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## End of Life Care for Children and Young People; at a glance

### Abstract

This article is part of an at a glance series on palliative and end of life care in Children and Young People. This article aims to provide detail on end of life care (EOL), including; the signs that death is imminent, how to manage the care of a dying child or young person and how to care for the patient after death.

### Introduction

Research suggests that caring for a Child or Young Person (CYP) at the End Of Life (EOL) is one of the most emotionally challenging and traumatic experiences of practice (Maunder, 2006). For the healthcare professional, it is known that this role can instil 'tremendous anxiety' among those who care for CYP in these circumstances (Together for Short Lives, 2017). McCourt, Power & Glackin's (2014) study into nurses' experiences of EOL in acute hospital settings, found that feeling a lack of education and knowledge on EOL, including symptom management and identifying when death was imminent is one of the key factors identified as a barrier in managing EOL. This at a glance article will provide a point of reference for healthcare professionals, to help increase confidence when providing end of life care for CYP.

NICE (2019) guidance identifies that EOL care is the period of time where the CYP is expected or likely to die within the next few hours or days. The goal of high quality EOL care is to ensure that the CYP is able to live as well as possible until they die and ensures that the needs of both the CYP and their family are identified and met through EOL and into bereavement (Together for Short Lives, 2019).

### Care Planning and Symptom Management

Many studies have been carried out which seek to examine the experiences of parents whose child has received EOL. Whilst the quality of life for CYP at EOL is often dependant on the child's condition, research has shown that children are often reported to suffer during this time and experience many unpleasant symptoms (Blume et al, 2014; Rosen & Wolfe, 2017). The most common symptoms which parents perceived to cause suffering for their child tend to be; pain, breathing difficulties, feeding difficulties, fatigue and sleeping difficulties (Wolfe et al, 2000; Blume et al, 2014).

In order to manage unpleasant symptoms for CYP during EOL, an Advanced Care Plan (ACP) should be developed as soon as this is clinically indicated. An ACP should include details about the CYP's condition and decisions should be made in conjunction with the CYP and their family (Together for Short Lives, 2018; NICE, 2019). The ACP is a formal document which can be completed either electronically or by hand and up to date copies of the plan should remain with the CYP, at the setting a CYP regularly attends, and in their medical notes (Child and Young Person's Advance Care Plan Collaborative, 2017). The ACP will include decisions made relating to choices of care in the case of both acute deterioration and the gradual deterioration of the CYP's condition, along with treatment options, symptom management and the CYP's wishes around resuscitation and organ donation (Together for Short Lives, 2019). It is important to remember that plans need to be flexible and may need to be altered in order to meet changes in the CYP or family's needs and wishes (Together for Short Lives, 2018; NICE, 2019).

### Signs that a CYP is reaching EOL

It is impossible to tell exactly when a CYP will die and this is often a source of great upset for those around the CYP. However, there are some signs and changes that nursing staff can observe for which have been identified by NICE (2019). These changes are listed below, along with possible symptom management strategies for each and summarised in Figure 1.

Figure 1. Signs, symptoms and treatment options for EOL

Sign	Symptoms	Treatment
Change of breathing pattern	Difficulty breathing Coughing or coughing up blood. Retaining secretions. Noisy breathing, "rattling". Increased anxiety.	Repositioning.  Medication such as: hyoscine hydrobromide, subcutaneous diamorphine or midazolam, buccal midazolam. Oxygen. Reassurance.
Impaired peripheral perfusion	Hands, feet and limbs may get cold. Changes in skin colour/pallor. Increased sweating.	Keep the CYP warm and comfortable.
Reduced oral intake	Reduced interest or inability to tolerate food or drink.  Signs of dehydration such as dizziness.	Sips of water, moist mouth swabs. Anti - sickness medication. Intravenous fluids/nutrition (in certain situations). Pain relief.
Fall in urine output	May be caused by urinary retention or obstruction which could cause pain and discomfort	Warm bath. Relaxing atmosphere. Gentle bladder massage. Catheterisation.
Altered level of awareness	Reduced consciousness, responsiveness, alertness, confusion and excessive sleeping. Increased agitation.	Reassurance. Calm environment. Continue talking.  If required: benzodiazepines, anti-anxiety and anti-psychotic medications.
Intractable seizures	Frequent, uncontrolled seizures  Convulsion, blackout, loss of bladder control, eye flickering, fixed gaze/ staring into space, muscle tightening.	Follow local seizure management protocols. Anti-seizure medication e.g. midazolam, lorazepam, phenobarbital.
New onset of profound weakness	Reduction in consciousness. Increased sleeping.	Calm environment. Gentle touch. Reassurance. Continue to talk to the CYP

Increasing pain	Reporting pain, groaning or crying, unsettled, agitated, reluctance to move, touching painful areas, reduced oral intake.	Pain assessment.  Appropriate analgesia for the type of pain.
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### Change of breathing pattern

There are several respiratory symptoms which can be expected to occur at EOL, of which the most frequent and distressing encountered in paediatrics tend to be difficulty breathing, coughing (including coughing up blood) and retained secretions (Craig, Henderson & Bluebond-Langner, 2015). Retained secretions can often cause noisy breathing, rattling or what is sometimes referred to as the 'death rattle' as patients are unable to clear their build-up of secretions (Together for Short Lives, 2017). Drugs can be used to help in this situation, including; hyoscine hydrobromide to dry up secretions, subcutaneous diamorphine or midazolam (Together for Short Lives, 2017).

Causes of breathing changes in EOL can also include anxiety, physical discomfort, environmental factors and medical disorders (NICE, 2019). Anxious CYPs should be encouraged to discuss their anxiety, be reassured and helped to manage their anxiety in appropriate ways, including the use of breathing techniques and anti-anxiety medications if required (NICE, 2019). Physical discomfort and environmental factors may be managed through simple strategies such as position changes and room temperature alterations (NICE, 2019). Lastly, medical disorders such as pneumonia, heart failure, sepsis or acidosis should be appropriately managed as clinically indicated (NICE, 2019).

Sadly, in some situations the CYP may experience a severe sudden onset breathlessness, if this occurs it can be a terminal event. The goal of care is always to get the child settled and comfortable as quickly as possible and buccal Midazolam and Morphine may be given until the child is settled (Together for Short Lives, 2017).

### Impaired peripheral perfusion

It can be expected that shortly before death, a CYP's hands, feet and limbs may get cold, and the colour of their skin may change from a healthy pink colour to a pale, grey pallor (NICE, 2019; Together for Short Lives, 2019). On occasion, the CYP's skin can become clammy, they may sweat profusely, and the skin may start to break down. Care of the CYP at this stage should focus on keeping them warm and comfortable but little can be done to improve these symptoms as they are caused by the initial stages of molecule breakdown in destructive metabolism in the body.

### Loss of interest in or ability to tolerate drinks or food

The CYP's appetite and thirst is likely to reduce at EOL which is often a source of concern for families as they worry that inadequate nutrition or dehydration may hasten death. It is important the families are supported to understand that CYP's at EOL require less fluid and nutrition to support them as their bodies are less active at this stage (Together for Short Lives, 2019). An inability to tolerate food or drink due to nausea or vomiting can be managed with anti-sickness medication (Together for Short Lives, 2017).

Management of decreased fluid and nutritional intake should be at the wishes of the CYP and what they feel able to tolerate (NICE, 2019). Sips of water, or a moist mouth swab can be helpful for

mouth care and to relieve thirst (Together for Short Lives, 2019; Together for Short Lives, 2017). CYPs who were previously fed via intravenous nutrition or enteral tube should be involved with discussions on whether continuing this method of nutrition is in their best interests (NICE, 2019). Dehydration may be managed if clinically indicated or it is felt to be causing distressing symptoms such as dizziness for the CYP (Together for Short Lives, 2017).

### A marked and unexplained fall in urine output

The amount of urine that a body produces often decreases at EOL but for some CYP, an inability to pass urine may be due to urine retention (often a side effect of opiates) (Together for Short Lives, 2017). If this is a cause of discomfort for the CYP, it can be managed through a warm bath, a relaxed atmosphere, or gentle bladder massage, though in some cases catheterisation may be necessary (TFSL, 2017).

### Altered level of awareness

Shortly before death, a CYP can be expected to display altered levels of awareness which includes reduced consciousness, responsiveness, alertness, confusion and excessive sleeping (NICE, 2019). CYP's who become agitated should be reassured, kept safe from injury and possible causes of the agitation explored (NICE, 2019). If pharmaceutical management is felt to be of use then benzodiazepines, anti-anxiety and anti-psychotic medications can be considered (Together for Short Lives, 2017; NICE, 2019).

When CYP's become unresponsive, there is growing evidence that suggests that they may still hear and be aware of what is going on around them, so families and healthcare professionals should continue to talk to the CYP (Leigh, 2001).

### Intractable seizures

For some CYPs seizures can be expected as EOL approaches, but on occasion intractable seizures may occur and these types of seizures will keep occurring even with optimal management. Whenever seizures occur at EOL, they should be managed with anti-seizure medication e.g. midazolam, and pharmacological managed unless this is proven to be ineffective (Together for Short Lives, 2017). Possible causes of the seizures should be explored, as drug toxicity in EOL care is known to contribute to seizures (Together for Short Lives, 2017).

### New onset of profound weakness

Usually at the stage of profound weakness, CYP's will also be experiencing a reduction in consciousness so this is less distressing than other symptoms. However, CYPs should continue to be reassured and have their anxiety managed during this time, examples of this would be through gentle touch, also continuing to talk and encouraging the family to continue to talk to the CYP.

### Increasing pain and need for analgesia

Managing pain early and well is the best way to avoid severe uncontrolled pain during EOL care. It is essential that drug doses are increased enough and that the right analgesia e.g. morphine is used in order to manage rapidly increasing pain for CYPs at EOL (Together for Short Lives, 2017). CYP's who are in pain should be assessed using an age appropriate pain assessment and consideration should be given to possible overlooked sources of pain such as neuropathic pain, gastrointestinal pain,

bladder pain, bone pain, pressure ulcers, headache, musculoskeletal pain or dental pain (NICE, 2019). Pain can be therapeutically and pharmacologically managed in accordance with guidelines.

## How to care for the CYP after death

When a CYP has died, the child should be cared for in a location of the family's choice where possible, whether this be a hospital, at home or a hospice. Many families will choose to wash their CYP and remove all medical equipment where possible, but this is a choice (Together for Short Lives, 2019).

Practically, healthcare professionals should recognise that it is useful to incline the head and shoulders slightly to prevent pooling of body fluids in the upper body and the body goes through the following processes (Together for Short Lives, 2019);

- Algor mortis – when the heart stops beating, the body immediately starts to become cold. This can take from 2-8 hours for the outer body.
- Changes to the eyes – immediately after death it is a good idea to close the CYPs eyes as these can become fixed open if this is not done.
- Pallor and loss of skin elasticity – the skin can become pale and dry due to the lack of circulating blood.
- Lividity - within 30 minutes of death, the skin will become discoloured a dark purple due to gravitational pooling of blood. It often pools at the part of the body that is touching a hard surface. After 10-12 hours this becomes fixed.
- Rigor mortis – this is a period of muscle stiffening which normally occurs 3-4 hours after death and disappears after 36-48 hours.
- Bleeding – due to the lack of blood flow, blood will not clot and stop normally, so any areas of bleeding may need to be packed to prevent continuous bleeding.
- Seepage or leakage of body fluids is common – families should be warned of this and fluids handling respectfully.

All deaths must be verified by an appropriately trained healthcare professional, who should establish that the death is expected, the DNR is signed in line with current guidance and that the death does not need reporting to the coroner (Together for Short Lives, 2019). Local guidelines will dictate the cooling and transport of CYPs after death, but families should be encouraged to be involved in the process of caring for their CYP after death as much as they wish. They may wish to collect memories of their CYP, including handprints, footprints and locks of hair.

## Bereavement Support

It is important to ensure that families have a network of support in place and each family's bereavement support should be individual to their needs (Together for Short Lives, 2019). As well as local bereavement support, there are various charities available which support families who are bereaved (Child Bereavement UK, 2020; Clic Sargent UK, 2020; Care for the Family, 2020).

## Support throughout EOL Care

It is important that healthcare professionals providing EOL care for CYPs, be aware that discussing the ACP can be distressing for CYPs and they may be reluctant to think about end of life care, have difficulties discussing end of life care, or have differences of opinion about the care plan (NICE, 2019).

Research into parents' priorities for EOL care has highlighted that they wish to have their faith respected, receive honest and complete information, have access to healthcare professionals when needed, have well planned care which is communicated clearly, ensure that the integrity of the parent-child relationship is preserved and witness emotional expression and support by staff (Meyer et al, 2006).

Lastly, it is widely identified that providing EOL care for CYPs is an emotionally difficult process for healthcare professionals. Healthcare professionals need support to reflect on this process and organisations should arrange a debrief for all staff involved in EOL care, to ensure that lessons are learned and to improve practice for the future (Together for Short Lives, 2019).

### Implications for practice

- EOL care is a difficult role for healthcare professionals but increased knowledge and understanding of this subject will ensure that the CYP is able to live as well as possible until they die and that the needs of both the CYP and their family are identified and met through EOL and into bereavement.
- Advanced Care Plans should be in place for all CYPs undergoing EOL care and should include decisions made relating to choices of care in the case of both acute deterioration and the gradual deterioration of the CYP's condition, along with treatment options, symptom management and the CYP's wishes around resuscitation and organ donation.
- CYP's and their family should be involved in all decision making at a level they are comfortable with.
- Whilst expected time of death can never be predicted, healthcare professionals should be alert to the signs that CYP may display which could show that end of life is approaching. These include; change in the breathing pattern, impaired peripheral perfusion, reduced oral intake, fall in urine output, altered level of awareness, intractable seizures, new onset of profound weakness, increasing pain.
- Knowledge of the process of care after death is vital to ensure this is well managed. This process includes verification of death, the washing of the CYP's body and the cooling and transport of CYPs after death. Families should be encouraged to be involved in the process of caring for their CYP after death as much as they wish and they may wish to collect memories of their CYP, including handprints, footprints and locks of hair.
- CYPs, families and healthcare professionals all need emotional support when experiencing EOL care. Both formal and informal networks including charities, family and the wider community, individual healthcare professionals and the healthcare organisation, may fulfil this role.

### Further Reading

- The following guidance provides useful reading for healthcare professionals involved in EOL for CYP;
- NICE (2016) 'End of life care for infants, children and young people with life-limiting conditions: planning and management'.
- RCN (2018) 'RCN Competencies: Caring for Infants, Children and Young People Requiring Palliative Care'.
- Together for Short Lives – range of resources on palliative and EOL care.
- Template ACPs are available from the Child and Young Person's Advance Care Plan Collaborative, (2017). Available at: <http://cypacp.uk/document-downloads/care-plan/advanced-care-plan-with-respect/>

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