

**Joan – A case study with** **long term conditions**

Joan is a 71 year old lady who has lived in your care home for 10 months. Joan has a diagnosis of COPD and has found it increasingly difficult to maintain her activities of daily living. Joan uses a wheelchair to aid mobility and relies on the nursing staff for assistance with her daily needs. Joan’s current physical condition has been deteriorating; Joan has recently had a hospital admission for an exacerbation of her condition which was treated successfully however on return to your home Joan appears more dependent and low in mood.

On attending to Joan one morning she comments to you that she “feels tired with her existence” and never wished to live in this way.

Joan has a large family. She has three daughters; Barbara, Edith and Rita, and two sons; Frank and James. Joan’s daughters visit on regular basis and are quite involved in directing the care Joan receives. It has taken some months for Joan’s daughters to gain trust in the care staff within your home as they have found handing the care of their mother to you difficult. Joann’s sons are less involved with her care although they visit on a regular basis. Following the recent hospital admission Barbara has expressed to you she feels her mum “can’t take any more”. Edith and Rita however were extremely impressed in the outcome of the Joan’s treatment and commented how well she always appears whilst in the 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**

Joan is phase 1/2 (gradual/rapid decline) of the North West Model for Life Limiting Conditions

The rationale for this is:

* Advanced COPD
* Resides in a care home
* Assistance with daily needs
* Poor mobility linked to COPD
* Current physical condition has been deteriorating
* Recent exacerbation of COPD requiring a hospital admission
* Increased dependency
* Low in mood

Use the discussion to illustrate the difficulty of prognostication for residents with long term conditions and how residents can move up and down the model.

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

*Consider: Cues*

Hopefully an advance care planning decision would be prompted by:

* Joan’s deteriorating condition
* Hospital admission
* Increasing dependence
* Low in mood

Cues:

*‘Tired with her existence’*

This cue may lead further into a supported discussion; it would be advisable to ask if the discussion could be taken further including Joan’s family - take the lead from Joan.

Aim for a family meeting however, this needs careful handling as the family members appear to be at different stages of acceptance of the disease process. Individual family members may need some support prior to the meeting (use of advance communication skills).

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

*Consider everyone’s needs and what approach may be best*

If Joan gives consent then involve all the family. The sooner you can elicit individual family members’ expectations the better in order for you to plan and offer support. Involve the wider team who are involved in Joan’s care i.e. GP, SW, CNS.

It is important Joan is involved and at the centre of all discussions; it can be difficult with families that have lots of dynamics to maintain the focus. The more input Joan can have will help the family and MDT to know they really are acting in Joan’s best interest when a time comes that Joan can no longer contribute to the decision.

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

The most appropriate person may not be the manager or care home staff in this case; it may need a professional who is not as closely linked into the daily care of Joan i.e. her GP.

This case study scenario however does need leadership which could be provided by the care home staff.

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

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

Effective communication is essential in this scenario. The family needs to know the door is open regarding the assessment and review taking place.

ACP needs to be communicated with all professionals involved in Joan’s care. Clinical nurse specialists may be key communicators between the care home and the acute sector if working across sector boundaries.

Think about systems in place to aid communication or what could be applied i.e. main file for ACP, brightly coloured ACP, ACP referred to in handover (always think, “how an agency nurse would know?‟).