End-of-life care – guidance

Introduction

Speech and language therapy in end-of-life care is a relatively new field, with an increasing recognition of SLTs' specific skill set in communication and dysphagia to be essential to good end-of-life care.

The guidance:

- clarifies the role of speech and language therapy in end-of-life care;
- provides guidance and support for RCSLT members through definition of terminology, and through giving an opportunity to standardise and promote best practice;
- informs members on current guidelines, policy and legislation, research and best available evidence around this topic;
- links to supporting information;
- is relevant for all RCSLT members working with end of life across the UK.

It is our vision that the end-of-life care speech and language therapy role will become established practice, supported by robust evidence and training opportunities. This guidance is the first stage to formalise discussion of key areas to achieve that goal, and ensure implementation is well-guided and appropriate.

For more end-of-life care information, see also:

- **Learning**
- **Influencing and campaigning**
- **Evidence and research**
- **Contacts**

For related topics, please see:

- **Augmentative and alternative communication (AAC)**
- **Brain injury**
- **Critical care**
- **Dementia**
- **Dysphagia**
- **Head and neck cancer**
- **Learning disabilities**
- **Mental health**

- **Neonatal care**
- **Progressive neurological disorders**
- **Respiratory care (adults)**
- **Stroke**

For professional guidance, please see:

- **Delivering quality services A to Z**
- **Outcome measurement**
- **Meeting the HCPC standards**
- **Settings**
- **Supported decision-making and mental capacity**

Definitions

Terminology for end-of-life care and palliative care can change from one service to another, and from one country in the UK to another. The RCSLT adopts definitions that align with the World Health Organisation (WHO) and the professional bodies of NHS services.

Palliative care

Palliative care is an appropriate term to use for those with diagnosis of a long-term and/or life-limiting condition; for example, lung/heart conditions or progressive neurological conditions. It may cover many years. Palliative care is defined by the WHO (2012) as;

- an approach that improves the quality of life of patients and their families facing problems associated with life-threatening illnesses through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, such as physical, psychosocial and spiritual.

Children's palliative care is defined by Together for Short Lives (2019) as;

- an active and total approach to care, from the point of diagnosis, throughout the child's life, death and beyond. It embraces physical, emotional, social and spiritual elements and focuses on the enhancement of quality of life for the child or young person and support for the whole family. It includes the management of distressing symptoms, provision of short breaks, care at the end of life and bereavement support.

End-of-life care

For the purposes of this RCSLT guidance, the term 'end-of life-care' is the approach taken for those in their last year of life, and includes the last days and hours. End-of-life care is defined by the General Medical Council (GMC), Royal College of GPs (RCGP), Royal College of Nursing (RCN), and Royal College of Physicians (RCP) as;

- support for those who are likely to die within the next 12 months. This definition covers help with physical, emotional, social and spiritual issues.

Clinicians can use the 'surprise question' to consider who this applies to: "Would you be surprised if this patient were to die in the next 6 or 12 months?" For many groups, it is difficult to predict the trajectory of the end-of-life phase; for example, those with learning disabilities, dementia and frailty.

It is important to note that some settings will make a distinction between end-of-life care for the last year of life and for the last days/hours, to help with care planning. This definition is supported by the Proactive Identification Guidance from the Gold Standards Framework (2016) and the Supportive and Palliative Care Indicators Tool (2018) in Scotland. Predicting the last days and hours of life can be difficult, and there can be unexpected improvement.

Further definitions of relevance to this guidance are:

- Neonates: defined as infants in the first 28 days after birth.
- Infants: defined as babies aged from one month old until their first birthday.
- Young people: while some services define young people as up to age 25 years, others offer adult services to 16-year-olds; for this document, young people are defined as up to the age of 18.
- Specialists in end-of-life care: usually doctors, nurses, therapists and counsellors working in a hospice setting, or community services run by a hospice, or specialist NHS palliative care teams, with additional training in this area of care.
- Generalists in end-of-life care: practitioners who are involved in supporting end of life, such as GPs, district nurses, care/nursing home staff, therapists and hospital staff.
- Multidisciplinary and interdisciplinary teams (Nancarrow et al 2013): interdisciplinary working describes an integration of roles and responsibilities across professionals in a team, and multidisciplinary teams (MDTs) are those where practitioners work together yet remain confined mostly to their professional role. For the purposes of this RCSLT guidance, the term ‘MDT’ will be used to refer to all teams.

Context

The current legislation and guidance in end-of-life care covers an ageing population, children with life-limiting conditions living into adulthood, and public expectations in making choices in their care.

It is imperative that high-quality end-of-life care is delivered to those who need it. It is also important that the family/carers are involved, as “how people die remains in the memory of those who live on” (Dame Cicely Saunders 1989). The importance of this has also been highlighted in reviews aiming to improve the care of people who are dying and their families (One Chance to Get it Right 2014).

High-quality end-of-life care means person-centred care, involving:

- good communication;
- ongoing assessment and coordination between services;
- family-focused support that is tailored to any set of circumstances – cultural, social, psychological, and spiritual.

Both child and adult end-of-life care services advocate the same principles in planning and management:

- use of a holistic approach;
- information sharing;
- advance care planning;
- coordinated care.

(NICE 2016, NICE 2011)

How many people receive end-of-life care at any one time?

Adults:

- Typically 1% will be in their last year of life (Dying Matters 2014).
- Two-thirds of adult deaths are in people aged over 75 years.
- Of the third who are under 75 years, there are more deaths in the age ranges 35-64 and 65-74 (Office for National Statistics 2017).

Infants, children and young people:

- There is a rising national prevalence of life-limiting conditions in children in England (Fraser et al 2012), reportedly a doubling of estimates from data gathered from 2000 to 2010.
- Around 6,000 infants, children and young people between 0 and 19 years die in the UK every year (Wolfe et al 2014).
- Approximately 40% of deaths for those under 15 years are neonatal deaths (Nasir 2016).

- Almost 50,000 children and young people aged 19 or under in the UK are living with life-limiting conditions.
    - More than 300 conditions are classed as life-limiting or life-threatening for children, including those with disabilities and complex health and social care needs; and for those children and their families, palliative and end-of-life care begins at diagnosis (Wolfe at al 2014).

What are the causes of death?

Causes of death are from;

- advanced, progressive, incurable conditions;
    - eg some cancers, progressive neurological conditions, dementia
- general frailty and co-existing conditions*;
- existing conditions that include a risk of dying from a sudden acute crisis
    - eg renal disease, congenital conditions
- life-threatening acute conditions caused by sudden catastrophic events;
    - eg injuries from a road traffic accident, or stroke
- neonates, infants or children with life-limiting conditions;
    - eg metabolic conditions
- neonates, infants or children with terminal conditions;
    - eg pulmonary, cardiac and/or multi-organ failure
- persistent vegetative state and withdrawal of treatment.

*As the average lifespan increases, the incidence of acute episodes that cause death is reducing while the prevalence increases of gradual deterioration of health leading to death (Bogaardt et al 2014).

Where do people die?

The settings for place of death can be:

- hospital;
- home;
- residential setting (schools, care/nursing homes, prisons);
- hospice.

Public Health England (2018) profiled the proportions of deaths by setting:

- Almost half of all deaths occur in hospital.
- Nearly a quarter of deaths occur in people’s own home.

- Approximately a fifth of deaths occur in residential settings.
- Just over 5% of deaths occur in a hospice.

Learning disability and mortality

- Average age at death of people with learning disabilities was 59 for males and 56 for females.
- More than a quarter (28%) of deaths were of people aged under 50 years.
- People with profound or multiple disabilities had an average age of death of 41 years.
- Those with mild or moderate learning disabilities had an average age at death of 63 years.

(The Learning Disabilities Mortality Review Annual Report 2017)

Concerns people have when a loved one is dying

Over 4 in 10 (44%) of those who had questions or worries wanted to know what physical or mental changes they should expect when someone close to them was near death.

- Whether to bring up difficult issues with their dying family member or friend before the end of their life (21%).
- How to make them more comfortable (58%).
- Whether they should die in a more comforting environment than a hospital ward (18%).
- The last words they should say to them (40%).
- Who should be there in the final moments (36%).

(Sue Ryder Care 2018)

What is the difference between end-of-life care for children and adults?

Together for Short Lives (2019) explains that children’s end-of-life care services are different compared with the care provided for adults in the following ways:

- Palliative and end-of-life care can last longer, and can be from a point of antenatal diagnosis.
- End-of-life care may require transition to adult services.
- Children can go through many repeated phases of last days of life, interspersed with improvement.*
- Priorities that influence decision-making for children and their families will change over time.*
- Children have varying levels of capacity, and some may want additional parental involvement in decisions around their care.*
- Psychological support is essential for families, from diagnosis and through bereavement, including siblings.*

*These points are relevant to some adult groups for example those with learning disability.
For more information, see the **Service planning and improvement pages.**

General risk factors for and impact on those receiving end-of-life care

End-of-life care can have a profound impact on those receiving it and their families/carers. This section sets out general risk factors that may negatively impact the experience of receiving end-of-life care.

Difficulty of identifying people approaching end of life

Identification of people approaching end of life is difficult, as the trajectory of some conditions can be unpredictable.

- GPs typically identify only 27% of those who are in their last year of life at their practice (GSF Primary Care Training Programme 2010).
- During the last weeks and days, there can be unexpected improvements.
- Murray et al (2005) give a framework of illness trajectory for cancer, progressive chronic illnesses and frailty.
- Diagnostic overshadowing (health professionals wrongly assuming physical symptoms as a consequence of mental illness or cognitive abilities) can happen for individuals with:
    - learning disabilities (Mason and Scior 2004);
    - mental health issues (Jones et al 2008).

Advance care planning (ACP) in place/not in place

An ACP enables people to make plans about their future health care. It can include:

- preferred place of care/death;
- who should provide care;
- a will;
- lasting power of attorney;
- advance directives.

There may be conflicting wishes between the person dying and the family/carer. It is also important for the team around a person to support the realistic managing of expectations.

Lack of coordination of care across services and settings

Coordination of care across services and settings could include the electronic transfer of notes/information. This is of particular relevance between acute and community services and the interface of ambulance staff, where choices over preferred place of care/'do not resuscitate', etc, may not be followed owing to lack of coordination of care.

Not respecting diversity

It is important to respect diversity approaching death – faiths, cultures, sexual orientation, physical and learning abilities, circumstances, personal values, and preferences. This includes:

- Food and drink preferences.
- The importance of worship and prayer.
- Medication requirements, including refusal to take medication.
- Discussing private issues with health- and social-care staff or non-family members.
- The person's ability/accessibility requirements.

Interpreter use

While involving families/carers in interpreting, and/or choosing an interpreter, are valuable for reasons that include their participation, there are occasionally risks in information not being shared and declining appropriate interpreters. Accessing interpreters within a suitable time frame can be difficult in some areas.

MDT differences

Differences between MDTs in composition and leadership, as well as ability to make collaborative decisions, can affect the quality of care provided.

The understanding of the role of the SLT by others in the MDT will affect the impact of, for example, dysphagia therapy (Moloney and Walshe 2018).

Social worker support not available

Social workers support discharge from acute setting to appropriate setting for end of life care, eg home, care/nursing home, community hospital, or hospice, as well as transitioning from home to a care home.

Inconsistent use of terminology

Inconsistent use of terminology by professionals and the public can lead to confusion and affect the quality of care provided.

Access to services

The type and quality of service will be different across areas; for example, not all acute/community trusts have a palliative care consultant.

Risks factors for and impact on neonates and preterm infants

End-of-life care may differ depending on the age of the person receiving it. This section sets out risk factors relating to speech and language therapy, and the impact these can have on neonates and preterm infants, as well as on their parents.

Communication

- Preterm infants and neonates subtly communicate needs and signs of stress through a combination of cues:
    - facial expressions;
    - body movements;
    - autonomic regulation.
- Recognising cues means appropriate care and comfort is given, with bonding opportunities for parents and other family members.

Feeding and swallowing

- Preterm infants are at high-risk of developing negative oral associations from intubations, repeated nasogastric tube (NGT) insertions, suctioning, or facial/nasal cannulae oxygen, owing to immature sensory systems.
- Some infants have difficulty safely and comfortably swallowing their own secretions.
- Some end-of-life care medications (benzodiazepines/anti-epileptics/sedations) can have an impact on swallow function.
- Co-morbidities, such as brain injury, cardiac/structural abnormalities and lung disease, may affect suck-swallow function or feed tolerance.

Breathing difficulties

Babies born prematurely:

- may require respiratory support owing to immature lung development;
- are at risk of prolonged respiratory distress syndrome and chronic lung disease;
- may struggle to safely or efficiently co-ordinate their suck-swallow-breathe patterns, placing them at risk of feed-induced apnoea, aspiration, stressful feeding experiences and/or poor growth;
- aspiration can exacerbate already present lung disease or respiratory illness.

Attachment

Some families shy away from visiting their baby to ease potential pain if survival is uncertain. This can lead to:

- babies not receiving important comfort care;
- parents losing opportunities to create memories.

Risk factors for and impact on infants, children and young people

End-of-life care may differ depending on the age of the person receiving it. This section sets out risk factors relating to speech and language therapy, and the impact these can have on infants, children and young people.

Communication

- Communication difficulties affect the ability to:
    - express needs, hopes and fears;
    - acknowledge and/or communicate pain;
    - comprehend information;
    - weigh up options and express a preference;
    - maintain and enjoy relationships: social closeness.
- Children may be at risk of receiving inappropriate care owing to staff with little or no knowledge of communication strategies.
- Communication strategies need to be responsive to fluctuations in their abilities, linked to, for example, medications or mental health; there will be optimal times in the day for important conversations.

Dysphagia

Children who experience dysphagia can be at risk of:

- chest infection, aspiration pneumonia or recurrent respiratory illnesses;
- dehydration;
- malnutrition;
- fear of or aversion to oral eating;
- poor oral hygiene;
- lack of experience of normal eating and mealtimes;
- difficult family-child interactions at mealtimes;
- death.

Eating and drinking in the last few hours of life

- An individual may not be able to take in nutrition because of their medical status (Pollens 2012), with the loss of ability to tolerate/need nutrition and hydration.

- Appetite and pleasure in eating and drinking reduces in the last few hours of life.
- There are powerful associations for families with eating/drinking and care.
- Aspiration risk may fluctuate.

Oral care

Oral care includes management of:

- ill-fitting/inappropriate dentures;
- saliva and secretions;

Poor oral hygiene can cause:

- mouth infection;
- increased risk of chest infection;
- discomfort to the individual and unpleasantness for family members.

Psychological factors

A person’s mood/denial can have an impact on decision-making.

Risk factors for and impact on families/carers

End-of-life care should also take into account families/carers supporting those receiving it. This section sets out general risk factors and the impact these can have on families/carers, which are important for SLTs to be aware of.

A ‘family’ may include more than relatives – eg friends, neighbours, colleagues, support workers.

Strain

A lack of adequate support for families can lead to:

- additional burden;
- development of maladaptive strategies;
- breakdown of relationships;
- feelings of guilt and difficulty with complex emotions;
- impact on mental health;
- financial problems;
- powerful allegations/complaints against healthcare staff in the context of grief/anger/injustice.

Families can find it difficult to adapt to changing relationships as roles transition into caring.

For parents of neonates receiving end-of-life care, there can often be minimal opportunities for private family moments.

Denial

Denial over diagnosis can disrupt the acceptance of help.

Risk factors specific to SLTs

There are risk factors specific to SLTs working in, or wishing to work in, end-of-life care, that can impact the ability of SLTs to deliver high-quality services. This section sets out risk factors to the profession that are important for SLTs to be aware of.

Education

- Training of students;
    - often end-of-life care training is given only as part of dysphagia training.
- SLTs work in end-of-life care is developing, so there is limited professional preparation.

- Differences in levels of speech and language therapy competence and experience in end-of-life care in MDTs.
- Ongoing educational restraints for speech and language therapy training;
    - it is positive to pursue training as a MDT and have access to generalist training (eg Sage and Thyme training: Connolly et al 2010).

Resilience

- End-of-life care is an area of work that has a high-level of emotional toll.
- Personal experience of end-of-life care will have an impact.
- Funding arrangements for speech and language therapy will affect how embedded a therapist is within the support of a MDT.
- Access to:
    - supervision;
    - Schwartz Rounds (Gannon 2014): structured forums for staff to discuss the emotional and social aspects of caring.

Changing role of speech and language therapy in end-of-life care

The role of SLTs in end-of-life care is changing, “SLTs [are] forging a self-identity in a sector that itself is constantly evolving [and] causes difficulties in defining their role” (Hawksley et al 2017).This can be helped by:

- people and their families understanding the SLT role in end-of-life care;
- sharing risk with the MDT; for example, over decision-making around eating and drinking;
- managing professional boundaries and collaborative working as roles evolve; for example, for nurses, physiotherapists as well as SLTs.

Decision-making: legal and ethical considerations in end-of-life care

Person-centred and supported decision-making in end-of-life care is imperative to delivering high-quality services. This section lays out the legal and ethical considerations SLTs need to take into account in end-of-life care.

See also RCSLT guidance on:

- **Supported decision-making and mental capacity**
- **Safeguarding**

Human rights

The Human Rights Act (1998) states the following:

- Give patients approaching end of life the same quality of care as other patients.
- Treat patients and those close to them with dignity, respect and compassion.
- Respect their privacy and right to confidentiality.

Mental capacity

The UK is covered by three different legislations relating to mental capacity:

- England and Wales: **Mental Capacity Act (2005)**
- Scotland: **Adults with Incapacity Act (Scotland) (2000)**
- Northern Ireland: **Mental Capacity Act (Northern Ireland) (2016)**

Having mental capacity means understanding the nature, purpose and possible consequences of investigations or treatments, as well as the consequences of not having treatment.

A person must be able to understand, retain, use, weigh up this information and communicate their decision to others in consenting to an investigation, treatment or decision.

Practitioners should start with the presumption of capacity of every adult patient; they should not withhold information from a person, including when asked by someone close to that person.

Advance refusal of treatment

This can be written or verbal and recorded in care notes.

Please see the Codes of Practice that supports the different legislations on mental capacity:

- England and Wales: **Mental Capacity Act Code of Practice (2007)**
- Scotland: Adults with Incapacity (Scotland) Act 2000: Code of Practice: For persons authorised under intervention orders and guardians (2008)
- Northern Ireland: Still in draft

These set out the criteria when advance decisions about life-prolonging treatments are legally binding. They differ depending on the geographical location of the person.

DNACPR (Do Not Attempt CPR/Allow Natural Death)

Cardiopulmonary resuscitation (CPR) has a low success rate, and can have harmful side-effects with adverse clinical outcomes.

If cardiac or respiratory arrest is an expected part of the dying process and CPR will not be successful, making and recording an advance decision not to attempt CPR can help a patient die in a dignified and peaceful manner. This does not mean other treatments are withdrawn or withheld.

Adults

If an adult lacks capacity:

- Act in their ‘best interests’.
- Include any previously expressed wishes or preferences.
- Weigh benefits, burdens and risks to determine ‘overall benefit’ of the treatment.
- Involve family/carers friends who know the person well.
- Discuss with someone who holds legal authority (lasting power of attorney for healthcare).
- Consider the need for an independent mental capacity advocate (IMCA).

Children

- At 16, a young person can be presumed to have capacity to consent.
- A young person under 16 may have capacity to consent, depending on their maturity and ability to understand.

If a child lacks capacity:

- Discuss with parents/carers:
    - Parents have role in assessing their child’s best interests.
    - This is challenging when there are uncertainties about the long-term outcomes of treatment; the clinician must take the most up-to-date clinical guidance to mitigate this issue.

- Act in their ‘best interests’.
- Include any previously expressed wishes or preferences.
- Weigh benefits, burdens and risks to determine ‘overall benefit’ of the treatment.

Neonates and infants

- Seek second opinion if the consensus is to withdraw clinically assisted nutrition and hydration (GMC 2010).

Role of speech and language therapy

The role of speech and language therapy in end-of-life care is evolving. For example, an expansion from provision of assessment and therapy to include information sharing and support in the role has been suggested (Kelly et al 2016).

This section outlines the possibilities for the role of an SLT in end-of-life care for different age groups.

Some aspects described below could be taken up by nurses, consultants or dietitians, depending on the multidisciplinary model and the experience and competency of those in the team.

Neonates

Speech and language therapy has the following roles in supporting neonates:

Communication/attachment

- Advocate early communication and interaction activities to comfort and calm the baby, eg parental touch, the use of voice, reading and singing.
- Support parents and staff in interpreting the infant’s motoric and physiologic cues for;
    - feeding readiness;
    - stress cues in response to physical, pain or environmental stimuli;
    - positive enjoyment or calming responses;
    - maximising comfort, appropriate rest and levels of stimulation.

Dysphagia/swallowing

- Diagnose feeding and/or swallowing difficulties, including ability to manage saliva, and identifying the impact of comorbidities.
- Maximise feeding potential and minimise risk of aspiration, unpleasant feeding experiences for parents and the infant, and poor nutrition.
- Identify the risk of aspiration or feeding dysfunction, to reduce the risk of premature death.
- Support opportunities for positive oral stimulation, feeding and bonding experiences; for example, skin to skin (Boundy et al 2016), colostrum mouth care, and positive facial touch.
- Assess readiness and safety for breastfeeding/bottle feeding.
- Advise on specialist feeding equipment if required, and on strategies around positioning, feeding technique, and recognition of feeding readiness and disengagement cues.

Lactation support

A role that overlaps with nurses and lactation consultants.

- Advise parents regarding feeding options, and offer mothers prompt support around breastfeeding/breast milk feeding and principles of responsive feeding.
- Support initiation/maintenance of milk supply for breastfeeding and/or provision of breast milk for nasogastric tube or bottle feeding.

Multi-disciplinary working

- Educate team members (doctors, nurses, parents, allied health professionals (AHPs)) on the impact of aspiration or feeding difficulty, and method of feeding on the infant's comfort, prognosis and infant-family relationships.
- Be involved in discussions around indications and contraindications for commencing/continuing/discontinuing supplementary feeding (nasogastric tube, orogastric tube, nasojejunal tube, percutaneous endoscopic gastric tube).
- Balance risks of oral feeding with the infant's quality of life and comfort, producing a clear feeding plan with the family.
- Promote good developmental care (Kenner and McGrath 2010), including:
    - allowing private moments as a family wherever possible: opportunities to bathe, dress and care for their baby;
    - reducing stress for infant and family.

Infants, children, young people and adults

There are commonalities for the role of speech and language therapy across different groups (age and cognitive ability). It has the following roles in supporting infants, children, young people and adults:

Communication

- Support speech, language and communication difficulties.
- Enable challenging conversations appropriate to end of life.
- Work proactively rather than re-actively.

Maintaining and supporting communication

- Assess, diagnose and manage planning of dysarthria, dysphasia, dysphonia, developmental language disorders, apraxia of speech, dyspraxia, speech sound disorders, communication needs due to hearing difficulties, learning disabilities, visual impairment.

- Recommend Alternative and Augmentative Communication (AAC) if required, eg low-technology and high-technology AAC.
- Facilitate person-centred communication goal setting.
- Enable strategies to communicate needs, express preferences and indicate pain.
- Support communication strategies of the person, family and staff alongside changing capabilities, enabling the person to participate in decision-making, and maintain social closeness to family and friends through:
    - speaking strategies: repetition, spelling, key words, breathing, relaxation, energy conservation;
    - conversation strategies: partner interpretation, confirmation, context, topic cues, attitude, humour;
    - non-verbal strategies: positioning, gesture, vocal tone, facial expression, eye contact;
    - low-technology AAC: communication chart. (Murphy 2004).

Enabling participation of people and their families in difficult conversations:

- Advance care planning can be considered in three ways:
    - affairs;
    - care/treatment (can include advance decision to refuse treatment);
    - personal values (Murphy 2018).

- Supported decision-making and assessment of cognitive status: can include independent mental capacity advocate, person as lasting power of attorney.
- Emotional support for communication-impaired people and their families, through conversations about death and dying.
- Explaining issues around eating and drinking in the last few days/hours of life.

The following care pathways have been created to support practitioners in delivering care to children and their families (Together for Short Lives 2019):

- Core care pathway for children with life-limiting and life-threatening conditions.
- Perinatal pathway for babies.
- Transition pathway to adulthood for young people with life-limiting and life-threatening conditions.
- Extubation pathway.

Dysphagia management

Nutritional intake can maximise energy levels to participate in activities and/or add to the quality of life for the person and their family in the last year/days of life.

- Assess, diagnose and manage eating, drinking and swallowing difficulties, which can include sensory, physical, environmental, and behavioural aspects of feeding, associated with a person's condition.
- Assess issues of eating, drinking and swallowing and determining risks of aspiration, dehydration and choking.
- Share these risks with the person dying (if they have the mental capacity) and their family to enable an informed decision over beginning or withdrawing artificial nutrition and hydration, and/or to support the MDT in making the least restrictive decision.
- Consider with the MDT the appropriate method of delivery of medication.
- Support maternal lactation initiation/cessation.
- Educate and train family, carers and multi-disciplinary team.

Oral care and saliva management

- Saliva management: pharmaceutical, behavioural, medical devices, positional.
- Stimulating saliva productions for a dry mouth due to medications or disease.
- Managing excessive drooling.
- Identification of ill-fitting dentures.
- Support for oral hygiene.
- Oral hygiene in the last few hours of life when the person is not taking in nutrition or hydration; it can also give families a caring role.

See resource of Mouth Care Matters (2019) from Health Education England and Marie Curie Mouth Care (2018)

Multidisciplinary working

- Involvement in discussions and decision-making around alternative feeding and/or acknowledged risk feeding alongside supporting people's family/client wishes on eating and drinking where this is perceived to improve the quality of life, so balancing risk with client choice, mental capacity and best interests.
- Awareness of care pathways and who is in the MDT.

See also RCSLT general guidance on **Care Pathways**.

Collaborative working

Collaborative working is a key component in delivering high-quality end-of-life care. This includes working with the MDT, family/carers and any others included in the advance care plan.

MDTs

MDTs will have different structures depending on whether they are hospital- or community-based. The composition of the team varies, for example, for learning disability or for children (can include community children's nurses).

The MDT will also include other AHPs (Management of symptoms in palliative care – the role of specialist palliative care allied health professional 2018).

For each team, there will be differences in leadership style, as well as varying levels of experience in collaborative decision-making.

Methods of communicating as a MDT will vary depending on the structure of the team, and if based in the community or hospital. For example, a community-based SLT may make an observation on a home visit that requires sharing with the GP, district nurse and clinical nurse specialist, and by attending the GP Practice Gold Standard Framework meetings, it can be communicated to all.

The role of the SLT in the MDT

Funding arrangements for speech and language therapy will affect how embedded a SLT is within the support of a MDT. This includes the number of sessions delivered to a setting, or whether there are different trusts and organisations employing members of the team.

For more information, please see **Collaborative working**.

Training and support

The RCSLT recommends that training and support is available to SLTs working in end-of-life care.

Education

- Training of students includes end-of-life care.
- Pursuit of training as a MDT and access to generalist training available (eg Sage and Thyme training: Connolly et al 2010).
- Joint working and shadowing opportunities across the MDT.
- Consideration of development of speech and language therapy-specific postgraduate training in end-of-life care.

Support

Working in end-of-life care can be challenging, and it is important that SLTs build up resilience by having access to:

- supervision;
- debriefing (eg Schwartz Rounds: structured forums for staff to discuss and debrief the emotional and social aspects of healthcare, Gannon 2014);
- peer support.

National guidance

Ambitions for Palliative and End of Life Care. **Ambitions for Palliative and End of Life Care** [online], 2015.

BMA – **Clinically-Assisted Nutrition and Hydration (CANH)**. [online], 2019

End of Life Care Fifth Report of Session 2014-15. Report, Together with Formal Minutes Relating to the Report. [online], 2015

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National policy

Here you will find links to relevant national legislation, policy and frameworks.

Please note that this list is not exhaustive. Please **contact us** if you have any suggestions.

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