

**Doris - A case study of a person with Dementia**

Doris is a 78 year old lady who has lived in your care home for nine years. Doris has advanced dementia and relies on care staff for all aspects of her care. The only person to visit Doris is the local Parish Priest who gives Doris a blessing each week as she is no longer able to take communion due to swallowing difficulties. There is no next of kin, family or friends recorded for Doris.

Your staff have become close to Doris over the years and have seen the deterioration from mild to advanced dementia. Doris is nursed in bed and is no longer able to verbally communicate with staff, however your care staff have developed ways of communicating using their knowledge of Doris and reading her non-verbal communication.

A number of your care staff have reported a change in Doris’s condition stating she appears weaker and is sleeping for longer periods however they are unable to be more specific. You have requested a GP visit, although Doris’ regular GP is currently on sick leave. You and your staff have strong views that Doris should be cared for in your home and not admitted to hospital.

**1** Identify where this resident would be on your end of life care register and state your rationale.

**2** How would you facilitate an advance care planning discussion?

**3** Who would you involve in this discussion?

**4** Who would be the most appropriate person(s) to undertake and lead on this discussion?

**5** How would you communicate the outcome of this discussion?

**Notes for Facilitator**

**1 Identify where this resident would be on your end of life care register and state your rationale**

Doris is at phase 3 (Last Days of Life) of the North West Model for Life Limiting Conditions.

The rationale for this is:

* Diagnosis of Dementia (9 Years)
* Assistance with all care
* Bedbound
* No verbal communication
* Weakness
* Sleeping for longer periods
* Swallowing difficulties
* Change in condition

**2 How would you facilitate an advance care planning discussion?**

*Consider: cues, timing, and environment*

Capacity is decision specific - Has a capacity assessment been undertaken to ascertain whether Doris is able to participate in any discussions?

Likely to be a GP who would undertake this assessment – 2 stage:

Doris has an impairment of the brain? – yes, dementia

Functional:

Does she understand the decisions that need to be made? – consider what these decisions are – uDNACPR, treatment of likely deteriorations, PPC

Is she able to retain information long enough to make a decision?

Is she able to balance the positives and negatives of any decision?

Is she able to communicate her decision? – what non-verbal communication can Doris make

If the answer to any of the 4 questions is no, then Doris is not deemed to have capacity

Good practice - reasons indicating why Doris has or doesn’t have capacity should be recorded

*Point to remember- Making an unwise decision does not mean that a person lacks capacity*.

Consider fluctuating capacity – there may be times during the day when Doris is more lucid and able to participate?

The evidence of Doris’s deterioration (as above) and knowledge of the disease process should indicate it would be an appropriate time to open discussions. (*comment – ideally this should have taken place when Doris had capacity*)

Find out how long the regular GP is likely to be on sick leave. Care staff would need to start this discussion with the covering GP.

It appears Doris would not be able to contribute to the discussion. Has a mental capacity assessment been recorded? If it is recorded that Doris does not have the mental capacity to contribute to this discussion a best interest discussion needs to take place to develop a Best Interest Decision.

**3 Who would you involve in this discussion?**

*Consider: The Mental Capacity Act*

Involve key care staff, home manager, Parish Priest (Is the priest aware of family or close friends?) and her GP. (All involved in care)

You may wish to involve an Independent Mental Capacity Advisor (IMCA). Increasingly being urged to involve IMCA’s in decisions where there is no family. NB – they are acting as an advocate and not the Decision Maker

Is Doris subject to a The Liberty Protection Safeguards (LPS)? - Need to inform Best Interest Assessor

**4 Who would be the most appropriate person(s) to undertake and lead on this best interest discussion?**

*Consider: knowledge and skills required*

The MCA states that there should be a ‘Decision Maker’ – for medical decisions this would be the GP however they would take into consideration:

* **Doris’s wishes:**
* What did she say when she had capacity?
* How was this documented?
* Did she have an Advanced Directive to refuse treatment? (Legally Binding)
* Does she have a Lasting Power of Attorney? (Register kept by Office of Public Guardian)
* Is there anything known about her lifestyle that would indicate how she wanted to be cared for? – religious beliefs, avoiding or seeking treatment…
* Is she able to participate in any discussions now with support? – glasses, hearing aids, pacing of information in appropriate language, suitable environment for discussions, non-verbal signs….
* **Views of others:**
* Parish Priest
* Care Home Manager and care home staff
* Other visiting professionals health/social work
* **Weighing the benefits and burdens of any treatment/intervention**
* GP makes a clinical judgement and does not have to offer treatments that they believe to be futile
* How is this deterioration likely to progress and how can it be managed? Consider management of inability to eat or drink, possible infections, pain management

Doris has been in the care of this home for 9 years and the regular GP is on sick leave.

Care staff may have information on Doris’s wishes from past discussions (is anything recorded?).

It is important care home staff know they can take the lead with this although it would be a team decision.

**5 How would you communicate the outcome of this best interest decision?**

*Consider: who needs to know, how would you review?*

There is a need to inform all staff of the outcome of the discussion and review date. It will help staff to understand the reasoning behind decisions even if they are not directly involved in the best interest meeting.

Inform **ALL** health and social care professionals involved in Doris’s care. Consider processes required to communicate with internal and external staff.

Think about systems in place to aid communication in your care home or what could be applied i.e. a main file for advance care plans, brightly coloured advance care plans.

Referring to advance care plans in daily handover (always think, “how an agency nurse would know)”