

Sophia

End of life events July 2015

Background Notes:

- Sophia had endured 13 operations since August 2001.
- Sophia lived in residential aged care from 3 November 2006 – 31 July 2015.
- Patricia was Sophia's third daughter and Medical Enduring Power of Attorney, since October 2006.
- GP involved in the end of life events and referred to below was Sophia's GP for approximately seven years until her death. Same GP telephoned Patricia on 18 August to check whether she was "okay" and to share some of his reflections on Sophia's end of life experience; with the benefit of hindsight he said he would have done the following:
 - Commenced regular doses of morphine earlier.
 - Called in palliative care to manage the medication – he did not realise the process would be so complex.
 - Obtained a syringe driver, which he believes would have better managed Sophia's pain.
- GP stated at the end of the telephone discussion that he did not believe that Sophia died in pain.

Sequence of end of life events:

- Thursday 23 July - GP advised Patricia that Sophia is at end of life stage, with increased frailty, unexplained weight loss and general systems shut down occurring. His prognosis was that Patricia had "weeks" to live. Morphine syrup PRN was prescribed to assist with pain management.
- Saturday 25 July:
 - 2pm daughter Franca arrived to visit Sophia, found her in pain; initial advice from nursing staff was that morphine syrup has not been ordered from Pharmacy.
 - 4pm Patricia arrived and staff advised that the Pharmacy has sent morphine injections as opposed to syrup because they did not have syrup in stock. However, staff further advised that morphine injections could not be administered as the prescription was for syrup. Search commenced to identify any pharmacy within 30km radius that has the morphine syrup in stock; however no pharmacy had this medication in stock.
 - GP was contacted and informed of the situation; he prescribed morphine injections PRN, which was subsequently administered to Sophia.
- Sunday 26 July – Franca visited Sophia and found her in pain and requested morphine; injection administered at 10am. Nursing staff assured Franca that Sophia's pain levels would be monitored throughout the day.
- Monday 27 July:
 - 9.04 am - Patricia visited Sophia and found staff crushing Sophia's regular medication. However, Sophia was clearly unable to swallow. Sophia informed Patricia that she had been in constant pain. Patricia sought clarification from nursing staff about when morphine was last administered to Patricia and was informed that it was 10am on Sunday 26 July.
 - Patricia reported concerns to staff that morphine PRN was not working as Sophia was very difficult to understand, even in Italian.
 - 12noon - Patricia reported to DON that Sophia was in pain, had refused lunch and struggled to swallow 2 teaspoons of her favourite cafe latte. Morphine injection was administered and lunch was reheated and offered to Maria an hour later. Sophia refused all food.

- 2pm - Patricia sought clarification about whether GP was contacted and advised that morphine PRN is not working? DON advised Patricia that she: "...cannot just call GP for no reason..." after Patricia became distressed DON suggested that whilst Patricia took a walk, staff would toilet Sophia and "see what is going on with her". The verbal exchange at this time between Sophia and Patricia was the last time Sophia spoke.
- Sophia was put to bed after this examination and never got out of bed again.
- 4.30pm - GP visited Sophia, examined her and apologised to Patricia for the sequence of events and agreed that morphine PRN was not working and prescribed regular 4 hourly doses of 2mg of hydromorphone, ceased all of her regular medication and ordered a line to be inserted for the administration of medication. GP advised that Sophia's final stages were much more rapid than he had expected and that her death could be hours or a maximum of 2-3 days.
- GP stated that it was probably too late to call in Palliative Care. Patricia questioned whether the same level of care could be provided by the Nursing Home. GP assured Sophia that there would not be any benefit added by involving Palliative Care.
- Tuesday 28 July:
 - 9am - Daughters visited Sophia. When Franca asked Sophia to squeeze her hand if she was in pain, Sophia clearly squeezed Franca's hand. This incident was reported to staff who advised that Sophia had just had hydromorphone at 7.45am and suggested that it might take longer for the medication to have an effect.
 - During the course of the day this process was repeated by daughters, with the same response from Sophia. Patricia requested that GP be contacted and advised that Sophia's pain was not being managed on the current medication.
 - GP visited late afternoon, examined Sophia and increased hydromorphone to 5mg every four hours.
- Wednesday 29 July:
 - 8am - Patricia visited Sophia and found her more alert than the previous day.
 - Franca & Patricia noted during the course of the day that Sophia was clearly in pain when Nursing Home staff repositioned her and requested that Sophia only be moved an hour after she has been administered hydromorphone. Nursing Home staff complied with this request.
- Thursday 30 July:
 - 9am - When all 3 daughters visited Sophia they noted she appeared less conscious, with her eyes often closed; although she was still very responsive to touch.
 - Breathing patterns changed during the course of the day, but Sophia was peaceful and did not appear to be experiencing any pain.
 - 3.30pm - Sophia started groaning. Hydromorphone was due at 3.45pm. Sophia was not administered hydromorphone until 4pm. This delay was caused by a changeover in shift and was further compounded by agency staff who required briefing.
 - During this groaning period, two staff members independently made comments to the effect that "... this sort of groaning should not be happening."
 - 5pm - Sophia stopped groaning for approximately 30 minutes and then recommenced.
 - Four family members present became very distressed; DON advised us that:
 - not all groaning is necessarily pain
 - her belief was that "the current problem" was due to the fact that Sophia had been on high levels of medication in the past and that was why current hydromorphone levels were "not working"?
 - she agreed to contact GP for further advice.
 - GP prescribed midazolam and suppositories. DON advised that if GP was to increase hydromorphone he could lose his registration and Sophia could become "toxic".
 - Patricia very loudly informed DON and Nursing Home proprietor, that the Nursing Home should not claim to provide palliative care as the care being experienced by Sophia was not

- palliative care. DON advises that the only other option was to call an ambulance as she had rung "palliative care and they were not helpful and not willing to get involved at this stage".
- Patricia rejected the suggestion of calling an ambulance and told DON that Sophia would not die on a hospital trolley in A&E.
 - 7pm - Franca overheard DON on the phone to the pharmacy, loudly stating that the suppositories were needed that night and that the patient could not wait for the pharmacy delivery the following morning. Suppositories were subsequently administered to Sophia that evening.
 - 8pm - Sophia's groaning ceased, whilst breathing patterns remained irregular and noisy, the distressing groaning was not present.
 - 10.30pm – During the staff shift change, two of the departing nursing staff independently commented on how much "better" Sophia was sounding.
 - Friday 31 July:
 - 2am – Patricia wakes from mattress next to Sophia and noted she had recommenced a low level groaning. Patricia immediately informed nursing staff and requested PRN midazolam.
 - 3.15am – Sophia's groans increased with added whimpering/crying. Patricia pleaded with nursing staff to administer the hydromorphone which was due at 3.45am. Sophia was not administered the due hydromorphone until 3.43am by a nurse, in a brash manner.
 - 4am – Patricia became distressed as there was no change to the groans with added whimpering/crying and requested PRN midazolam to be administered. During this period one staff member asked a Nurse whether there was anything that could be done to "help" Sophia and relieve her distress.
 - 5am – Patricia informed the Nurse in Charge that the current situation was "cruel" and demanded that she either contact the GP and get authorisation for breakthrough hydromorphone immediately or that she call for an ambulance as it would be too cruel to leave Sophia groaning/whimpering/crying until her next dose of hydromorphone, which was not due until 7.45am.
 - 5.30am – The nurse in charge apologised to Patricia for the delayed response as another resident had passed away and advised that GP had authorised an additional 2mg of hydromorphone and was on his way to the facility.
 - 6am – Sophia's groaning/whimpering/crying gradually ceased, the irregular noisy breathing continued.
 - 6.15am - GP visited Sophia and asked Patricia whether the breathing noises that Sophia was currently making were the noises that had been distressing her since 3.30pm the day before? Patricia said "no", that it was the groaning/whimpering/crying noises, that he had not heard, that were distressing. GP explained that his overnight reflection was that Sophia was possibly experiencing withdrawal as she had been on alprazolam for many years and had not had any since Monday. He had also consulted with a Palliative care specialist and he was going to prescribe alprazolam drops to keep Sophia comfortable but would not increase hydromorphone as he was concerned that she would become "toxic".
 - 6.40am – Sophia's breathing pattern changed significantly.
 - 7.15am – Sophia passed away.

Patricia
August 2015