# End-of-life issues: Case 2

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Jenny, aged 42, has rapidly advancing cervical cancer unresponsive to antitumour therapy. Her husband, Michael, has asked you, her general practitioner, to make a house call, as Jenny is very drowsy today. You believe sepsis has intervened, worsening her renal failure (which is caused by malignant ureteric obstruction). Jenny has told Michael in the past that she would not like to "linger". However, Jenny's parents have left you frantic messages asking that she be admitted to hospital — they feel that Michael isn't "coping" and Jenny's children have not had time to adjust to the fact that she is dying.


## ABSTRACT

- When a dying patient lacks decision-making capacity, the general practitioner needs to collaborate with family members in making decisions about forgoing life-sustaining treatment.
- The key to working out the best course of action is for the doctor to have a very clear idea of which treatment options he or she considers acceptable or unacceptable.
- The choice of treatment depends on a thorough evaluation of all the clinical information and careful reflection, bearing in mind that medicine has its own proper limits.
- Life-sustaining treatment may legitimately be forgone if it is (a) therapeutically futile, (b) overly burdensome to the patient, (c) not reasonably available without disproportionate hardship to the patient's carers or others, or (d) refused by the patient.


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THIS IS A VERY DIFFICULT yet relatively common scenario in end-of-life care. Jenny has an eventually fatal illness and has now developed an acute complication that will soon result in her death unless something is done quickly. Her case is complicated by the fact that you are unable to easily involve her in the decision-making process and there is disagreement within her family about what to do next.

To decide how to proceed, you need to sort out several preliminary issues. In particular, you need to (a) evaluate Jenny's medical condition and determine what kinds of treatment and care should be offered to her;[1] (b) identify the key ethical issues; (c) identify the person who is to be Jenny's representative in decision-making and will act as the primary locus of consultation with and information-giving to the rest of the family; (d) collaborate with that person in deciding what is the best thing to do for Jenny; and (e) implement that decision and decide what to do should your treatment plan "fall over".

This scenario could arise with a patient you have known for years. But, just as likely, it could happen one rainy Saturday night when you are on call and you are called to someone else's patient whom you have never met before and about whom you have little information. Careful evaluation of Jenny's clinical situation is the cornerstone to resolving the issues that confront you. This step is important whether a patient can be involved in the decision-making process or not.

## Evaluate the patient's medical condition

Firstly, it is important to clarify the diagnosis and its natural history, the known extent of the disease, the treatment options, what treatment has and has not been given and the prognosis. We know some of this information but not all of it. Do we really know that the drowsiness is due to renal failure? Is there evidence of sepsis? Could Jenny be hypercalcaemic? Has she taken the wrong dose of morphine? And there are other questions to be answered. How rapidly is the disease progressing? Does Jenny have metastases elsewhere? Does she have a stent? How long is she likely to live? In a patient with cancer, the situation is rarely so urgent that there is not time to take a history and conduct a focused physical examination and some basic investigations (such as a full blood count and biochemical tests).

We do know that Jenny has rapidly advancing cervical cancer and that there are no more antitumour treatment options available. Let us assume some further facts: she has a pelvic mass that is causing obstructive uropathy, a ureteric stent that is now blocked, a urinary tract infection and sepsis. Let us also assume that she has a serum creatinine level of 800 μmol/L and a potassium level of 6 mmol/L. You know that without treatment Jenny may have only a few days to live. To sustain her life beyond that, she will need admission to hospital, rehydration, intravenous antibiotics, an urgent stent change and possibly haemodialysis. Even with all these interventions, Jenny's prognosis is still measurable only in weeks.

## Identify the key ethical issues

The decision that now has to be made is whether to admit Jenny to hospital for life-sustaining treatment. At this point, you need to recall four key aspects of medicine's own ethic: life-sustaining treatment may legitimately be forgone if it is

- *Therapeutically futile.* Much of the literature on medical futility turns on a disagreement between (i) a relatively

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recent (but, in our view, mistaken) idea that no treatment that prolongs life is "therapeutically futile"; and (ii) the more traditional idea that a treatment that could make no significant contribution to the patient's cure or improvement, nor sustain the patient in a tolerable condition, may be forgone (because it is therapeutically futile). It is this more traditional idea that will help show the way forward.

- *Overly burdensome to the patient.* Benefits hoped for (maintenance or improvement of health, preservation of life and relief of discomfort) need to be balanced against foreseeable burdens (eg, pain, discomfort, loss of lucidity, breathlessness, extreme agitation, alienation, repugnance, financial hardship). In thinking through these possibilities, you might need to call on the expertise of palliative medicine colleagues, whose experience of introducing the main elements of "death preparation" into complex decision-making at the end of life can be of invaluable assistance.[2]
- *Not reasonably available without disproportionate hardship to the patient's carers or others.* This consideration (which may be *abused* as a smokescreen for the abandonment of a patient) is reasonably clear in itself, even though it is more often assumed rather than explained in the literature.[3]

*OR*

- *Refused by the patient.* Strictly speaking, this consideration does not apply in this case, although you have a responsibility to give due regard to Jenny's previously expressed wish to her husband that she would not like to "linger".

## Identify the "decision-maker"

If Jenny were competent, she would be the one to make decisions about her own healthcare. Very sick and even confused patients are sometimes able to make these decisions, or, if not, to make their wishes known to others. But if, as seems likely, Jenny now lacks the capacity even to take part in decision-making about her own healthcare, you will need to collaborate with her family and, in particular, with the person who can best represent her wishes and make decisions on her behalf (ie, the person who is most involved with Jenny and most knowledgeable about her preferences on these matters).

## Consult with the decision-maker

You need to consult the proxy decision-maker (ideally, in circumstances that involve Jenny's whole family) to find out (a) any information about what Jenny herself would have wanted (we know that she has said she doesn't want to "linger"); (b) any signs as to what Jenny herself now wants; (c) the capacity of Jenny's family to continue to look after her; and (d) the views of the family on the appropriateness of further treatment or care.[4]

You need to get some sense of what is at issue in the family "disagreement". How much do Jenny's children know and really understand? Might something be gained for them if the current medical complication was dealt with and Jenny's life sustained for a few weeks? How well is Michael really coping? Is he trying to avoid his responsibility to care for Jenny, or is he just more realistic about Jenny's prospects than her parents? If the disagreement between them really is intractable, then you will need to decide which of the two parties better represents Jenny.

While you should provide the highest possible standard of professional care for Jenny, you are not obliged to do "whatever the family wants": treatment decisions ought to be made with *her* welfare in mind, and you should be ready to hand over responsibility for her care to a colleague in the event that you are pressured to act against your own sense of what is best for her.[5]

## Implement the decision

At this point you have to decide whether you are prepared to consider offering life-sustaining treatment or not, and, if so, exactly what modalities this will involve (eg, hospital admission, antibiotics, dialysis, surgery, admission to an intensive care unit, cardiopulmonary resuscitation). Central to the art of medicine is the clinician's ability to choose what treatment options to offer. In Jenny's case, an urgent decision is needed, and consensus within the family, and between the family and the doctor, may not be achievable. In this situation, you may need to make a unilateral decision in the short term (based on the information available) about which treatment is in her best interests and start administering it, while at the same time sorting out who is going to be her representative in the longer term. If Jenny had no family members present when you made the house call, and it is unclear whether life-sustaining treatment should be withheld, then you should err on the side of sustaining her life until the appropriate goal of care can be clarified.

In all this, it is important to document in the medical record the decisions made, including the treatments and care that will be offered if life-sustaining treatment is to be withheld. In implementing the decisions made (including symptom control if life-sustaining treatment is being withheld), the use of a time trial of one treatment can be helpful in assisting a family to reach consensus. In consultation with Jenny's representative, you should be ready to change the decisions you have made at any time in accordance with significant changes in Jenny's condition, provided the new treatment choice continues to serve her overall welfare. You should also be prepared to respond to challenges to these decisions, as disagreements may arise about the appropriateness of your treatment decisions or about Jenny's capacity to indicate her own wishes. Indeed, Jenny herself may have moments of lucidity that offer you opportunities to elicit her present wishes.

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