



Addressing End of Life Care Needs

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The Case of John

57 years old, CEO of a catering supply firm

- ◆ 2002: noticed changes in handwriting and winding up watch
- ◆ 2004: MND diagnosed
- ◆ August 2007: referred for palliative care
 - ❖ Deteriorating limb strength
 - ❖ No dysphagia, but quality of voice changing
 - ❖ Taking IGF-1 injections
 - ❖ FVC 71%





- ◆ Early September: more breathless, pyrexial
 - ❖ Sent to hospital by GP
 - ❖ Collapsed in A/E, in respiratory failure
 - ❖ Started NIPPV with good response and returned home after a week
- ◆ Stable through the autumn
- ◆ December: John said he would want a PEG, but he and family found discussion of end of life issues difficult



- ◆ January: started lithium
- ◆ A few days later: acute difficulty breathing with copious secretions. Family called GP who had no hyoscine/glycopyrrolate
 - ❖ Hospice CNS went round with crisis box
 - ❖ Settled to sleep after glycopyrronium given
- ◆ Wife concerned about deterioration in John's swallowing
 - ❖ CNS discussed future planning for a PEG tube, but difficult to engage John in this because of his urge to remain positive



- ◆ SaLT assessment at home:
 - ❖ Marked weight loss
 - ❖ Unable to clear laryngeal secretions because of breath weakness
- ◆ Admitted to hospital for feeding tube assessment and NIPPV adjustment
 - ❖ Not well enough for PEG or RIG so given nasogastric tube
 - ❖ Hospital palliative physician met re end of life issues but John and family still reluctant



Back at home with NGT

- ◆ Now needs a reclining wheelchair
 - ❖ Wheelchair on order for two months but now unsuitable because of deterioration
 - ❖ A suitable wheelchair is in stock but can't be assessed until he has a hoist
- ◆ Computer-aided communication system obtained via SaLT team as speech getting very difficult to understand
 - ❖ But is incompatible with John's laptop
 - ❖ Sorted out, but John still finds it cumbersome to use
- ◆ End of January: Less well – family blame this on hospital admission
 - ❖ John not sure if he wants CPR
 - ❖ Discussing diaphragmatic pacemaker with neurologist
 - ❖ Hoist arrives – not tall enough



- ◆ Mid-February: Breathing is worse, initially associated with constipation, but then developed chest infection:
 - ❖ Can only manage 5 minutes without NIPPV
 - ❖ Antibiotic from GP
 - ❖ John decides he wouldn't want a tracheostomy
 - ❖ Has sessions from Hospice at Home and Marie Curie night sitters



- ◆ John gradually improves with antibiotics
 - ❖ Reluctantly accepts morphine and midazolam via a syringe driver to help with sense of breathlessness
 - ❖ Gets response from unusually low doses of anticholinergics for secretions
 - ❖ Asks: "Where is this going?"
 - ❖ Says he is not frightened of death – he just wants to be at home with his family around him
- ◆ PCT is reluctant to fund further night sits and suggests a nursing home if John has continuing complex needs...



- ◆ Mid-March: NIPPV now only being used for an hour in the day and an hour at night
 - ❖ Morphine dose reduced and midazolam withdrawn
 - ❖ But feels more anxious without the midazolam, particularly when being hoisted
 - ❖ So midazolam 5 mg/24h reinstated and home massage arranged to aid relaxation
- ◆ Now using a communication board, which John finds slow and frustrating



- ◆ Late April: another chest infection
 - ❖ Back to using NIPPV for all but 5 minute breaks
- ◆ Family wondering what happens when NIPPV loses its effectiveness altogether
 - ❖ Wife has the impression from hospital that a “very large dose of morphine” will be given
- ◆ Joint home visit from palliative physician and chest physician
 - ❖ John close to respiratory failure
 - ❖ Family discussion about what we and they could do
 - ❖ Buccal midazolam available
 - ❖ Morphine and midazolam titrated in syringe driver
- ◆ Over the next three days: mostly sleeping, but awake and lucid for periods of 10 – 15 minutes

At 17.30 the following Sunday:

Urgent call to hospice home care CNS:

- ◆ John acutely breathless, possibly having aspirated
 - ❖ Family called ambulance
 - ❖ Paramedics have found John to be pyrexial and hypoxic
 - ❖ Paramedics want to take him to hospital, but wife knows he wanted to be at home





- ◆ CNS goes to the house with the duty palliative medicine consultant
 - ❖ John breathing with considerable effort
 - ❖ Agreed to stat dose of 2.5mg midazolam
 - ❖ 30 minutes later, colour changed and John quietly died, held by his family

Key Issues

- ◆ Preparation for end of life issues as disease progresses
 - ❖ At the patient's pace but with our encouragement
 - ❖ Hearing the family's perspective
- ◆ Who coordinates the different services?
 - ❖ Timely and appropriate input
 - ❖ Transitions
- ◆ Pro-active preparation for foreseeable symptoms
 - ❖ Breathlessness
 - ❖ Dysphagia
 - ❖ Choking
- ◆ Crises happen when they happen, not when it is convenient to the professionals
 - ❖ Ensure the availability of practical help out of hours

