

Nutrition and Hydration - issues in the last few days of life

Outcomes:

Patient related outcome:

People in their last few days of life and their families feel supported by nurses and carers in the receiving of holistic person centred nutritional and hydration care.

Carer related outcome:

Nurses and carers knowledge is increased to support skill development and compassionate and confident behaviours in

- recognising and supporting people's nutritional and hydration care needs in their last days of life
- providing support to and increased communication with dying person's families to enhance their coping through increased sense of control and understanding of care requirements of their dying relative

Recognising dying:

As someone enters the last few days and hours of their lives their physical body naturally slows down and physical systems start to stop.

The dying person's dying process is unique to them and is likely to be influenced by their underlying condition/s and its management. However the dying person is likely to show

- A decrease in their general alertness and responsiveness
- increase in time spent asleep
- changes in their ability and desire to eat and drink

Supporting the dying person with eating and drinking as long as they are able to swallow

If the dying person's alertness or clarity of mind changes, the care giver may need to support the patient with their nutritional and hydration intake. It is the care giver's role to offer frequent sips or drinks or alternative meals that are more manageable to the dying person. Tips may be given considering the "Remember the Ps" guidance. (can be elaborated here if not already included)

Strategies that are proving useful eg small portions or preferred dietary options eg yoghurt/omelette should be communicated with other members of the care team and the

patient's family and detailed in the care plan so that it is considered in menu selection and at meal times. Chefs may be willing to respond to specific requests or family members willing to prepare preferred meals for the dying person.

Caregivers should monitor the patient's intake sensitively and record intake in the contemporaneous notes. Family members often wish to know what someone has eaten and drunk and need reassurance that food and fluid was offered and the patient supported to eat and drink as able. Studies (Raijmakers et al, 2013; Teno et al, 2011; Orrevall et al, 2004) have shown that dying people and their relatives lack communication with healthcare professionals around reduced oral intake, managing eating problems or improving food intake.

Sensitivity is required to ensure no burden is placed on the dying person to eat or drink any more than they feel able to do so by professional carers or families and visitors. In a systematic review carried out by Del Rio et al (2012) 7 studies showed that families of people with cancer are usually more concerned about oral intake than the dying person as families often believe continued oral intake would improve their quality of life and extend their survival. Frustration and conflict can occur because of this. Giving the family members opportunities to express their concerns about poor oral intake is important at this time as well as explaining the dying person's reduced need for food.

As the dying person's ability to eat and drink changes, their ability to swallow may reduce and this may be manifested by extended periods of the food being in the mouth before it is swallowed. There may be episodes of coughing or choking with food and fluids as the person's swallow reflex deteriorates. At this time ensuring the dying person is in an upright position when taking oral fluids and using a straw, feeding cup, teaspoon or 5 ml syringe to give small volumes of fluids or the sucking on ice chips or lollies may be more effective. A trial of thickened fluids may be useful for a brief period. It is at this time that the care team will need to monitor, assess, agree any actions required and regularly review the dying person's risk of aspiration (where some or all of the oral intake is passing into the person's lungs rather than their stomach).

Communication and decision making as swallow deteriorates:

As the dying person's swallow deteriorate, decisions will need to be made by the care team in consultation with the patient about how this will be managed. Options considered may be:

- referral to speech and language therapist for swallow assessment and recommendation of actions
- clinically assisted (also known as "artificial") hydration and nutrition
- comfort care only

Where the patient has been assessed not to have capacity for such a decision, best interest decisions will need to be made by the doctor with the care team in consultation with the family and or Lasting Power of Attorney-Welfare (LPA). If the patient has made an Advanced Directives to Refuse Treatment (ADRT) or Advanced Care Plan (ACP) this should be consulted. Such decisions involve weighing up potential benefits versus potential risks and harm and are medical treatment decisions. Thus they are the responsibility of the responsible doctor alone (see GMC, Treatment and care towards the end of life: Good practice in decision making.p22-23. GMC 2010.) GMC guidance advises this should be made following discussions with family members and healthcare team members to ascertain any previously highlighted patient preferences. Indeed studies (Malia et al 2011;Rurup et al, 2006;Teno et al, 2011;have shown that patients and families wish to be involved in such decisions. Such decisions should be fully explained and documented.

Family members usually respond to an explanation relating the natural process of dying. Where further explanation is required it can be explained that research (Danis, Arnold & Dizon, 2013) has shown that artificial hydration when someone is dying may cause increased symptoms of chest secretions, oedema and vomiting from excess of gastric juices.

Studies (references needed please) into the benefits of clinically assisted nutrition and hydration at end of life is mixed and does not provide sufficient evidence for or against the medical intervention of artificial hydration in the last few days of life. In some cases consideration may be given to a trial of clinically assisted hydration or artificial hydration. These are considered medical treatments by law. Sub cutaneous fluids may be as effective (??) and may be a more compassionate way of administering artificial hydration to the dying person. Sub cutaneous artificial hydration can often be managed in the home situation under the supervision of the community nurse.

As the dying person's ability to swallow and the plan of care changes it is essential that this is explained to the relatives and communicated to all care staff including ward volunteers/ housekeepers/ward clerks and catering staff.

Where a patient has become mainly unresponsive and his prognosis is expected to be short days or hours the care team with the patient/relative/LPA may agree that comfort measures only should be the main focus of care and decisions will need to be made as to when to stop giving oral nutrition and oral hydration as the risk and distress caused to the dying person outweighs any potential benefit.

Dying people do not usually complain of thirst where regular mouth care is given. *Studies (??references needed here) has shown that thirst is not a commonly reported symptom in the dying.*

The plan of care should be reviewed regularly by the nurse, care staff and doctor.

Mouth Care:

As the dying person's oral intake decreases care should include regular mouth care performed with sensitivity and compassion. The care giver should continue to explain to the dying person and relatives the plan to carry out mouth care. If the dying person closes their mouth shut during attempts to give mouth care then this should be taken as the dying person's indication that mouth care is not wanted at that time and mouth care should cease and be offered again at another time. Some family members may like to be involved in mouth care and should be supported by caregivers to do this. See Doncaster Mouth care for guidance...

Comfort measures

In addition to regular mouth care, position changes, care of hygiene and elimination needs should be attended to regularly or at least 4 hourly where patient's tolerates this. Regular review of the patient's for distressing symptoms should be undertaken and prompt treatment given. Anticipatory prescribing or the prescribing for common symptoms in the dying before they are present is best practice. The prescribing of prn (as required) analgesics (pain killers), sedatives and medications for chest secretions (sometimes known as the "death rattle") should be considered. Continued communication with the dying in a respectful and dignified manner should continue even when the person is unconscious as their sense of hearing can continue until death. Individualised care should respect the individual's and family's cultural, religious and spiritual needs or practices.

Remember in holistic end of life care it is "the little big things that matter". This may be offering to sit with someone for a period to talk about or with the dying person or raising the height of the bed for a relative to be in a more comfortable position to attend or be close to the dying person.

Family centred care

The care of family members becomes ever more central to the holistic care of the dying person. Their prime need is to be reassured of the patient's comfort.

Provide regular opportunities for the family member to understand or be updated on the condition, treatment and or care given to the patient. Consider at what pace family members may like to know what changes to expect and how they will be managed. Make the family feel welcome at all times and consider what arrangements can be made to offer them space to rest and eat and drink close by. Some family members may wish to stay with the patient continuously or others may wish to be called back if death is close by. Some may wish to be involved in direct care giving. Provide advice and support as needed.