Improving experience for relatives of dying patients in a cancer centre

Martha Knowles, Richard Berman, Wendy Makin, Karen Anthony, Elizabeth Elliott. The Christie, Manchester, UK
10.1136/bmjspcare-2017-00133.117

Background I felt strongly about improving the services for end of life relatives staying for long periods with their loved ones. I wanted to find out what they felt was missing from our care, and how we could improve their time with us.

Method I conducted a survey of twenty EOL relatives asking about their experience generally and what could be improved. I asked the questions in a safe place, questions around this are obviously of a sensitive nature and I wanted them to feel free to answer openly and honestly.

Results/findings
• Relatives want more information about what to expect during the dying process, such as physical signs and symptoms, as well as around what services are available.
• No facilities for relatives to make their own drinks and often feel they cannot approach busy staff.
• No facilities available for relatives who arrive without any of their own belongings.

Conclusion/actions
• I created A relative’s guide for loved ones in the last days of life. This booklet contains information about signs and symptoms they may see in a dying loved one; services available across the hospital; and a summary about what support they offer.
• I instated a scheme where EOL relatives are entitled to a meal card activated with credit worth £5 per day so they are able to buy refreshments from the canteen and restaurant. This reactivates at midnight and can be used throughout their stay.
• I compiled a relative’s overnight pack-a mini washbag, containing toothbrush, toothpaste, wipes and tissues for when they need to stay unexpectedly.

Good palliative care is essential - for a patient’s loved ones as well as themselves. I would like to continue to make changes and create some positives in what can be otherwise a wholly negative experience.

Use of baclofen in a continuous subcutaneous infusion

Helena Myles, Faith Cranfield. St. Francis Hospice, Dublin, Ireland
10.1136/bmjspcare-2017-00133.118

Introduction This case report illustrates the effective use of a continuous subcutaneous infusion of baclofen to improve spasticity in a patient approaching end of life.

Report The patient was a 56 year old lady with a diagnosis of motor neurone disease (spinal onset; ‘definite’ by the El Escorial research criteria). She was admitted to the hospice for end of life care. She was severely dysarthric. She had a flicker of movement in her left hand, but no movement in her limbs otherwise. She communicated by nodding or shaking her head. She did not have a percutaneous endoscopic gastrosomy (PEG) tube in situ, and she was too frail for consideration of same. At the time of admission, she was taking baclofen 10mg po tds for spasticity.

As she weakened, she couldn’t swallow her oral medications, necessitating discontinuation of her baclofen.

Three days later, she developed painful spasticity of her temporomandibular joint muscles. She was very distressed by this symptom. It persisted over the following five days despite opioid analgesia and benzodiazepines. A literature review revealed a case report demonstrating the effective and well tolerated use of subcutaneous baclofen in a patient who could no longer take his medications via PEG.

A decision was made to commence a continuous subcutaneous infusion with baclofen 10mg over 24 hours and NaCl as the diluent. The intrathecal formulation of baclofen was used.

The following day, the patient reported improvement in her spasticity, and she was able to open her mouth. The improvement was sustained over the following four days, and she experienced no skin reactions at the infusion site. At this time she could no longer communicate, and she was beginning to die. The baclofen was discontinued as she was no longer benefiting.

Conclusion This case illustrates the effective and well-tolerated administration of baclofen via subcutaneous infusion. If appropriate, we may consider this route again.

Retrospective analysis of the timeliness of completion of paperwork and communication to general practice (GP) following death

10.1136/bmjspcare-2017-00133.119

Aims Primary aim: Assess compliance with national standards for completion of death certificates within 1 working day.

Secondary aim: Evaluate speed and form of communication of death to GP.

Background It is understood that effective and prompt communication to GPs facilitates provision of bereavement support to relatives after a death. Delayed paperwork delays funeral arrangements and causes unnecessary distress to those bereaved. There is very little research on how timing of paperwork and communication to the GP impacts on bereavement. This audit forms the initial work to address these issues in greater depth.

Methods Retrospective review of clinical notes in an acute cancer hospital between 1/12/15 and 31/3/16.

Results 87 patients died during the audit period. Death certificates were completed within 1 working day for 91.9% (79/86) patients. 1 patient was referred for post mortem so was excluded here. GPs were informed of death via discharge summaries or telephone conversations. Overall it was documented that 78% (68/87) GPs were informed of the patient’s death. Summaries were completed within 1 working day of death for 60.9% (53/87), 2 or more working days for 17.2% (15/87). For 21.8% (19/87), the summary was not completed. 20% (17/87) deaths were communicated by phone.

Conclusion Overall, death certification was completed in a timely fashion. Discharge summaries were completed promptly for most, but 21.8% were never completed.

The discrepancy in communication with GPs highlights the need for interventions to ensure information is communicated promptly and effectively to facilitate ongoing bereavement support. This could be achieved with dedicated proformas,