Case study

Caring for a patient who has made an advance decision to refuse treatment

Patient notes

- James Lang – 83 years old, lives in a care home since his wife died in 2016, diagnosis of vascular dementia since 2015, which has deteriorated.

- Has expressive aphasia and difficulties finding words. It is felt he understands what is said to him.

- He has a choroidal melanoma diagnosed 2013. In 2014 he made an advance decision to refuse treatment (ADRT) for the eye tumour. He was aware this tumour may eventually lead to his death. The ADRT was signed and witnessed and is both valid and applicable.

Dr Pires, a GP not known to James, has been contacted by the care home. They have two new concerns:

1. James’ affected eye is bulging
2. James has been coughing up green phlegm and has spent the last 24 hours in bed not eating

Dr Pires does a home visit and sees him with a member of staff who can communicate with James.

Dr Pires notes that James looks unwell – he is thin, has a fever and looks unkempt. His eye is bulging. Dr Pires examines him and confirms he has a chest infection.

Dr Pires explains to James that he thinks he has a chest infection. He suggests James could be treated with antibiotics. James nods and says “yes”. Dr Pires is confident James has capacity to consent to treatment.

Dr Pires is aware of communication challenges and therefore prepares. He does not presume James lacks capacity based on his appearance.

He assumes James has capacity and that he can make simple medication decisions.
Dr Pires has difficulties understanding James so utilises the help of care worker who knows James communication well.

Dr Pires rechecks with James that he still wishes not have treatment in accordance with ADRT.

Dr Pires asks about his eye and asks if it is giving him any problems. James nods and says "problem". Dr Pires asks if it is giving him pain, James nods and says "yes, problem".

Dr Pires offers regular analgesia to which James nods.

Dr Pires asks James whether he should be seen in the eye hospital due to the recent changes. James becomes agitated and says some words Dr Pires cannot make sense of, although he seems to repeating the word "problem". Dr Pires asks a care worker to help him. After sometime James becomes calmer and says "no hospital".

Dr Pires confirms that he is aware of the ADRT, which states that if he were to worsen and be a threat to life he does not wish to have treatment. James nods at this in agreement. Dr Pires says he will record this for him.

What does GMC guidance say?

The key points from *Treatment and care towards the end of life: good practice in decision making* (2010) are:

- Start with the presumption that a patient has mental capacity (paragraph 11).
- Support your patient to understand their options and make a decision (paragraph 12).
- Do not assume a patient lacks capacity based on age (paragraph 65).
- Make use of carers and loved ones who know your patient well (paragraphs 17-21 and 22).
- Take reasonable steps to plan for a foreseeable change in a patient’s capacity (paragraphs 68).