Case study – terminal agitation vs pain in dementia
Lady P

- 85 yr old lady
- Dx of Vascular dementia, diverticulitis, rectal haemorrhage and haemorrhoids, HTN, high cholesterol, dermatitis, macular degeneration, visceral detachment and ganglion of ankle/foot joint, TIA 2020, MI 2019
History summary

- Mild stroke (February 2020) resulting in an admission to hospital, then moved to rehabilitation, then to a residential home for two days until being discharged back home.
- Multiple moves and then very disorientated on return home.
- Moved to 24 hour care in May 2020
- Poor Sleep hygiene, poor appetite
- High risk of falls, at this time no pain recorded.
July 2020 presentation

- Anxious, restless.
- Able to converse and mobilise
- Sleep disturbance
- Some insight
January 2021 presentation

- Episode of urine retention, catheterised and developed a UTI
- Increase in agitation and anxiety which did not alleviate once UTI treated.
- Paracetamol 500mg QDS (weight was below 50kg)
- High pulse
March 2021 presentation

- Screaming words instead of talking
- Highly agitated
- Not expressing pain
- Not sleeping
- Psychiatric medications changed – from citalopram, trazodone to mirtazapine and lorazepam PRN
Cont....... 

• No changes in presentation so Olanzapine trialled however Rapid Response and Assessment Team (RRAT) called in to do a top to toe due to distress
• No physical problems found
• By this time Lady P was on a mattress on the floor screaming, no comforting.
• Staff and family very distressed
Discussion questions

Is this terminal agitation? Precluding dying phase
Is this advancing dementia?
Is this pain?
Ethical dilemma

• Not actively dying
• Very rapid decline – 2 months prior was independently walking, talking and managing food and fluids
• Are EOL medications suitable as still taking some things orally and refusing at other times so would injections be suitable?
Solution

- Discussion with our Palliative care consultant resulted in Rx of levomepromazine BD
- She felt if this did not settle her within 24 hours to increase the dose and consider some PRN oramorph for pain as assessment was difficult
- More experience of this deterioration with people with dementia
• By day 2 a syringe driver was set up as much less agitated and the addition of morphine significantly reduced her distress further.

• By day 4 Lady P had passed away very peacefully with her family at her side.
Concluding thoughts

• Talk to the specialists
• Air ethical concerns with family, GP and team to ensure the decisions are agreed in the persons best interests
• For advancing dementia sometimes the terminal stage is longer than the ‘dying’ stage.
• This terminal stage needs more research and addressing but in the mean time undiagnosed pain goes unmanaged.
• Levomepromazine is definitely more effective than Haloperidol for the more agitated person.
• Don’t assume agitation is not driven by pain. If one thing is not working don’t be afraid to try something else.