Care of the dying adult

Michael Brookes, RCGP Clinical Fellow for End of Life Care
GP Principle, Reeth Medical Centre

During the recent RCGP conference, I attended a debate entitled ‘NICE: friend or foe’. The concerns from the floor at the time were about loss of autonomy of individual practitioners, feeling that protocol-driven medicine was depersonalising the all-important doctor-patient relationship and that guidelines drove defensive medicine as they were a tool which lawyers could use to prey on clinicians.

Had the new ‘Care of the Dying Adult’ guidelines been published at the time, I am sure that the audience would have been much reassured. The most striking feature of the 266 page draft document is the distinct lack of protocols and flowcharts. These are replaced by flowing prose, which acknowledges the lack of evidence around a lot of what we do in palliative and end of life care as well as stressing the need to individualise patient care. This puts clinicians and patients firmly in the driving seat and allows a sensible and informed discussion. The guideline development group is represented by primary and secondary care as well as the wider healthcare community, again quelling an often cited complaint of lack of representation.

For me, one of the key areas in the new guidelines is around the discussion of clinically-assisted hydration. This was an area of controversy during the discussions about the Liverpool Care Pathway as families often expressed concerns about dehydration and the withdrawal of fluids. The advice in the draft recommendations is quite explicit that giving clinically assisted hydration is unlikely to prolong life or the dying process and equally withdrawing clinically assisted hydration is unlikely to hasten death. This may change in the final published version but it is a welcome and supportive message for clinicians having discussions with patients and those closest to them.

The guidelines raised issues around cyclizine, which is the most common antiemetic used in end of life care, citing the facts that it is less efficacious than other antiemetics, poorly tolerated by people at the end of life and incompatible with many other drugs in a syringe driver as well as being frequently associated with site reactions if administered subcutaneously. Curiously cyclizine then finds its way onto the top of the prescribing table in the pharmacology section, so perhaps this anomaly needs ironing out in the published version. The development group also stress establishing an underlying cause for the nausea or vomiting in order to consider other management options to alleviate the trigger and to avoid over-medication, which in my view, is often over looked in the misplaced but well-intentioned haste to titrate symptom control drugs.

Managing noisy respiratory secretions is always an area which I find difficult and the assessment of the efficacy of various medication options was helpful. In particular, the move away from hyoscine to glycopyrronium, as it does not cross the blood-brain barrier and therefore less likely to cause sedation and agitation side effects. I have never used atropine eye drops sublingually to treat respiratory secretions, but knowledge of this option may come in useful for needle phobic patients or if other medicines fail to provide a benefit. Again the clinician has NICE to support the discussion with the statement that, ‘although the noise can be distressing, it is unlikely to cause discomfort’.

NICE also raises the question of anticipatory prescribing versus prescribing on demand. I have often considered that end of life care generates a lot of unused drugs, as many patients are prescribed medication ‘just in case’ and doses and drugs change rapidly with the evolving clinical situation. The evidence review suggests this could be 60-70% of the medication prescribed. Most of us would not consider cost as our priorities are rightly aligned with relieving suffering of the patient and their loved ones, yet in today’s society, cost and waste are increasingly important considerations. In many ways, the debate about demand and anticipation prescribing is
superfluous because access to medicines outside core hours is often very limited, particularly in rural areas.

In summary, the draft guidelines provide a supportive but not overbearing presence for clinicians caring for people who are in the last few days of life. Much of the pharmacology reflects existing practice, but there are little gems for all of us to sharpen our knowledge and understanding in primary care. The guidelines also give us a strong sense of how much we know we don't know, which just shows the great opportunity for research and development as well as improvement in caring of dying people.

The Care of the Dying Adult guidelines are due for publication in December 2015.