5.5 End of Life

The end-of-life period is generally considered to be the final days and weeks of life. This stage is usually recognized when the child's condition continues to deteriorate despite maximum appropriate treatment, with little chance of improvement.

Revisiting Goals of Care

Goals of care should be established to guide the aims and focus of treatments corresponding to what is most important to the child and family. As end of life approaches, goals of care may shift from dual goals of cure and comfort to comfort-directed care alone. As long as the child's quality of life is considered to be good, prolonging life and maximizing comfort are often concurrent goals. The following suggestions may be discussed to create an approach that will most likely achieve the child and family's goals.

1. Location of care (home, hospice, hospital) will be determined by child and family choice, and may change over time. If hospital care is preferred, an individual room (if not already in place) allows the family more private time together. The decision about care at home includes interventions still desired as well as nursing and medical support available. Care in hospice may be preferred by some families to provide access to increased medical supports in a home-like setting. (Please refer to Sub-Section 5.3 Settings of Care)
2. Review of interventions with discontinuation of those that are no longer desired. Interventions that may be discontinued include blood work, antibiotics, IV fluids and medications, oxygen (unless indicated for comfort) and transfusions. Discussion about natural reductions in appetite and thirst at end of life is essential. The suggestion of offering the child food and drink but allowing their body to determine the need is often helpful to families.
3. Allow a natural death: Confirm that cardiopulmonary resuscitation (CPR) is no longer in the child's best interest, the benefits and harms of oxygen and suctioning, complete care directive if indicated and provide Do Not Resuscitate Confirmation (DNR-C) form.

The DNR-C form is used by healthcare facility staff and Regulated Health Care Providers. It is a provincial form used in situations where a plan of treatment has been developed in which CPR is no longer medically indicated. Without this form, Emergency Medical Service Providers are required to perform CPR. When the family provides this form it allows the responders to provide comfort-based support including oxygen and suction.

To obtain a supply of DNR-C forms through the Government of Ontario Central Forms Repository, please submit a request via email to Ontario Shared Services (OSS) at OSSDistribution@ontario.ca using the Forms Order Request.

Physical Changes That May be Seen at End of Life

Physical changes that may be seen as end of life approaches include the following:

1. Changes in gastrointestinal functioning with failure to absorb drugs, food and fluid; diarrhea or constipation. Discussion of these changes may improve understanding of decreased appetite and thirst outlined above.

2. Renal dysfunction with oliguria or anuria. Children who are receiving intravenous fluids may become incontinent as end of life approaches, and may have evidence of peripheral and pulmonary edema. If these occur, discontinuation of IV fluids may be helpful.
3. Neurological changes with reduced level of consciousness or seizures. This may initially be seen as a gradual decrease in the child's interest as they focus their energy on things that are most important to them.
4. Abnormalities of central control evident close to end of life:
    a. Altered patterns of breathing (Cheyne-Stokes, Kussmaul patterns);
    b. Altered heart rate (often tachycardia, followed by progressive bradycardia); and
    c. Temperature (hyper- and hypo-pyrexia).
5. Changes in skin colour with cyanosis that fluctuates, mottling and peripheral shutdown.

Care Interventions That May Improve Comfort as Death Approaches

Care interventions that may improve comfort as death approaches include:

1. Review of medication, with discontinuation of all non-essential medication. Oral medications should be converted to subcutaneous or rectal routes (or IV if central line is present).
2. Medications made available for symptoms that may occur, and instructions on when these medications should be used. Symptoms may include pain, agitation, respiratory tract secretions and nausea and vomiting.
3. Positioning:
    a. Child to identify most comfortable position if able to do so; otherwise, caregivers should use their best judgment based on the child's appearance.
    b. Consider pressure-relieving mattress to avoid or alleviate pressure wounds.
4. Eyes may become dry if there is protrusion of the eye or if the eyelids do not close fully. Lubricating eye drops may increase comfort.
5. When fluid intake is minimal, attention to mouth care is essential. Lubricants can be provided or frequent moistening with water (still or carbonated soda water) is comforting.

Other Considerations

1. Support is essential throughout the trajectory of disease but especially during the days and weeks leading to death. Maintaining connections with the oncologist, Case Manager RN, clinic staff, POGO Interlink Nurse, social workers and Spiritual Support caregivers can allow family-trusted people to provide emotional support and coping skills. If not already in place, referral to home palliative care is advised.
2. Memory-making including photographs, hand/foot prints, plaster castings, memory box, scrapbook, etc.
3. Religious/spiritual needs discussed and plans put in place.
4. Funeral planning may be done in advance or after death is confirmed. Identify who will assist family in this planning.
5. If death is to occur at home, identify whom to call (MD support, nursing support, spiritual support) including who is able to confirm death and who should be notified after death.
6. Autopsy – if medical need, family need, legal requirement.

7. Organ donation: Children who die in an Ontario hospital need to be registered with the Trillium Gift of Life Network (TGLN) unless the institution has an exception policy in place. If children or families are interested in tissue donation, TGLN can be contacted in advance or after death to confirm donor eligibility.
8. Bereavement resources available in the community for parents, siblings and extended family members should be provided.

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Record of Updates

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