learning disability presents with a new behaviour, or existing ones escalate, you should not dismiss these symptoms as simply due to their learning disability but consider physical, psychiatric and social causes:

- Physical and psychiatric causes – see above.
- Social causes – change in carers, bereavement, abuse.

Take-home messages

- Patients with learning disabilities have the same right to respect for patient autonomy as other patients.
- Make sure you involve patients with learning disabilities as fully as possible in decisions about their care.
- When those close to patients consult you about their relative's/spouse's care, you need to address their concerns in an empathic and supportive way.

Tasks

- Re-run the scenario with Raymond's housing keyworker attending on her own, asking what they should do if Raymond's breathing worsens.
- Re-run the scenario with Raymond and Stephanie attending together to discuss making an advance directive.
- Re-run the scenario with Raymond attending on his own with ear wax. What other issues might you want to discuss?
- For MRCGP[INT] candidates there may be differences in the degree of patient autonomy and the position of relatives in relation to power of attorney and other country-specific legal issues. Re-run the scenario focusing on how the relative feels in relation to the hospital event, discussing what to do if Raymond becomes breathless again and raising the possibility of his death.

1-minute explanations for patients

- Explain what Down's syndrome is.
- Explain what lasting power of attorney is.
- Explain to a relative how capacity is assessed.

Ideas for further revision

Some Clinical Skills Assessment (CSA) stations will primarily be concerned with issues around professionalism and ethics. These topics are specifically covered in the GP curriculum. You should be familiar with the curriculum document and also with key professional guidelines, including those related to confidentiality and consent.

Further reading

e-GP resource has e-learning modules covering the RCGP curriculum, including several on the care of patients with learning disabilities www.e-gp.org

General Medical Council. *Confidentiality*. London: GMC, 2009 www.gmc-uk.org

General Medical Council. *Consent: patients and doctors making decisions together*. London: GMC, 2008 www.gmc-uk.org

Lindsay P (ed). *The Care of the Adult with Intellectual Disability in Primary Care*. Oxford: Radcliffe Press, 2011

RCGP curriculum statement 3.3 – Clinical ethics and values-based practice www.rcgp.org.uk

RCGP curriculum statement 14 – Care of people with learning disabilities www.rcgp.org.uk