

Challenges at the very end of life

- Edith, 84, vascular dementia & multiple TIAs. Resident in local EMI care home.
- Increasing day & night-time agitation & aggression as dementia advanced not responsive to Risperidone, Temazepam or Lorazepam. Recently started Quetiapine.

21 Nov - referred to ellenor for end of life care –

very weak but persistent loud calls 'Help me, help me'. Daughter distressed and expressing frustration at staff.

?pain ?anxiety ?infection ⇒ antibiotics,
↑ Butrans 10mcg & Paracetamol suspension.

*ellenor.**

- 24 Nov – Edith very frail, extremely distressed & calling out constantly between snatches of sleep. Injectables prescribed, Quetiapine stopped. Midazolam 2.5mg s/c with good but short-lived effect.
- 25 Nov – Distress & agitation continue. Midazolam ↑ 5mg s/c stat. Syringe pump commenced Morphine 10mg & Midazolam 20mg
- 26 Nov – Edith more settled, but still calling out intermittently and needed several stat doses
- 27 Nov - extremely frail but still requiring stats. Pump ↑ Morphine 15mg & Midazolam 30mg

- 1 Dec – too weak to call out but agitated & whimpering. Pump ↑Morphine 25mg & Midazolam 30mg
- 2 Dec – groaning & unsettled. Levomepromazine 25mg added to pump. Stat dose of Levo 6.25mg s/c with good effect.
- 3 Dec – rousable but peaceful. No stats required.
- 4 Dec – died quietly. Daughter & staff exhausted and frustrated at how long it took to manage Edith's distress.

Challenges caring for people with dementia at EOL

- Titrating drug dosages – balancing caution with the need to effectively relieve symptoms.
- Imagining how the person with dementia is feeling – completely vulnerable,
- unable to make sense of their suffering, unable to communicate effectively, probably aware how ill they are and fearful

Supporting families at this last stage when they have already experienced the ravages of dementia on their relative.

Acknowledging that we have limited professional guidance or robust research to support clinical decision-making for people with dementia at EOL

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