Eating and Drinking and End of Life Care

- For individuals living with a terminal illness, dysphagia (swallowing difficulties) can be a common occurrence. Advance care planning is important - discuss with the person their priorities and their wishes should they lose their ability to swallow.

When managing dysphagia during end of life care, you should consider:

- Comfort and pleasure. If eating and drinking appears uncomfortable and distressing, offer only if requested. It is often sufficient to maintain good oral hygiene and moist mouth/lips to maintain comfort

- The person's posture & position when eating or drinking – upright if possible.

- Food offered "little and often" is often easier to manage than a few larger meals. Do not worry about nutritional value of food intake. Follow the lead of the person regarding what they feel like eating. Softer or modified food is often easier to eat.

- Advising the person to take small mouthfuls and chew slowly. The person may require assistance.

- Try easier textures for food, **moving down** the IDDSI levels. Move down the IDDSI levels one by one. EG. If on normal diet, try level 6. If on Level 6, try level 5. If on Level 5, try level 4. Complete the Food Swallow diary pre-and post trials so you have clear rationale for making any changes permanent.
- If the person is coughing with fluids, it may be more comfortable to try naturally thicker drinks (eg. Milkshakes, smoothies, thick fruit juices). If they manage these more easily, they may benefit from some thickener in their drinks, which the GP/ANP may be able to prescribe. This won't necessary stop aspiration, but may be more comfortable at end of life

- Capacity and Consent- does the person have capacity to assess the risks vs benefits of eating and drinking. The person must be provided with the relevant information to make an informed decision. See ‘Capacity Assessment’
- It is vital that the individual is supported to eat and drink if desired and able to (NICE 2015). If issues with swallowing are identified, the risks and benefits of continuing to eat and drink must be discussed with the service user, their loved ones, carers, and other professionals involved in their care (NICE 2015). If the person is assessed as having mental capacity, their wishes must be honoured through treatment delivery as outlined in Sirona’s policy for the care of individuals at the end of life (2022). If the person lacks mental capacity, a best interest decision must be made as a multi-disciplinary team. See information about ‘Eating and Drinking at Acknowledged Risk (EDAR)’.

- **Mouth care should be conducted regularly regardless of the presence of dysphagia however, the frequency of mouth care should increase if someone is dysphagic (RCN 2021). Frequency will be individual to each person however during someone’s last days mouth care should be carried out hourly or as tolerated by the person. Mouth care should aim to make the person as comfortable as possible in the least invasive way (HEE 2019)**

  See ‘Oral care guidelines’ and ‘Oral Care Products’. This can be found in our resources library or as a hyperlink in the questionnaire

  You can contact sirona.SLTcarehomesadvice@nhs.net for further advice or guidance.

Some conditions that can cause dysphagia at the end of life include:

• Stroke
• Motor neurone disease (MND)
• Dementia
• Parkinson's disease
• Multiple sclerosis (MS)

- Cancer, particularly cancer in the head or upper gastrointestinal tract
- Older age
- Lack of consciousness
- Cachexia (weakness, fatigue, deconditioning)