Anticipatory prescribing for end of life care

JOY OGDEN

In patients receiving end of life care at home, anticipatory prescribing can provide a back-up for when urgent symptom control is needed. This article discusses the practicalities surrounding anticipatory prescribing, including the use of ‘just in case’ boxes, the role of family members and how to handle difficult conversations with patients.

As Woody Allen famously said: “It’s not that I’m afraid to die. I just don’t want to be there when it happens.” If you are one of the lucky ones who die in “the happy no-time” of sleeping,1 you will be spared an active part in your own death. Many others of all ages, who die after a life-limiting, debilitating illness lasting months or years with consequent physical and psychological effects, will ‘be there’ when it happens. As more people live longer, growing numbers are in that situation and many, who have had time to think about it, say they would rather die at home than in a hospice or hospital.

The GMC defines ‘end of life’ as when patients are expected to die within the next 12 months, including those expected to die within hours or days. The first national End of Life Care Strategy published in 2008 recognised the increasing numbers of people expressing a wish to die at home. NHS England, which has paid tribute to the strategy’s achievements in reversing the upward trend of people dying in hospital and making significant improvements to end of life care, has set out its commitments to build on them in its Actions for End of Life Care: 2014–16.2

In the document’s foreword, Dr Bee Wee, national clinical director for end of life care at NHS England, said: “We now need to ensure that living and dying well is the focus of end of life care, wherever it occurs. This is the challenge: together we can and must achieve it.”

What is anticipatory prescribing?
Providing a good death at home is obviously challenging for families and carers but it also presents distinct problems to the primary care team, especially when the patient’s own GP and pharmacist might not be accessible.

Anticipatory prescribing has been developed to provide a back-up when help is needed urgently. It aims to ensure that drugs – and the equipment necessary to
administer them – are available in the patient’s home to provide prompt relief at whatever time they develop distressing symptoms. It avoids the problem of calling an out-of-hours doctor, who is unfamiliar with the patient, to prescribe for them at this vulnerable time. Anticipatory prescribing is not only intended for cancer patients but is also of potential benefit to those with cardiac, neurological and respiratory diseases and is based on the proposition that many of the acute events occurring during the end of life period can be predicted and prepared for in advance.

Dr Catherine Millington-Sanders is the RCGP and Marie Curie national end of life care clinical champion. Alongside her clinical work as a GP in Surrey, she is Kingston CCG’s Macmillan GP with several years’ experience as a speciality doctor in palliative medicine. She has first-hand experience of the role of anticipatory prescribing in end of life care, and applauds its multiple benefits in anticipating and providing control of common end of life symptoms such as sickness, terminal agitation/restlessness, pain and breathlessness, as well as enabling dignity.

Dr Millington-Sanders explains: “It’s important to give the patient and carer ‘control’ and reassurance that symptom management will be available whenever it is needed, because patients and families often fear being in pain or having symptoms. Anticipatory prescribing can be particularly important out of hours in order to enable seamless, well-planned care in the case of a planned, expected death at home or in a care home.”

‘Just in case’ boxes

GPS and nurse prescribers (particularly palliative care specialists) can provide the anticipatory drugs. These are usually supplied in a specially marked container, commonly called a ‘just in case’ box, and are available not only for a clinician but also for the patient’s family to administer in certain circumstances. Once prescribed, the drugs belong to the patient, with the same legal status as other prescribed controlled drugs.3

What goes in the ‘just in case’ box?

Professor Bill Noble, executive medical director at Marie Curie, explains the rationale behind the decisions for inclusion in a patient’s ‘just in case’ box. He says: “You’re prescribing with the knowledge that a number of symptoms are common in the approach to death. First, you need to think about what the patient is suffering at that moment and what other medication you can give when the patient can no longer swallow.”

The changes occurring in the final stages of terminal care can happen quite suddenly, and might happen out of hours. “The whole point of anticipatory prescribing is that your prescribing anticipates a change that you’re not going to be able to respond to because you’re not there,” adds Professor Noble.

“The next step is to anticipate other symptoms as the patient approaches death, where pain might be worsening, and you need to consider not only a non-opioid way of prescribing an analgesic but perhaps a different, more powerful one, at a starting dose. That means also prescribing an antiemetic least likely to cause sedation – to combat the nausea-inducing analgesic. Then you might anticipate the patient slipping into a terminal coma and becoming delirious.”

Professor Noble continues: “If you are content that you have eliminated the reversible causes of delirium, in advance of that happening, you would prescribe an antipsychotic, and anticipating that it might not work, you’d also prescribe a sedative. Finally, you can anticipate that when a patient is in a terminal coma, they will develop respiratory secretions, so respiratory secretions start pooling and bubbling – known as the ‘death rattle’ – and you’d prescribe something to reduce these secretions.”

Where someone already has some of those symptoms, you would adjust prescribing appropriately, explains Professor Noble. He adds: “You would only prescribe something you’d be happy for a nurse to give straight away and wouldn’t want dose ranges that might not work. You would only prescribe higher doses of analgesics when you know the lower dose hasn’t worked but hasn’t caused excessive sedation. Those are the basic principles.”

Table 1 outlines the BMA guidance on best practice in anticipatory prescribing for end of life care.4

Follow-up and monitoring

So who is responsible for following up and monitoring what happens to the drugs left in the ‘just in case’ boxes?3

- The health professional authorising administration of a presupplied anticipatory drug has to accept responsibility for that decision. The availability of such medication in the patient’s home is in no way a substitute for proper clinical evaluation at the time of a change in the patient’s condition
- The list of usual anticipatory drugs supplied should be agreed locally, with input from the local medical committee (LMC), other lead GPS, and specialist palliative care professionals such as the local hospice and Macmillan teams
- The normal starting doses should be agreed and available on a preprinted sheet to minimise the chance of prescribing error
- Quantities supplied need to be balanced between adequate supply and waste. For example, as a minimum, sufficient quantities should be provided for a patient over a bank holiday weekend
- ‘Just in case’ boxes should contain as a minimum the anticipated drugs, administration equipment, written instructions as to dose and indications, and a means for recording administration
- The prescriber needs to be satisfied that the patient and carers understand the reasons for the provision of the medications at that time. This is a good time to explore with the patient and family the prognosis, and to ensure they understand how to access care appropriately in the event of deterioration in the patient’s health
- The out-of-hours service, and all others involved in the care of the patient, must be made aware of the clinical situation and of the availability of drugs

Table 1. Focus on anticipatory prescribing for end of life care – BMA guidance for best practice4

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Professor Noble says: “If they’re controlled drugs, it’s the responsibility of the district nurses to see to them if they are not used. Doctors are not allowed to do it, only nurses and police officers. When I was a GP I would only occasionally dispose of drugs in the presence of a police officer but that was rather rare; mostly the district nurse would see it all.”

Family involvement
In some circumstances, the patient’s family can administer the drugs – so how much training are they given and how often does this happen? Professor Noble says: “This is not well worked out. Basically, family members can only give analgesics via oral, sublingual or intranasal routes. There are just a few circumstances in which you would train a family member to do the injections but it’s not standard, it’s not common and it’s potentially a big disadvantage if someone is looking after a loved one with a terminal illness. Somebody always gives the last injection – then there’s always the question: ‘Did I cause their death by doing that?’ You don’t want that to be a member of the family. That’s the problem, whereas people don’t generally feel the same way about oral drugs.”

Dr Millington-Sanders sounds a similar note of caution: “With training and safety features in place, I think there is an opportunity to support families to administer drugs but this would not be appropriate for everyone.”

Who helps the patient with planning their end of life care?
Clare McDonald, Karen Chittick and Yvonne True are three independent prescribers, all qualified nurses and Macmillan clinical nurse specialists with palliative care degrees working in the community. They cover the day time, while their colleagues in the team – the district nurses and hospice nurses – cover the nights as part of their 24-hour service.

They are involved in the care of patients with complex needs following a palliative diagnosis up until the end of life, and then with the patient’s family in the aftermath of the patient’s death.

If you find opening discussions about end of life difficult, the following conversation openers might help:

- Would you mind if we talked about…?
- What do you understand about your diagnosis/what the doctor said at the hospital/the progression of your illness?
- Do you have any thoughts or concerns about the future?
- If you did become more unwell, what are the most important things for us to know about?
- Do you have any spiritual beliefs that are important to you?
- Some people like to choose a family member or friend, who knows their wishes, to make important decisions for them if they become unable to. Is this something you have thought about?
- In thinking about the future, have you considered where you would prefer to be cared for if your illness progresses/gets worse?
- You mentioned that you are planning to stop the chemotherapy as it is giving you too many side-effects/not working. Would it be helpful to talk about the positive things that we can do to look after you going forward? (Focusing on quality of life, what is important to them, personal goals of care, symptom control, etc.)
- I understand that you’re not keen to talk about practical details/resuscitation/your concerns at the moment. Would you mind if I/the district nurse offered another conversation on this in the future? Or if you would like to talk about this another time, please let me know and we’ll discuss things at your pace.

Helping patients to plan their care is a big part of their jobs, says Karen Chittick. The care details are down to the individual patient’s wishes but, she says: “We would – tactfully – bring up some of the hard questions.”

So, what are the hard questions? Clare McDonald responds: “We would ask, ‘Do you want to be resuscitated? Do you know where you want to die?’ Though we might not say it quite so bluntly as that. If they were having regular blood transfusions, we would talk about whether and when these would need to be stopped and the implications of that; we’d talk about the implications of continuing or stopping palliative chemotherapy. If it’s a younger person, we would even say: ‘We think you ought to let your children know what is happening.’

“Sometimes, the choices a patient makes are not the same as their family’s, so you try to support your patient’s choice and also support the family with the decision. We try to support them all.”

The three colleagues also support each other. They say they speak to each other every day, ring if they need to discuss any problems, and join forces every week for peer reviews and to keep up to date.

Table 2. Possible openers for end of life care conversations

Handling difficult conversations
Dr Catherine Millington-Sanders, in addition to her other roles in palliative medicine, is also the co-founder and clinical lead for Difficult Conversations, a social enterprise that provides training via multi-professional workshops on handling the difficult conversations that many health professionals face on a daily basis.

In a medical setting, such as general practice, most if not all health professionals will have contact with patients or their carers, notes Dr Millington-Sanders. Everyone has a role to play on a human compassion level as well as on a professional level, therefore it is helpful for them to understand their responsibilities within their professional role.

She says that information should be patient centred, and for a patient living with a life-limiting illness, it is important that the conversations in the usual 10 to 20-minute appointment slots are based around issues such as: their understanding of their illness and care; their preferences for discussions and their care; their cultural, psychosocial and spiritual needs, sexual orientation, etc. If you do not ask your patient to record their preferences for care and for death, you are
not giving your patient choices, but are potentially leaving their fate to chance, she explains.

Dr Millington-Sanders cautions: “People sometimes do not want information or discussions at a particular time and this must be respected. But it’s not to say they may not want this information or opportunity for discussion at another point. If you don’t ask and offer the opportunity, then you will not find out. This clearly needs to be done sensitively and at a pace right for the patient.”

Table 2 suggests some possible conversation openers that might make it easier to initiate end of life care conversations with the patient.

Yvonne True also stresses the need to respond to patients’ changing needs for engagement: “Our patients might want to see us initially but then we step back, maybe for a while, because they don’t need us. Then things change and you might have more involvement. We can see our patients for a couple of years but then we get another patient we see for a very short time.”

**Principles of palliative care**

Have the three nurse independent prescriber colleagues noticed any recent changes in palliative care? Treatments and therapies are changing, and ways of working, too, they say. People are generally living longer but are often more ill, because many treatments are available and they can choose to be treated or not. More dementia patients are included in palliative care, whereas before they were largely overlooked. The inclusion of anyone with a life-limiting illness has expanded palliative care patient numbers, and with this, the need for nurse prescribers to expand their knowledge.

Professor Noble notes: “End of life is difficult to predict. What we are left with are a number of principles that underpin palliative care, including discussing with the family what everybody requires: making plans, being explicit about those plans, being clear about the uncertainties and putting in place all the contingencies needed – part of that is anticipatory prescribing. Anticipatory prescribing in hospitals is no problem; everybody has drugs on their hospital chart that they don’t take regularly but that would be given if they were required. This is just extending that idea to the community.”

The community nurses seem to be united in welcoming it. As Clare McDonald remarks: “I think it’s a privilege to go into a person’s home, to be alongside them in their journey and – even though it’s part of our job – it feels more than that for us because we are with them at a time when they are at their most vulnerable. It means that we can hopefully support them and their family.”

**References**

5. Difficult Conversations. www.difficult-conversations.org.uk or email: reception@difficultconversations.org.uk
7. GMC. Handling difficult conversations: thoughts from Dr Catherine Millington-Sanders. www.gmc-uk.org/guidance/29123.asp

**Declaration of interests**

None to declare.

Joy Ogden is a freelance journalist