



**Ian Anderson Continuing Education Program  
in End-of-Life Care**

**Module 12**

**DECISION-MAKING  
IN PEDIATRIC  
PALLIATIVE CARE**



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## **KEY WORDS**

[Adolescents](#)

[Advance directives](#)

[Antenatal](#)

[Artificial nutrition and hydration](#)

[Autonomy, ethical principle](#)

[Best interests](#)

[Child/adolescent as decision-maker](#)

[Children's concepts of death](#)

[Communication](#)

[Community involvement](#)

[Competency or capacity](#)

[Conflict](#)

[Continuity](#)

[Culture and spirituality](#)

[Demographics](#)

[Urgent decision-making](#)

[Disclosure](#)

["DNAR" orders](#)

[Documentation](#)

[Framing decisions](#)

[Goals of care](#)

[Informed choice](#)

[Involving children](#)

[Last days or hours](#)

[Location of care](#)

[Siblings](#)

[Starting discussion](#)

[Terminal sedation](#)

[Training](#)

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## I. A Patient's Story

Daniel is a 3<sup>1</sup>/<sub>2</sub>-year-old who presents with a 5-week history of weight loss, anorexia, limping, and intermittent abdominal pain. He has always been a “picky” eater and had a preceding history of “failure to thrive”, having fallen off his growth curves.

Daniel lives about 1 hour's drive away from the tertiary care center where he receives his care. He lives with his 6-month-old sister, Maria, and his parents, Keith and Teresa. Daniel loves books. He is able to describe his pain as an “owie” and will tell his



parents when he is hurting. He had been sleeping poorly and was irritable. These symptoms resolved with regular doses of acetaminophen and codeine.

Investigation of an abdominal mass confirms neuroblastoma (a cancer originating in the neuro-endocrine cells above the adrenal gland, typically presenting in early childhood at an advanced stage). A metastatic work-up shows stage IV disease with involvement of parietal bones, pelvis, right hip, eighth rib, multiple vertebral bodies, and bone marrow. In children older than 1 year with advanced stage neuroblastoma, the average long-term survival rate is 15-25%. For those who survive to undergo bone marrow transplant, there is a 40-50% survival rate. Treatment is associated with significant short-term morbidity and can be associated with long-term morbidity.<sup>1, 2, 3</sup>

Daniel receives treatment with chemotherapy, radiation, and surgery. This is followed by a bone marrow transplant (BMT) when he is 4 years old. He requires hospitalization for neutropenia-related infections, nausea and vomiting, and mucositis. He requires artificial nutritional support with nasogastric feeds and hearing aids.

In the year following his BMT, Daniel enjoys going to the petting zoo, picking strawberries, bird-watching, doing crafts, and working on his computer.

However, this is not the end of Daniel's story. You will get to know him and his family better as you read this module, witnessing their difficult times and decisions during Daniel's illness and life.

### **Reflective Question**

*What would you consider to be the unique and major challenges of decision-making during the care of children and adolescents with life-limiting or life-threatening illness?*

## **II. Introduction**

In 2001, there were more than 6,500 deaths amongst Canadians under the age of 20. Caring for infants, children, and adolescents during critical illness and up to the end of their life is one of the most difficult aspects of pediatric practice. One fundamental aspect of this care is working with young patients, their families, and the healthcare team to make difficult decisions. These include decisions about forgoing potentially restorative or life-sustaining treatments, implementing treatments aimed at relieving symptoms, and providing for the patients' and families' needs during the last part of their lives – be that hours, days, or months.

### ***Audience***

In pediatric practice, the inherent difficulty of such decisions is compounded by the relative infrequency of childhood deaths, as well as the diversity, uncertain prognoses, and complex symptom profiles of life-threatening pediatric illnesses. Additional confounding factors include an overarching societal orientation to cure, especially when the patient is a child, and the fact that the responsibility for decision-making during pediatric illness generally resides with someone other than the patient.

Despite its obvious importance and impact, many clinicians have little training or experience in this area. This module aims to address this gap by providing practical guidance for achieving collaborative decision-making during care for pediatric patients with life-threatening or life-limiting illnesses. Although written for physicians, the content is appropriate for nurses, those in advanced practice and those in training, as well as for clinicians from the allied health professions including those from social work, psychology, child life, and the fields of theology and bio-ethics.

The background and skill set of clinicians from these fields will vary widely. Some will be from a pediatric background with little exposure to palliative and end-of-life issues as compared to their colleagues in adult healthcare. This latter group may have more exposure to palliative and end-of-life issues but may not have an extensive background in pediatrics. This module is designed to address the needs of both groups and various disciplines, although the reflective questions and suggested scripts may need modification depending on the clinician's focus. The term "clinician" will be used throughout to refer, in general, to the health care professional, except where it is necessary to refer to a specific clinical discipline, such as when referring to the findings of a research study.

### ***Module content***

The module includes information about the major challenges to decision-making in pediatric palliative care, the various participants in such decision-making, the decisions themselves, the process of discussing options and reaching consensus decisions, and methods for resolving conflict within this process. The immense variety of clinical situations and decision points encountered in pediatric practice is illustrated with multiple brief patient stories. Each illustrates key learning points and prompts thinking with reflective questions. The stories and content relate to infants, children, and adolescents. This grouping of individuals will generally be referred to as "children" or "child". Where aspects relate to particular groups within the pediatric population, such as adolescents, this will be specifically stated.

The final section suggests some techniques and materials for continuing your training in this area and for supporting colleagues involved in this challenging area of work.

### III. Learning Objectives

Following completion of this module, the learner should be able to:

1. Describe the major factors that complicate decision-making for children living with and dying from life-threatening conditions.
2. Improve knowledge about how to effectively involve families, children and adolescents, substitute decision-makers, and the healthcare team in pediatric decision-making
3. Be familiar with a variety of creative methods that can be used to communicate with young patients about care decisions and how to access these methods
4. Demonstrate an understanding of the legal, ethical, medical, and social aspects of decisions necessary in the field of pediatric palliative care related to:
  - o Identifying the goals of care
  - o Treatments aimed at ameliorating or curing disease
  - o Treatments aimed at potentially life-sustaining treatments
  - o Treatments aimed at relieving symptoms
  - o Planning care for the last days and/or hours of life
  - o Location of care
5. Understand that discussions concerning palliative care treatment options should begin early and continue as often as required with patients who may die prematurely and/or their families, and that such discussions can be conducted without eroding hope
6. Have an increased repertoire of statements, approaches, resources, and questions that can be used with patients and families when discussing palliative care options
7. Recognize that children and adolescents have an ever-evolving understanding of illness and death, and that assessments of this understanding should be done individually and repeatedly
8. Understand how to appropriately frame discussions and facilitate consensus-building during pediatric palliative care decision-making
9. List techniques for improving continuity with the healthcare team, and between the patient, family and healthcare providers during pediatric palliative care
10. Understand that disagreements are common during pediatric palliative care decision-making but that good communication skills and a structured process for working through disagreement can help prevent conflict in most cases
11. List a variety of methods for training healthcare professionals in pediatric palliative-care decision-making and for providing support for healthcare professionals doing this work
12. Become acquainted with the published literature concerning aspects of decision-making in pediatric palliative care

## IV. The Basis of Palliative Care Decision-making

There are several ethical principles that inform the basis for healthcare decision-making. They are outlined in this section as background to the entire module.

### ***Beneficence: Considering “best interests”***

For the majority of pediatric patients, substitute decision-makers are required and parent(s) are usually the best people to fulfil this role. Parent(s) or a substitute decision-maker are expected to make decisions that are in the best interests of the child and to take into consideration any wishes he or she has expressed.<sup>17, 12, 13</sup> Clinicians play an important role in helping parents and others with this task and decisions are best made through collaboration and consensus-building. The goal is to combine the clinician’s knowledge and experience with the understanding, values, beliefs, and expectations of the patient and parent(s) to achieve optimal outcomes for the patient.<sup>15, 33</sup>

In addition to this collaborative work with parents or other substitute decision-makers, clinicians are ethically and legally responsible for ensuring that the decisions made are in the patient’s best interest.<sup>33, 40, 4, 8</sup> However, there is no universally agreed upon definition of “best interests” and this leads to the majority of disagreements and conflict between parents and healthcare professionals during pediatric palliative care decision-making.<sup>17, 15, 33, 8, 5, 6, 7</sup> Disagreement and conflict can be minimized when each person involved is open to the perspectives of the others. It is also important to explicitly and repeatedly recognize that everyone is doing everything in their power to ensure that the child’s best interests are served.

If a clinician believes that a decision is being made that is not in the best interests of the patient, he/she has three choices. He/she can:<sup>17, 15, 33, 40, 8, 9, 12, 13, 7</sup>

- attempt to resolve the disagreement through discussion, time-limited trials, and/or third-party mediation – this process is discussed in more detail in the later section of this module titled “How do we work through conflict?”
- implement a decision that is not in keeping with the expressed choice of the designated decision-maker(s) – such a decision should be made in keeping with the standard of care and, whenever possible, be preceded by consultation with colleagues and legal counsel
- as a last resort, if resolution is not possible through any other channel, refer the issue to the courts where the substitute’s authority as decision-makers may be overruled.

### ***Respect for the principle of autonomy: Assessing capacity***

In general, an individual’s right to make decisions for themselves is legislated on the basis of age or life experience (see Appendix A). In the latter case, the individual may be referred to as a mature or emancipated minor.

The ethical principle of respect for autonomy, along with recent legal decisions and legislative changes in several jurisdictions support the use of competence or capacity, rather than age or life experience, as the test when deciding whether an individual has the right to make their own healthcare decisions.<sup>42, 8</sup> In other words, if a person has not yet reached the age of majority and is not considered an emancipated minor, but is able to understand the proposed interventions and their consequences, then he/she is considered competent or capable of making his/her own decisions. Throughout this module, the word capacity will be used because it is a more encompassing term.

This trend in legal and ethical thinking has led to increased involvement of children and adolescents in health care decision-making.<sup>47, 20</sup> It has also led to the recategorization of pediatric patients as

mature minors or non-mature minors, on the basis of capacity rather than age, in hospital and other policies.<sup>17, 33, 40, 9, 10</sup>

Within this ethical and legal framework, clinicians have become responsible for evaluating every pediatric patient's capacity to make decisions and for ensuring that the patient's best interests are being served.<sup>40, 12, 9, 13</sup> Clinicians should use a standardized method for assessing capacity. The format used at one Canadian healthcare centre is presented in Appendix I as an example. The general criteria for assessing capacity are presented in **Box 1**.

Once an assessment of capacity has been made, the decision reached by the patient is durable and should be implemented subsequently even if the patient's capacity changes. Capacity can change with time, the physical, cognitive and emotional effects of illness on the child, and with the nature of the decision being made.<sup>40, 9</sup> For example, a patient may be considered capable of making the decision to forgo experimental drug treatment and yet later be considered incapable of making a decision to forgo life support. Thus, capacity must be assessed individually at each decision point. Once made, the clinician must respect this assessment and, as a consequence, respect the choice of the capable person even if the clinician disagrees with the decision made.

**Box 1: General criteria for assessing capacity**<sup>40, 9, 11</sup>

The patient must:

1. Know that there is a decision to be made and be able to receive and appreciate information necessary for making that decision;
2. Be able to understand the potential consequences of the decision;
3. Be willing to make a decision;
4. Be able to communicate the decision by some mode;
5. Be able to integrate the information in such a way as to produce the decision; and
6. Be able to weigh conflicting factors in a decision and reach a resolution by application of a stable set of values or priorities.

***Disclosure, understanding, and informed choice***

As with any other treatment decisions, palliative care decisions must be informed choices. Informed decision-making is best achieved when there has been an ongoing process of disclosure and family education, along with mutual exploration of the child's, family's, and healthcare professional's expectations, perceptions, misperceptions, beliefs, and values. Clear understanding and true informed choices can be achieved through this process, even if it occurs quickly during a rapidly progressive illness.

Briefly, an informed choice is commonly considered to consist of four components:

1. competency or capacity on the part of the decision-maker
2. disclosure of all appropriate information concerning
  - a. the nature of the illness
  - b. reasonable treatment options including forgoing potentially curative or life-prolonging treatment
    - i) likelihood of benefit
    - ii) common, serious and special risks and side effects
3. understanding of the provided information by the decision-maker
4. voluntary decision-making, free of coercion or manipulation.<sup>33</sup>

Achieving this standard of informed decision-making is an essential but difficult task for clinicians caring for critically ill children.



## V. Challenges of Decision-making in Pediatrics

Healthcare decisions for children with life-threatening or life-limiting illnesses present a wide range of challenges. Some of these challenges are similar to those experienced during palliative care for adults, but many are specific to pediatric care.

### *The dynamics of pediatric demographics*

Pediatric patients suffer from a large number of life-threatening and life-limiting diseases and disorders, each of which has its own unique trajectory, treatment options, and decision-making points (**Box 2**).<sup>14</sup> The duration, type, and intensity of care required varies tremendously between patients, and within the same patient at different times during the illness. As well, many of the individual illnesses are rare and encountered only in pediatric practice (**Box 3**) and there is often a great deal of uncertainty concerning the prognosis and likelihood of death.<sup>15</sup> This huge variation in care requirements and high level of uncertainty can make it difficult for healthcare professionals to raise the issue of palliative care options and add to the difficulty of making decisions about these options.<sup>20, 35, 16</sup>

### *Societal perspectives on the seriously ill child*

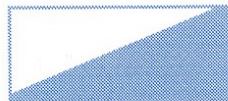
When an adult is seriously ill, the patient and family may accept the approach of death and reflect on the person's achievements and the fact that they lived a "full" life. When the patient is a child and death is imminent, hope for a full life can remain prominent.

The death of a child is considered much less "natural" than that of an adult and amongst the worst losses a family can experience.<sup>17, 18</sup> Due to an inherent need to do everything possible for an ill child, any technology or intervention tends to be considered simply because it is available and confers hope of continued life.<sup>19, 20, 35</sup> This tendency and the pace of technological innovation are mismatched with the paucity of balanced, evidence-based approaches to their use. The wish to "protect" populations that are viewed as vulnerable, including children and the terminally ill, has prevented research initiatives from which they could have benefited. Also, it is difficult to collect and apply

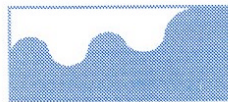
### **Box 2. Trajectories of pediatric illness<sup>†</sup>**

A number of the possible trajectories of pediatric illness are illustrated below. Others include the child who is seriously ill but then fully recovers.

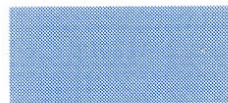
#### **Curative and Palliative Care Relationship**



As the illness progresses the emphasis gradually shifts from curative to palliative treatment.



Highly technical invasive treatments may be used both to prolong life and improve quality alongside palliative care, each becoming dominant at different stages of the disease.



No cure is possible and care is palliative from the time of diagnosis.



At first it is not apparent that this will be a terminal illness and palliative care starts suddenly once that realisation dawns.

**Key**      □ curative      ■ palliative

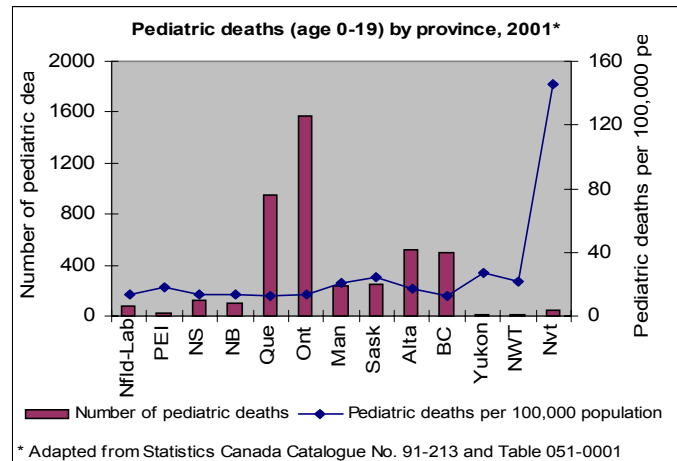
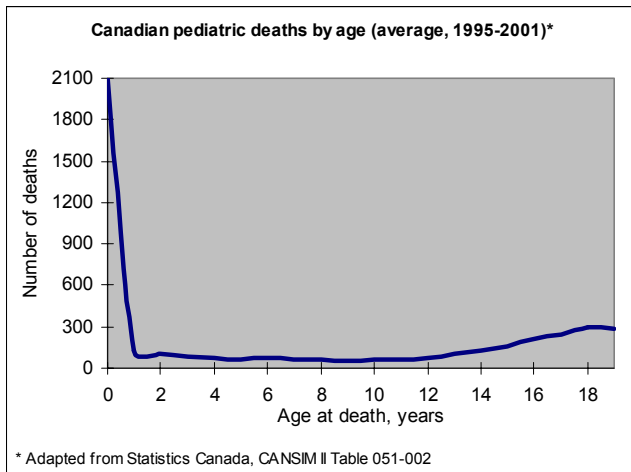
<sup>†</sup> Excerpted from: Royal College Paediatrics and Child Health, *Guide to the Development of Children's Palliative Care Services*. 1997, p.8.

quality of life and outcome data about children's varied and rare illnesses.<sup>20, 21, 22</sup>

### Box 3. Demographics of pediatric death and palliative care

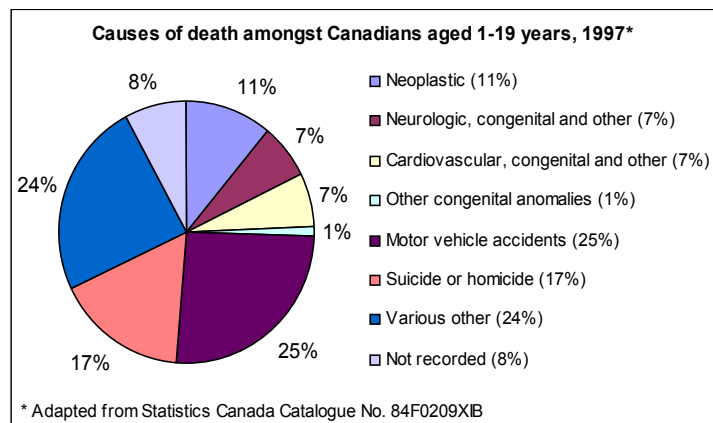
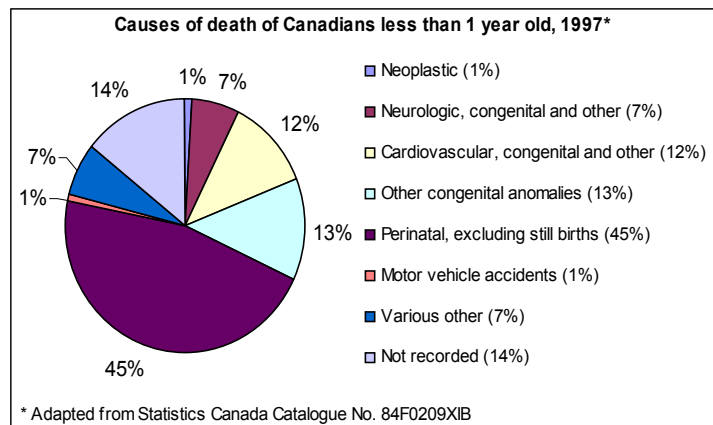
Between 1995 and 2001, there were, on average, 6,524 Canadians aged ≤19 years dying annually. Over the same years, an average of 2,097 (32%) of these deaths were among infants (under 1 year of age). On a provincial basis, the population-adjusted rates of pediatric death are generally comparable but higher rates were found in Nunavut, the Yukon, the Northwest Territories, Saskatchewan, and Manitoba.<sup>23, 24, 25</sup>

The common causes of death during the first year of life differ markedly from those during the rest of childhood and adolescence. Canadian infants <1 year old most often die from perinatal causes and congenital anomalies. Amongst 1-19 year-olds, adolescent deaths predominate, mostly due to motor vehicle accidents, suicide, or homicide.



With improvements in medical and pharmacological therapy, many children with life-limiting illnesses are living longer – many into adulthood. Although pediatric deaths are declining, an increasing number of children are living with very complex illness and therapy, accompanied by continual uncertainty concerning when or if premature death will occur. These children have an ongoing need for support, information, discussion regarding palliative care options, and open communication about death and the dying process before death becomes imminent.

Children living with HIV/AIDS provide a vivid illustration of this trend. Since the beginning of the HIV epidemic, median life expectancy for perinatally infected infants has increased from 4 years to 13 years.<sup>26, 27</sup> Although pediatric infection with HIV is now relatively rare in developed nations (approximately 200 cases per year in the U.S.<sup>28</sup>), each of these children is likely to live a life filled with medications, side effects, opportunistic infections, organ compromise, AIDS-associated illnesses, and the threat of death. Their care is often complicated by the tragedy of multigenerational disease (almost all pediatric HIV infections in developed countries result from mother-to-child transmission), continuing reluctance to inform children about their HIV status, social stigma, and lack of appreciation and treatment for their acute and chronic pain.<sup>26, 27, 29</sup>



### ***When and how to integrate palliative care***

When a child is diagnosed with an illness that may cause premature death, there should be early discussion about the goals of care and about options for integrating care aimed at curing the illness with care focused on providing the best quality of life possible.<sup>19, 20, 30, 34</sup> During all discussions with patients and families, healthcare providers must endeavour to provide accurate and realistic information without eroding hope. Maintenance of hope is essential to many families and patients who are coping with devastating disease and the possibility of death.<sup>34, 15, 31</sup> Although the focus of this hope may shift from hope for cure, to hope for symptom control, or hope for realizing individual goals such as getting home, its importance is not altered. For some children and families, the hope for cure continues even onto death.

Many pediatric patients are unable to participate in decision-making concerning their own treatment. Substitute decision-makers, usually the child's parents, are required.<sup>32, 35</sup> The designation of a substitute does not, however, relieve clinicians of all responsibility for decision-making. Optimally, the clinician's knowledge, experience, and relatively objectivity should be combined with the values, beliefs, and expectations of the parents, and child, where relevant, to achieve optimal outcomes for the patient.<sup>15, 33</sup>

Discussions and decision-making during pediatric palliative care may involve, directly or indirectly, the patient's parents, siblings, entire families, and communities.<sup>32, 35</sup> A patient may return home for end-of-life care and wish to have visits from friends, continue with some school work, and be cared for by extended family. For one 8-year-old who loved books, the school community scheduled themselves for daily visits to read to their friend and classmate. The school and family worked together to ensure consistent availability.

Each care decision requires weighing and periodic re-evaluation of the potential benefits, burdens, and risks. The relative importance of these factors varies between situations and families, and may fluctuate over time as the goals of care change with disease progression.<sup>32, 34</sup>

Seriously ill pediatric patients often require specialized care. Not only are many life-threatening pediatric illnesses rare, but young patients also have different social, physiological, pharmacokinetic, and developmental differences compared to adults that influence management.<sup>35</sup> The requirement for specialized care can create difficulties for patients, families, and healthcare professionals as the required skill set is often not available locally and advice must be sought from distant centres.<sup>36</sup>

The preceding paragraphs have outlined the main challenges to effective, ethical, and humane pediatric palliative care decision-making. Addressing these challenges requires collaboration and relationships based on trust and mutual respect between families, patients, and healthcare providers, and amongst the members of the healthcare team.<sup>15</sup>

### ***Clinicians' grief and the impact on decision-making***

The impact on clinicians of caring for critically ill children and how this influences care decisions must be acknowledged. The experience of caring for the dying child has been shown to be highly stressful for clinicians, and accompanied by grief.<sup>37, 38</sup> This experience is influenced by the clinician's perceptions concerning the loss of the child, and how their grief is expressed. The clinician's role, interventions, and contribution in the care of the dying child can also influence their grief.<sup>38, 39</sup> In general, clinicians with clear roles during end-of-life care (eg., hospice nurses), experience less stress compared with other clinicians. This has been attributed to reduced role ambiguity and conflict.

The training and orientation of clinicians is nearly wholly focused on finding out what is wrong with a patient and directing efforts to "fixing" it. Clinicians experience great role ambiguity and helplessness when shifting goals of care alter their role from that of a "fixer," to what may be identified as a "bystander" to an irreversible disease process. The sadness when clinicians find themselves unable to do the job for which they are trained is significant and pervasive (**Box 4**). On occasion, this distress may translate into unrelenting attempts to continue to "fix" what is not reparable.

Clinicians receive little, if any, training in measures used to support and comfort children and families when cure or amelioration of the disease is no longer achievable. Such training can help clinicians feel more comfortable and competent when providing end-of-life care. They may also learn that the will to help and to do good, can be sustained, even in the setting of tragedy. Suggestions for training in this area are discussed in detail in a later section of this module, titled

“How do we train and support clinicians for decision-making in pediatric palliative care?”

Despite the sadness of caring for a dying child and family, physicians have related inherent satisfaction through the provision of pain and symptom relief, comforting physical care, and psychosocial and spiritual support. As described by a pediatric oncologist, “For me, the greatest satisfaction is to see the child depart (die) without suffering.”<sup>38</sup>

#### **Box 4. Reflections of pediatric physicians**

“The most difficult aspect for me is when they all expect me to do something, yet I do not know what. In reality it’s not dealing with death anxiety, but rather, with being there, unable to do anything and feeling medically and emotionally helpless and powerless.”

“I manage to keep a certain distance, because I am deeply affected during the terminal period. I ought to say something to the parents but I am at a loss for words.”<sup>38</sup>

## VI. Who is Involved in Decision-making?

### VI.1. Involving families

Family-centred care is a core value in pediatric palliative care. When chronic or critical illness occurs in a child, the family is intimately affected and challenged. When such an illness is life-threatening or life-limiting, the family's core values, relationships, and emotions are exposed and stretched to their limits. One of the primary purposes of a family is to raise healthy children, protecting them from danger and discomfort. When a family's ability to fulfil this purpose is eroded by some catastrophic event or illness, their sense of control and justice can be deeply disrupted.

#### ***Balancing autonomy and paternalism: Supporting families during decision-making***

All children need the support, love, and resources of their families. For the ill child, one key resource is the family's involvement in decision-making.<sup>15, 35, 34, 40</sup> Parental wishes regarding decisions about forgoing potentially life-sustaining treatments are one of the most important factors considered by clinicians.<sup>41, 42, 43</sup> If the family is in turmoil, feeling out of control, or emotionally exhausted they are less likely to be able to participate effectively in this process.

When caring for an ill child facing possible or probable death, clinicians must address not only the needs of that child but also those of the family. Establishing a relationship of mutual respect and trust with the child and family, and working with the family unit to make decisions collaboratively, are essential components of caring for any child.<sup>45</sup> This relationship assumes even greater import when the family is involved in decision-making at the end of life, providing an opportunity for the family to be empowered in the midst of turmoil.<sup>46, 49</sup>

Decision-making has been associated with an increased sense of control and healthier grieving in some families.<sup>17, 15, 47, 48, 49</sup> Other families find the responsibility of decision-making onerous and prefer to relinquish care decisions to the healthcare team.<sup>15, 50, 51</sup> Some clinicians minimize family involvement in decision-making because they wish to avoid burdening families with such responsibility.<sup>43, 52</sup> However, families who feel they have no control during decision-making may be at risk for unresolved grief and complicated bereavement.<sup>53</sup> **Box 5** highlights some family perspectives on end-of-life decision-making. Clinicians need to find methods of involving families in decision-making without letting them feel the full burden of responsibility.<sup>42, 54</sup> The art of communication and facilitation during decision-making is

#### **Box 5. Several family perspectives on decision-making**

- ❑ “They treated me as an active member of the treatment team. They would definitely listen. Before they made a decision they would always ask for my input. And they were honest about not knowing how it was going to go, but they would do everything they could to keep her within the comfort zone. That was so important to me. And the fact that they acknowledged that this is a situation that is not going to have a good outcome.”<sup>31</sup>
- ❑ “I have been looking at all the options. I don't have any bit of the experience and expertise that the doctors have who work with this all the time. How do I know which one to pick? I need their help and they are asking me what we should do. I don't know if what I decide is the right decision, the best choice. What if I'm wrong?”<sup>44</sup>
- ❑ “During those early days of living with terminal illness, we again scrambled to find out all there was at this stage, to uncover whatever options existed. We felt absolutely clear that we wanted Liza to be home with us as much as possible. We felt absolutely clear that Liza should be as comfortable as possible. We knew Liza would know that she was going to die even if we did not tell her and that we would not leave her emotionally alone with anything she had to face.”<sup>114</sup> [Reprinted by permission of Elsevier Science from *Liza's death: a personal recollection*, by E. Lister, *Journal of Pain and Symptom Management* Vol. 21, No. 3, pp 243-9, 2001, by the US Cancer Pain Relief Committee.]

addressed in a later section of this module.

The team may establish relationships with the entire family, with a single parent or caregiver, or with family members who share an adversarial relationship. All of these relationships may vary over time, requiring the clinician to be flexible and accommodating. Over time, supporting the family, even one in conflict, throughout their discussions may help build comfort and consensus concerning the decisions to be made.

## VI.2. Involving children



**Derrick** is a 12-year-old with combined variable immune deficiency. This causes him to have repeated infections of his sinuses and lungs. Also, he has had a corneal transplant for refractory Herpes simplex infection and hemolytic anemia. He presents with an acute abdomen, thought to be appendicitis. Laparotomy shows a lymphoma of the small intestine which pathology identifies as a high-grade mixed B-cell lymphoma. Metastatic workup is positive for liver involvement.

Derrick's potential for successful outcome is somewhat less than that for a child without an underlying immunodeficiency. His chance for cure is estimated to be 50-60%, at best. With treatment, Derrick improves but subsequently relapses. During treatment for this relapse, he has progressive respiratory compromise that necessitates transfer to the pediatric ICU. That evening, the PICU staff and Derrick's parents discuss the options for ventilatory support and having a lung biopsy done. Then they have to decide how to talk with Derrick about these options.

### Reflective Questions

1. What phrases or methods could be used to engage a child in discussions about treatment options?
2. What value do you see in involving children in discussions about their care when the final decisions are made by their parents or other substitute decision-makers?

### *Involving children through discussion*

There is great variability in the ability of children and adolescents to participate in decision-making.

Many critically ill pediatric patients are too young or incapacitated to understand and/or express their wishes concerning their palliative care. As discussed above, parents or other substitute decision-makers make the decisions in such situations.<sup>35</sup>

Some older children and adolescents have achieved a level of maturity and understanding that gives them the capacity to make their own decisions. This situation is discussed below under the heading, "When children or adolescents are the decision-makers."

In between these two extremes, there is a large group of children who have the ability to express their wishes despite severe illness. These young patients should be encouraged to ask questions and to express feelings and preferences concerning their care (see **Box 6**). Great weight should be given to any clearly expressed views, such that they figure predominantly and directly in assessing of the child's best interests.

This effort demonstrates respect for the child's individuality and is essential for ethical decision-making, providing high quality care, ensuring mutual understanding, and addressing differences of opinion before they become the basis for conflict.<sup>17, 33, 34, 40, 9</sup> For example, a parent may opt for a treatment that the child has stated they do not want. However, this disagreement must be acknowledged openly and seriously considered in the weighting of harms and benefits. How this conflict could be resolved to the satisfaction and ultimate comfort of the child requires deliberate attention.

The involvement of children in discussions and decisions regarding palliative care is influenced by several factors. Children vary in their ability to understand death as an irreversible event, and this



understanding can change with time and life circumstances.<sup>19, 89</sup> The experience of chronic illness generally accelerates the development of a child's maturity but the reverse may be true for some children, particularly those whose illness impacts cognition. Some families wish to protect their child by not informing them about the diagnosis, prognosis, and treatment options for their illness.<sup>17</sup> Some people also believe that children are not able to freely express their wishes nor make coercion-free decisions if they are aware of the wishes of authority figures such as parents and clinicians.<sup>55</sup> Some children will not discuss their understanding or raise their own wishes and concerns in an attempt to "protect" their parents.

Each child is part of a family unit and decisions about that child must be made within that context, but there is often debate amongst professionals concerning exactly how this is to be achieved, especially when the wishes of the patient and family are not congruent.

Whether or not a child is considered capable of making decisions, he/she should be involved, to the maximum extent possible, and in a developmentally-appropriate manner, in discussions concerning these decisions.<sup>20, 54, 56, 57, 91</sup>

### ***Involving children through other media***

Involving children in healthcare discussions and decisions can be challenging. Many clinicians have little training or experience in this area.<sup>35, 34, 41, 58</sup> Creative methods are available to assess the level of understanding and perspectives of children. These methods include art, music, writing poetry or prose, play-acting, storytelling, and many others. As seen in the accompanying examples (**Box 9, Box 7, Box 8**), these techniques can allow great insight into the child's emotions, state of mind, and perspectives on treatment, and provide an opportunity for therapeutic interventions. Such techniques may also decrease a child's fears and sense of isolation, and help him/her begin to feel some mastery over what is happening.

#### **Box 6: Two examples of listening to children**

- A seven-year-old girl told her parents that she was too tired to fight anymore, and that she wanted to give up. She added: "If I have to continue suffering, I would rather be in heaven."

These statements were major determinants in the parents choosing a solely palliative care plan without any further experimental treatment for her.<sup>90</sup>

- "An eleven-year-old girl was offered the option of radiation therapy for pain control. She said: "I'm scared because I'm not so good at making decisions. My parents want me to have radiation, but a little voice in me tells me not to... My mother always said that if I die, she wants me to die happy and at home. If I had radiation, I'd have to come into the hospital every day. And I don't know if radiation will really help, or if I would die anyway."<sup>90</sup>

This second vignette highlights several crucial issues in the children's role in decision-making:

1. The potential burden on the child ("I'm scared because I'm not so good at making decisions.")

When are we giving the child too much of a role in his/her own end-of-life decisions?

2. The way that hope can cloud intellectual/cognitive understanding of a medical situation and thus impact decision-making: This child knew that the radiation therapy was palliative, in that it was being offered for pain relief and not with curative intent. However, faced with the decision, she reverted to the hope that it might be life-saving (...and I don't know if radiation will really help, or if I would die anyway.)

### Box 7. Poem by Barrie R. Pettipas<sup>59</sup>

Barrie wrote this poem at age 18, in the same year that he died of an ependymoma of the brain.

*If you only knew*

As I lie here in bed  
So many thoughts go thru my head  
Why have I not yet gone  
Why must I continue on?

I've been chosen to survive  
Even tho' it frustrates me to be alive  
I've lost my sight and my taste  
And my talent has gone to waste.

If you only knew what I'm going through  
Then maybe you could see  
Just how it's hurting me.

I just play games with my mind  
I'll probably do this till the end of time  
My body is so very weak  
Even tho' it's sunny, the days are bleak  
I'm in pain and so depressed  
My whole life's a great big mess.

All the fears I have inside  
The ones I cannot hide  
Is it any wonder why  
I break down and cry?

If you only knew what I'm going through  
Then maybe you could see  
Just how it's hurting me.

### Box 8. Play with stuffed toys<sup>†</sup>

A three-year-old boy played the same game with a stuffed duck and a toy ambulance each time he was hospitalized. The duck would be sick and need to go to the hospital by ambulance. The boy would move the ambulance, making siren noises.

*Therapist:* How is the duck?

*Child:* Sick.

*Therapist:* Where is he going?

*Child:* To the hospital.

*Therapist:* What are they going to do?

*Child:* Make him better.

*Therapist:* Is he going to get better?

*Child:* Yes, better.

During what turned out to be the boy's terminal admission, he played the same game with the duck. However, the ritual changed dramatically in its outcome:

*Therapist:* How is the duck?

*Child:* Sick.

*Therapist:* Is he going to get better?

*Child:* [shaking his head slowly] Ducky not get better. Ducky die.

<sup>†</sup> Excerpt from *Armfuls of Time: The Psychological Experience of the Child with a Life-threatening Illness*, by Barbara M. Sourkes, ©1995. Reprinted by permission of the University of Pittsburgh Press.

### Box 9. Mandala by an 11-year-old girl describing how she felt when diagnosed with cancer<sup>†</sup>

"Red is for *shock* – it's like coming to a stoplight, or like being hit by a bolt of lightning. *Anger* is black because it's a very, very dark feeling. You feel *scared* all the time of what is going to happen to you (purple). *Alone* is blue, for tears, because you are so *sad*. I chose yellow for *hope*, because it's a sunny color, with a lot of light. *Helpless* (green) is little in my drawing, because that's just how you feel – tiny and scared. I made *confused* a mixture of all the colors together. You're just confused about everything going on and how this could all be happening to you."



<sup>†</sup> Excerpt from *Armfuls of Time: The Psychological Experience of the Child with a Life-threatening Illness*, by Barbara M. Sourkes, ©1995. Reprinted by permission of the University of Pittsburgh Press.

In general, communication and understanding is most enhanced when the family is present during these creative sessions. However, at times it is best to work with the child alone and talk with the family afterwards. Some children are eager to show off their creative projects and communicate their new-found understanding or insight with their families. If this does not occur, the healthcare professional should carefully consider the child's right to confidentiality and the relationship of the child with the family, and then decide how and what information to share with the family.<sup>118</sup>

There are valuable resources and professionals, such as child life specialists, pediatric psychologists, and social workers, who are experts in this area and whose expertise should be incorporated by the team.<sup>60, 90, 118</sup>

### ***When children or adolescents are the decision-makers***



**Sandy** is a 15-year-old with Duchenne muscular dystrophy (DMD). In general, males with DMD die before, or as they reach, young adulthood. Death usually occurs as a result of respiratory failure, intractable heart failure, pneumonia, or aspiration and airway obstruction.<sup>61</sup>

In the past 6 months, Sandy has been having difficulty swallowing and chokes on secretions, which terrifies him. You plan to meet with him to review his options for ventilatory support. He also wants to know what could help with the secretions if he chooses not to have ventilatory support.

In planning for meeting with Sandy, you have done some homework by reviewing his chart and talking with several team members about their perceptions of Sandy and his understanding of ventilatory support. You have discussed ventilatory options with the consultant neurologist and spoken with the Palliative Medicine Specialist regarding options for symptom control with Sandy's current and anticipated respiratory compromise. These specialists are both willing to meet with Sandy and his family. You have also had a curbside consult with Sandy's neurologist who cares for children who opt for ventilatory support and those who do not. The neurologist, in addition to being willing to meet with Sandy, provides the names of three teenagers with DMD and their families who are willing to meet with Sandy and his family for some detailed discussion about growing older with DMD.

#### **Reflective questions**

1. As Sandy's clinician, what questions do you anticipate he will have for you?
2. How do you prepare Sandy, his family, and yourself for this difficult discussion?
3. What options would you propose?
4. Think through and/or write down how you would frame the available options to Sandy, trying out different phrases until you find the words that feel right.

Adolescents with life-threatening or life-limiting illness face all of the challenges of normal adolescence – establishing identity, autonomy, body image, and intimate relationships, and achieving milestones in school and other endeavours. In addition, seriously ill adolescents may face complex and painful therapy, difficult changes in appearance, restricted activities, frequent absences from school and peer relationships, and increased dependence on family members for basic care and advocacy. **Box 10** provides one adolescent's perspective on this process. The dependence on others can make it very difficult for adolescents to establish a sense of autonomy and can lead to

ambivalence and anger towards healthcare professionals and family members, particularly parents.<sup>62, 63, 64</sup>

This is especially true when the adolescent has been judged capable of making his/her own decisions but his/her choices are not in agreement with the outlook of his/her parents and/or healthcare team.<sup>17,</sup>

<sup>35</sup> Some capable adolescents may justifiably wish to make their decisions without consulting their family but, in most instances, the ideal is collaborative decision-making involving the adolescent, family, and healthcare professionals.<sup>17</sup> This collaboration works best when the adolescent feels an acceptable sense of independence but also receives sufficient support and encouragement.<sup>11</sup> This balance can be difficult to attain and maintain, especially when disease progression leads to increasing dependence on family and healthcare professionals. Practical suggestions for helping adolescents with this difficult balance are included in **Box 11**. **Box 12** proposes some language for discussions with adolescents who are reluctant to talk.

### **Box 10: An adolescent perspective on decision-making during life-threatening illness<sup>†</sup>**

*Interview with Katharine, age 19, who was diagnosed with osteogenic sarcoma at age 16*

*Clinician:* You once said that being sixteen was the hardest time in life to get cancer.

*Katharine:* I still believe that. Younger children are not developed in themselves yet, in their own persons, in their own individualism. They can still be with their mother. Older people are away from their mother; they're detached, more adult. When you're in the middle, parents don't want to let you go. You want to be set free a little bit, but you want to be able to come back. I just felt that I was denied any sort of chance. I wish I could look back and see: "Would Katharine have been popular? Would Katharine have had lots of boyfriends? Would Katharine have starred on the varsity?" I look now, and would that have been what I wanted? I don't know. I never had the chance to find out. Instead it was decided for me: "You are going to mature very fast right now. You have to make life-and-death decisions. You have to accept things that children who are young adults between the ages of thirteen and nineteen don't normally have to face." It's like: "Grow up right now and become what you have to become to deal with this." I never had the chance to be sweet sixteen. I never had the chance to be gay old seventeen. I had to automatically be an adult, and it was very hard.

<sup>†</sup> Excerpt from *The Deepening Shade: Psychological Aspects of Life-Threatening Illness* by Barbara M. Sourkes, ©1982. Reprinted by permission of the University of Pittsburgh Press.

### **Box 11: Supporting adolescent decision-making** <sup>65, 66, 62</sup>

Providing support:

- As much as possible, ensure privacy and confidentiality
- Enable the adolescent to participate in his/her own care.
- In keeping with the adolescent's changing intellectual and emotional maturity and his/her expressed preferences, provide information concerning diagnosis, prognosis, and the benefits and risks of treatment options.
- Encourage open discussion of treatment options and expression of emotions, concerns and hopes.
- Answer all questions honestly and with empathy.
- Offer choices and opportunities for negotiation, even in small matters, whenever possible.

Promoting independence:

- Allow the adolescent to create an individualized space in the hospital – decorating it as he/she wishes, allowing friends to stay overnight, etc.
- Enable interaction with other adolescents (ill and healthy) as much as possible.

### **Box 12: Suggestions for starting difficult discussions with an adolescent**

I know you have been through some very tough times and I imagine you may not want to spend any more time talking about being sick. (Pause ..... )

I think you may find if we spend some time on this now, it will be helpful in at least a couple of ways. (Pause..... )

It can help us to know how we can best care for you, particularly if you become sicker. (Pause... ..)

Some of these wishes would be things like where you would like to be cared for and who you would want to be there. (Use responses and further questions to pace the conversation.)

It would also help us both later if I could have some idea now about how you would like to be cared for if we got to a point where we didn't think we'd be able to get you through it. (Pause ..... and wait for patient's response.)

For example, if your illness hurt your lungs so much that we thought you wouldn't be able to continue to live and that you might die. I wonder if you have had any thoughts about that? (Pause... ..)

Some people worry about how that might feel. What about you? (Pause.....)

You know that we would be very careful to make sure you are comfortable. We would be giving you medication to help you not mind the feeling of your lung problem. You would probably sleep through that time. (Pause....) Have you had any other ideas, such putting you on a machine that would try to do the work of your chest and lungs? (Describe what that would involve and how it would feel.)

### VI.3. Involving non-parental substitute decision-makers



**Jody** is a 15-year-old with severe cerebral palsy and profound cognitive impairment. She is quadriplegic with marked spasticity in all limbs and her jaw, which makes eating difficult. Multiple assessments and observations by her professional and volunteer caregivers all agree that she is not able to understand or communicate verbally or using assistive devices. To improve her comfort, she receives regular analgesics and muscle relaxants. She is dependent on others for all activities of daily living and is cared for in a foster home by a loving couple. She has had two recent admissions for respiratory compromise, which were notable for progressive hypoxemia and hypercapnia. She narrowly escaped intubation during both admissions. A discussion with her foster parents and her trustee from Children's Services, who is her legal guardian, is being arranged to discuss the goals of care.

#### Reflective questions

1. How would you start the discussion?
2. Who would you ask to attend the discussion?
3. What topics should be covered during the discussion?
4. How would the outcome of these discussions best be communicated to Jody's many healthcare providers?

Although parent(s) are the usual substitute decision-makers, situations arise in which the parent(s) are unavailable or unwilling to act in this role. Clinicians may also conclude, after thorough assessment, that the parent(s) are not capable of acting as substitute decision-makers. In any of these situations, a substitute decision-maker must be designated. According to ethical principles, legislation, and hospital policy, there is a step-wise chain of people who may be designated as substitute decision-makers for a pediatric patient judged incapable to make his/her own decisions (see Appendix C).<sup>40, 9, 12</sup>

Following computerized searches and consultations with experts in the field, we have found that there is nothing published in the healthcare literature concerning the involvement of non-parental substitute decision-makers, such as other relatives or public trustees, in pediatric palliative care decisions. This is likely due to the rarity of such situations. However, such situations may lead to particular difficulties and conflicts during decision-making. This may be particularly true if the parents remain involved but are unwilling or considered incapable of being the decision-makers.

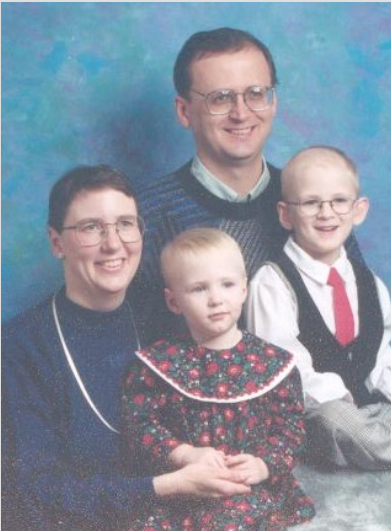
#### **VI.4. Involving the healthcare team**

Within the context of palliative care decision-making, there are a variety of skills and roles that may need to be fulfilled by professionals. These include providing education about available options, problem-solving, emotional and spiritual support and counselling, and conflict mediation. Although certain skills and roles are often associated with a particular profession, there are no rules. A team is often constructed on an ad hoc basis to meet the needs of a given patient and family. Such a team may include mental health professionals, nurses, personal care attendants, primary care clinicians, pharmacists, social workers, spiritual care providers, and volunteers. These primary caregivers may consult with specialists in pediatrics, palliative care, and/or other areas but the continuity of care, ready accessibility, and emotional support that they can provide is extremely valuable.<sup>35, 67</sup> This method of providing care requires excellent collaborative and coordinated interdisciplinary work.<sup>19, 35</sup> The attitudes and behaviour of the members of this team during decision-making can greatly influence both the quality of care provided to the dying patient, and the coping and grieving processes of the family.<sup>17</sup>

Collaborative work can become difficult when there are differences of opinion amongst the involved professionals concerning the patient's prognosis, treatment options, and/or the ethical nature of decisions being taken. Such differences of opinion are not uncommon and have been investigated by several researchers. Clinicians can have markedly different attitudes concerning the appropriate intervention for a given patient.<sup>68, 69</sup> Their attitudes and practices concerning end-of-life care, and their comfort level with providing such care, may vary with their country of origin, their age, the length of their professional experience, the seniority of their professional position, the number of intensive care beds in their institution, and how important religion is in their own lives.<sup>69, 70, 71, 72, 73</sup> Clinicians should make a conscious effort to identify and consider how their values influence their perspectives on what is the "right" choice in a given situation. Dealing with differences of opinion requires excellent communication and consensus-building skills. These topics are addressed in a later section of this module.

## VII. What Decisions Need To Be Made?

### VII.1. Identifying the goals of care



**Daniel** is the boy we met at the beginning of the module. He was diagnosed with Stage IV neuroblastoma and had multimodal treatment including bone marrow transplant one year ago. Daniel is now 5 years old and has come to the hospital with his parents on Christmas Eve with increasing hip pain. Work-up shows a recurrence of his cancer.

At this point, Daniel's parents decide to shift the goals of his care, knowing that cure is no longer attainable. They wish to pursue measures that are intended to help Daniel live as long as possible with a good quality of life.

Escalating pain is managed with opioids, focal radiotherapy, and multiple co-analgesics. With progression of his disease, Daniel has nausea controlled with a variety of medications. He continues to enjoy eating small amounts of his favourite foods.

Daniel's mom, Teresa, modifies his stroller, enabling him to be quite mobile. It has a steering wheel and horn attached to

it within Daniel's reach, so he seems very much in control. He dislikes being in the hospital for any extended period of time although he visits happily enough.

There are multiple possible goals of care throughout the trajectory of life-threatening and life-limiting illnesses. These may include:

- cure
- slowed progression
- remission
- contribution to research
- prolonged life span
- achievement of life goals
- maximizing normal life experience
- maximizing periods of lucidity
- maximizing comfort
- maximizing family access
- having care and/or death occur in their preferred location.

These goals may or may not be achievable, depending on the patient's clinical status and the availability of treatments and resources. They are also not necessarily mutually exclusive and multiple goals may be identified and pursued at any one time. However, at times goals must be prioritized in order to guide treatment decisions.



## VII.2. Decisions about treatment aimed at ameliorating or curing disease

With quality of life as their main goal, **Daniel's** oncologist and parents discuss treatments that may be life prolonging but do not have significant toxicity. They also consider his previous treatment, his response to it, and his current tumor burden. One option is oral daily chemotherapy that does not involve swallowing large numbers of pills and does not generally cause severe neutropenia, so that hospitalization for febrile neutropenia would not be expected. Another option is to travel to another province for systemic radiotherapy. The radiopharmaceutical MIBG is used for scans but with higher doses can kill neuroblastoma cells. This option is better established outside of Daniel's home province and would require a 9-day outpatient stay in the treatment region. The possibility of not pursuing either of these treatments is also included as an equally reasonable option.

Daniel's parents opt for palliative focal radiotherapy and therapeutic MIBG. This treatment is generally well tolerated. However, in children like Daniel, who have already received extensive myelosuppressive treatments, protracted myelosuppression, particularly of platelets, may be an inadvertent consequence.

Daniel's family embraces the trip for treatment as an opportunity to spend some time together. They incorporate fun, family time into the travel, visiting special places, swimming in the wave pool, and buying some special treats, like a cowboy hat for Daniel and a special gift for his sister, Maria.

### Reflective Questions

1. Are you a person who would offer treatment options for which the chance for cure is small or negligible?
2. Would you ever consider limiting the range of options offered to the patient and family? If so, at what point in the illness or at what degree of burden?
3. Given Daniel's parents' expressed priorities, what options do you believe are most appropriate to discuss?

When there are treatments available that may ameliorate or cure the disease, much of the decision-making will be focused on these options. In many instances the choice to pursue these options is obvious. However, when the possibility of benefit is small and the burden of treatment is high, the decision about whether to implement such treatment may be extremely difficult. Decision-makers must balance the potential risks to the patient against the desired benefit and the emotional value for the patient, family, and healthcare providers of pursuing intensive treatment. It is helpful for the team of health professionals to first meet and filter the myriad of available options, identifying those that are likely to be unduly burdensome, and presenting these as less worthy of serious consideration. The balance of the discussion can then focus on those options that are reasonable to consider for the given patient. The clinician's willingness to discuss the rationale (side effects, quality of life, etc.) for the choices offered with patients and parents can preempt misunderstanding or conflict. Even families who are intent on "going for the gusto" generally respond favourably to discussions about what is most reasonable for their child, from amongst all the options available. Families appreciate guidance in this process. For several family perspectives on this process, refer to **Box 3**.

Regardless of the decisions made, a degree of guilt, regret, and/or anger may arise later on. For some families, knowing that "everything possible was done", even for a brief period, may prevent magnification of these emotions and ease grieving.<sup>74</sup> Understandably, such decisions are laden with ethical debate, differences of opinion, religious and cultural influences, and the potential for conflict. The key in such situations is good communication – listening carefully to the patient and/or family perspectives, considering the impact on the child including whether the proposed interventions may

cause the child to feel worse, realistic discussion of the possible outcomes, mediation of differences in opinion, and conflict resolution.<sup>75</sup>

Another set of decisions faced by many patients and families is whether and when to enroll in clinical trials and begin receiving experimental treatments, and whether and when to withdraw from such regimens. A majority of children with cancer are enrolled in clinical trials at some point in their illness.<sup>76</sup> For patients and parents, such decisions involve understanding complex information and risk concepts. They must balance the risks of adverse effects and the burden of the treatment regimen against the benefits of receiving the most advanced treatments possible and contributing to the care of other children in the future.<sup>56, 76</sup> They may also be more vulnerable to overt or subtle coercion when they have a long-standing relationship with the clinician-researcher or when they view the study intervention as their only chance for extending life or achieving cure.<sup>77</sup>

### VII.3. Decisions about potentially life-sustaining treatments

**Adam** is a 4-year-old with a history of progressive neurodegenerative disease and complex seizure activity from an essential enzyme deficiency resulting from an in-born error of metabolism, with premature death anticipated within the next 2 years. He has had a g-tube for several years. Previous discussions have clarified goals of care relating to the level of invasive interventions. Over the past 6 months, Adam's family has come to understand and agree that resuscitation will not be attempted in the event of cardio-respiratory compromise.

Adam presents to his local hospital in status epilepticus. Three hours later he is transferred to the tertiary care center. His seizures prove very difficult to treat and finally stop after loading with several combinations of anti-convulsants. A follow-up CT scan shows complete obliteration of grey-white matter differentiation, in keeping with a profound and global ischemic injury. This matches the clinical picture of Adam being even significantly more neurologically compromised than he had been prior to this event.

#### Reflective Question

1. Do you personally believe there is a difference between forgoing resuscitative interventions versus forgoing artificial hydration or nutrition? If yes, how would your approaches differ?
2. What information might you provide to families so that they can make informed decisions about these kinds of interventions?

Adam's parents are provided the option of forgoing artificial hydration or nutritional support. They ask questions about whether Adam will feel any discomfort with this option. They are reassured by the information that Adam is unlikely to have discomfort because children as ill as Adam do not generally wish food or fluid and that usual measures, such as keeping the mucous membranes moist, can help ensure comfort. They are also informed that medications can be given to ensure comfort if there are any concerns that Adam is showing behaviors consistent with pain or other distress.

Despite their understanding of this, Adam's parents express the wish that nutrition be maintained and a plan is implemented to assess Adam's response to feeds over the next week. Over the ensuing 3 days, Adam demonstrates a new inability to tolerate g-tube feeds despite very slow increments. He experiences gastro-esophageal reflux despite appropriate positioning measures and pro-kinetic medications. He shows signs consistent with aspiration and his abdomen becomes significantly distended, causing him to breathe with a grunting expiratory pattern. This is believed to be due to his new CNS insult, potentially compounded by gut ischemia. Options such as TPN are not feasible in the long-term and a short-term measure for maintaining hydration would involve repeated IV access, insertion of a central line, or subcutaneous infusions. The family does not wish

any operative interventions and this is congruent with the approach proposed by the clinicians who have come to know Adam and his family well since his diagnosis 3<sup>1</sup>/<sub>2</sub> years ago. If unable to feed enterally, Adam's parents do not wish any other artificial interventions directed to food or fluid.

### Reflective Questions

1. What has been your professional experience with patients receiving artificial nutrition and/or hydration at the end-of-life, including discussions with them and their families?
2. Have you had similar discussions with colleagues about options for artificial nutrition or hydration?
3. How do you imagine yourself responding if you were a parent faced with a similar situation?
4. How do you think you would respond to a parent's remark that they feel guilty for the choice they have made?

Potentially life-sustaining treatments include organ transplantation, mechanical ventilation, dialysis, vasoactive medications, antibiotics, insulin, chemotherapy, artificial nutrition, and artificial hydration.<sup>40</sup> The Canadian Pediatric Society has stated that use of such life-sustaining treatments may not be acceptable in situations in which:

- there is irreversible progression of illness and death is imminent
- the treatment will be ineffective or harmful
- life would be shortened regardless of therapy, and non-treatment would allow a greater degree of caring and comfort
- with treatment, life will be filled with intolerable and intractable pain and suffering.<sup>12</sup>

Several recent studies have provided valuable information concerning the pattern of practice in this area. Some 32-91% of pediatric patients who die as inpatients have treatments withdrawn or limited within the last days of life.<sup>42, 43, 78, 79, 80, 102</sup> The majority of these patients have a serious underlying disease prior to admission, most of which are chronic (>30 days in duration).<sup>78, 79</sup> The treatments most commonly subject to limitations or withdrawal are mechanical ventilation and vasopressors.<sup>78</sup>

Among children who have involvement with formal palliative care services, potentially life-sustaining treatments and invasive procedures are used less frequently at the end of life than in children who do not receive such palliative care services.<sup>81</sup> Forgoing invasive treatments near the end of life is thought to increase the quality of the remaining span of life. Discussions and decisions about forgoing potentially life-sustaining treatments should be part of caring for all pediatric patients with life-threatening illnesses.

Decisions to forgo treatment include both those decisions made to avoid instituting a particular treatment ("withholding") and those decisions made to discontinue a treatment after it has already been started ("withdrawing"). Although these two forms of forgoing treatment may feel different on an emotional level, they are generally considered to be ethically and legally equivalent.<sup>40, 54, 74, 75</sup> This is an essential point because health professionals may avoid instituting treatments with uncertain benefit because they are afraid of incurring extra responsibility and liability if they later discontinue it. The common pattern of decision-making influenced by this perception should be avoided. An intervention should be implemented if it is potentially beneficial to the patient and the decision-makers have not made an authoritative decision to forgo it. An invaluable option to make available is that of intervention on a time- or outcome-limited trial basis. Such an intervention may be discontinued at a later time if the decision-makers agree that its risks or burden have come to outweigh its potential benefit.<sup>17, 40, 75</sup> This is the approach that was used with Adam.

Each decision to forgo or limit a specific treatment applies only to that particular intervention and implies nothing about how other interventions are to be implemented. A decision to forgo a potentially life-sustaining treatment should certainly not lead to abandonment of all care for that patient but may lead to careful review and discussion of all current and planned interventions.<sup>40, 57</sup> All patients and

families should be reassured that they will continue to be cared for and supported regardless of whether they decide to forgo or continue with treatments.<sup>20</sup>

As can be appreciated from the two case studies presented at the beginning of this section, decisions about forgoing potentially life-sustaining treatments are amongst the most difficult and controversial.<sup>13</sup> Before engaging in such discussion, patients/families and healthcare professionals need to have recognized, at least intellectually, that premature death is the probable outcome of the patient's illness. Such acknowledgement may not occur until shortly before death. Although continued hope for survival can be an important coping mechanism for patients and families, lengthy denial of the realistic prognosis can lead to delays in the implementation of palliative care options.<sup>101</sup> Early and realistic discussions and decisions are important because they provide direction for treatment and offer the patient and/or family some control over the final life-sustaining possibilities and, in some cases, the timing of death.<sup>20,43</sup> Clinicians should be proactive in initiating such discussions because only a minority of patients/families bring up these topics and multiple discussions may be needed before a decision is reached.<sup>78</sup> Approaches to early discussion are the subject of a later section of this module titled, "Getting the timing right – earlier rather than later"

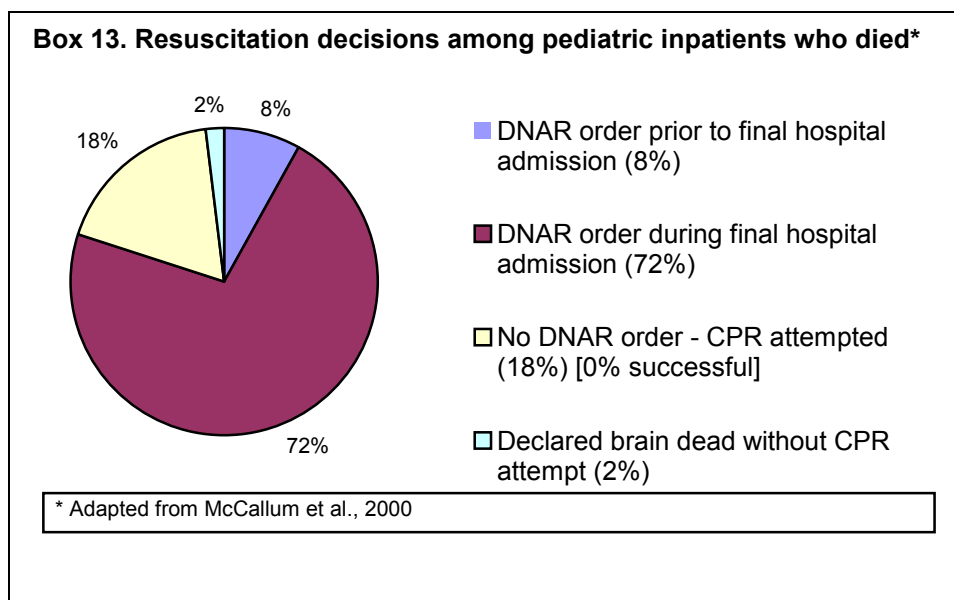
### Resuscitation orders: DNR, DNAR, AND

In many cases, the consideration of palliative care options begins with a discussion about "do-not-resuscitate" (DNR) orders. Alternative language for DNR orders is being implemented in many centres so that "do-not-attempt-resuscitation (DNAR)" or "allow natural death (AND)" orders are being used instead. This is more than just a change in language usage because words can influence perceptions about what is possible. Although many pediatric patients do have DNAR orders documented prior to their death, discussions concerning such orders are commonly documented only during their final hospital admission.<sup>78, 80</sup> **(Box 13)** This short interval is concerning because CPR attempts in infants or children with life-threatening or life-limiting illnesses are very rarely successful. In many cases, multiple discussions are required over a lengthy period of time before families understand that a successful resuscitation attempt is unlikely.<sup>19, 78, 80</sup> Delaying discussion of this difficult topic until death is imminent may not allow sufficient time for these discussions, leading to guilt and regret that can extend far past the death of the child.<sup>19</sup> The provision of focused palliative care can enable earlier discussion and implementation of DNAR orders, decrease the number of inappropriate CPR attempts in such patients, and lead to the provision of care that is congruent with the child and/or family's wishes.<sup>81, 101</sup>

The discussions about DNAR orders encompass more than just the interventions relating to CPR. For example, in a child with progressive neuromuscular disease, the potential for, feasibility of, and wishes for pursuing ventilatory assistance should be discussed before the need for this decision presents itself.

### Artificial nutrition and hydration

Many clinicians and families find it very



difficult to make the decision to forgo artificial nutrition and hydration, even after having decided to forgo all other forms of life-sustaining treatment. We have an instinctual need to feed dependent children and the prospect of withholding food and water from a child can evoke strong emotions. These values and emotions should be acknowledged and discussed amongst clinicians and with families. However, a clear distinction must be made between oral feeding and hydration, without medical intervention, and the invasive interventions of artificial nutrition and hydration. As with any other medical intervention, decisions to implement or forgo artificial nutrition and hydration involve evaluation of the benefits and burdens of such interventions.<sup>54, 57, 82, 83, 84</sup>

The common perception is that artificial nutrition and hydration may lead to prolonged survival. However, these interventions do not appear to lengthen survival and may cause additional suffering.<sup>83</sup> If artificial nutrition and hydration only prolong the dying process, the burden of this extended lifespan may outweigh its benefit.

Whether artificial nutrition or hydration is provided by enteral or parenteral routes, there are burdens of discomfort and bodily invasion. Such devices may also limit the ability of patients to be held and comforted by family and healthcare providers. All such interventions also carry risks such as infection, obstruction, metabolic derangements, hepatic injury, and side effects including nausea, vomiting and diarrhea. Studies have shown complication rates of 15-76% attributable to artificial nutrition via central venous catheter or enteral feeding tubes.<sup>83</sup>

Given our own familiar sensations of thirst and hunger, artificial nutrition and hydration may be viewed as comfort measures rather than life-sustaining therapies. However, the evidence is mounting that fasting or limiting food and water intake during the final phase of life may be more comfortable and preferable to the patient.<sup>83</sup> Competent patients often refuse food and fluid intake near the end of life. In addition, fasting patients experience marked decreases in respiratory secretions, coughing, nausea, vomiting and diarrhea, all of which may make them more comfortable. Fasting substantially reduces hunger sensations whereas ingesting small amounts of food can lead to intense hunger. Thus, the patient may be more comfortable with complete withdrawal of nutrition rather than partial feedings. Finally, the simple intervention of moistening the oral mucosa, something that families can often do for their child, can relieve any sensation of dryness that may accompany limited fluid intake.

## VII.4. Decisions about treatments aimed at relieving symptoms

**Daniel**, the young man you met earlier, is now 5½ years old with relapsed Stage IV neuroblastoma. Over the 6 months following MIBG treatment, Daniel has been enjoying doing crafts and watching the family cat have her kittens. He now develops shortness of breath due to a large pleural effusion, compounded by anemia. His parents and health care providers must decide whether to use thoracentesis to drain the effusion while implementing



other measures to ensure Daniel's comfort. This option is not pursued.

Daniel is transfused because his anemia could be contributing to the dyspnea. His sensation of breathlessness is relieved with systemic opioids and anxiolytics, and he is positioned to ensure maximal comfort. Daniel dies at home 1 week later.



### Reflective Question

1. You already know Daniel's condition and his dislike for being hospitalized. What else do you consider to be important factors in deciding about interventions for Daniel at this time?

Throughout the care of an ill child, symptom relief and comfort should receive considerable attention, regardless of prognosis. Intensive treatments aimed at curing or ameliorating the illness or prolonging life are often accompanied by adverse symptoms and discomfort that are accepted because the treatment carries significant potential benefits. If the illness progresses to the point where the potential benefits of such interventions are outweighed by the burdens of discomfort or other symptoms, the focus of care should shift to finding less-burdensome methods of intervention and/or focusing on relieving symptoms and ensuring comfort. This change in focus occurs at different times for different patients and all communicative children should be included in discussions about whether the discomfort and side effects of intensive treatment are bearable.

Once care is focused on symptom relief, there are multiple treatment options possible, depending on the clinical situation, family values and beliefs, and available resources. In some cases, invasive interventions such as surgery or chest tube placement may be considered for the purposes of relieving symptoms. In others, less invasive treatments such as analgesics and sedatives, combined with non-pharmacological approaches such as guided imagery and relaxation techniques, are more appropriate.<sup>78</sup> Key considerations when making such decisions are summarized in **Box 14**. Again, early recognition of probable premature death and discussion of symptom relief options can lead to

improved quality of life at the end of life.<sup>101</sup> This can also provide durable reassurance for the family as they look back on their child's last days, weeks, or months.

### ***Sedation at the End of Life***

Ensuring comfort while maintaining and maximizing function is a primary goal in symptom management. There are rare occasions when function cannot be maintained without compromising the child's comfort. In such an instance, medications including sedatives and analgesics should be titrated to provide adequate relief from symptoms, even if this means that cognitive, respiratory or cardiac function becomes compromised as a result.<sup>17, 19, 34</sup>

This practice is commonly referred to as sedation at the end of life, abandoning the emotionally-laden and confusing descriptor, "terminal sedation". This approach can be easily misunderstood by patients and families as an active hastening of death or euthanasia.<sup>34</sup> Before making decisions concerning such treatments, patients, families and healthcare providers must clearly understand that these medications will be given only for the purpose of relieving symptoms and are not given to cause or hasten death. The medications may have the secondary, unintended, effect of shortening life by a few hours or days.<sup>19, 34, 75</sup> This is referred to as the "principle of double effect" where the intended intervention (*ie.*, sedation to ensure comfort) has an additional unintended potential consequence (*ie.*, respiratory compromise). The health professional, family, and patient, as appropriate, should have information about how the patient will look and about what the patient will and won't be able to do. This discussion also prepares the patient and family to have some interactive "good-byes" before the patient becomes unable to communicate through sedation.

Euthanasia, in which the clinician actively administers therapy with the aim of causing death, is illegal in all Canadian jurisdictions but remains ethically controversial. Many individuals and some organizations, such as those identified as advocates for individuals living with disabilities, are concerned that instituting a social policy supporting euthanasia in one particular area or circumstance will lead to an extension of that policy beyond its original scope ("the slippery slope"). They are concerned that this could lead to life and death decisions being made "on behalf" of individuals living with disabilities on the basis of someone else's beliefs about what constitutes a life worth living. Proponents of euthanasia argue that the principle of respect for autonomy and the need to relieve suffering outweigh the sanctity of human life.<sup>57</sup>

The dominant argument against euthanasia is that, although the principle of respect for autonomy allows the patient to refuse potentially life-saving or life-sustaining treatment, it does not legitimize a demand that some other person perform an action to end the patient's life.<sup>54</sup> At the root of this debate, and of many patient and family inquiries about euthanasia, is the fear of suffering, isolation and loss of dignity at the end of life.<sup>16, 57</sup> Effective communication and integration of palliative care treatment options can alleviate these fears and provide comfort and dignity during the dying process. Once these points are addressed, interest in euthanasia almost always disappears.

#### **Box 14. Key considerations when making decisions regarding interventions aimed at symptom relief.**

- Degree and duration of relief anticipated to result from the procedure
- Impact of the procedure on the child including the potential for and the magnitude of physical or emotional distress
- Child's expressed wishes
- Preferences indicated by parents
- Child's proximity to death
- Location of available treatment approaches
- Alternative approaches: availability and efficacy
- Financial implications

## VII.5. Planning care for the last days and/or hours of life



**Gina**, a savvy, independent 15-year old, enjoys cheerleading and a wide circle of friends. She presents with hip pain that is initially treated as bursitis and then as osteomyelitis. When the pain does not resolve, she has a more extensive work-up. A pelvic mass is found, which on biopsy proves to be Ewing's sarcoma. Gina is treated with chemotherapy and limb salvage surgical excision including total hip replacement. Presumptive microscopic residual disease is treated with radiotherapy.

Three months after completing therapy, and shortly after representing Nova Scotia at the Miss Teen Canada Pageant, Gina presents with new onset back and hip pain, accompanied by paresthesias of her right leg. Investigations show involvement of the vertebral body of L3 and bilateral pulmonary metastases. At initial diagnosis, pelvic Ewing's sarcoma has a 5-year relapse-free survival rate of 50%. Prognosis depends on the size and location of the tumor, and whether metastases are present. Once relapse occurs the prognosis is extremely poor.<sup>61, 85, 86</sup>

Gina requires a nephrostomy tube for obstructive uropathy secondary to hardware and scarring from her operative procedure, possibly compounded by the radiotherapy. She also starts receiving a different course of chemotherapy and expresses her wish to have a bone marrow transplantation if it would enable her to achieve remission.

Unfortunately, Gina's cancer continues to progress through the chemotherapy. Her oncologist discusses with her that it is no longer possible that the treatment will have a curative outcome and that the previous consideration of a bone marrow transplant is no longer feasible. Gina wishes to continue well-tolerated oral chemotherapy with the hope that this will keep her symptoms at bay and possibly limit the rapidity of the spread of her cancer. Regardless of her prognosis, or the treatment she chooses, Gina's healthcare team reassures her that they are committed to her on-going care.

She subsequently requires admission for cord compression secondary to tumour invasion of the cauda equina region. As a result, she needs self-catheterizations to drain her non-obstructed right kidney and a nephrostomy tube for her obstructed left kidney, and feels terribly despondent and frustrated by fecal incontinence. Normally a real socialite, Gina refuses to spend time outside of her home or have friends over to visit due to this incontinence. With various techniques, Gina is able to achieve continence, which is incredibly important to her especially because she was planning a trip to California with her boyfriend, father, and step-mother. Relaxing in a hot-tub is one of the goals for her trip.

### Reflective Questions:

1. How would you talk with Gina about her own wishes and the reasonable interventions to pursue if she was unable to breath for herself or her heart stopped?
2. What do you know about Gina that would indicate her degree of receptivity to such a discussion?
3. Consider how you would frame such a discussion.

Gina goes to California as planned, with a letter describing her desire that resuscitation not be



attempted and about measures to ensure her comfort. She goes to the beach, gets into the hot-tub in a racy bikini and enjoys herself.

While at Sea-World in San Diego, Gina has a seizure, during which she becomes apneic and pulseless. Her father and nurse do CPR and she is transferred to the regional emergency department, where she regains consciousness. Ventricular dysrhythmias are documented on the cardiac monitor. Despite the directive outlining the degree of intervention to be taken in such a circumstance, she is defibrillated at least 5 times in the next 12 hours and is treated with intravenous anti-arrhythmics in the hope that her dysrhythmias are transient and reversible. The shared goal for Gina, her family, and the health professional team is to get her back home to be with the rest of her friends and family.

Gina is stabilized over a 5-day stay in the CCU during which a large right-sided intra-cardiac mass and a markedly reduced ejection fraction are documented, consistent with a metastatic lesion. After being transported back to the PICU in her home hospital, Gina asks, "I was brought back here to die, wasn't I?"

**Reflective Questions:**

1. What are the kinds of things you want to discuss with Gina at this time?  
With her family?
2. Do you believe we sometimes try to support hope in order to reduce our own discomfort?
3. Do you believe, as a healthcare professional, that we can make it easier or harder for a person to have hope?

In the final stages of life, some families feel that they need to continue maximal treatment until death is imminent so that they know they "did everything." This tendency must be weighed against the burden felt by the dying child during this time. This burden may involve the discomfort of intensive and invasive procedures, and, potentially, a lack of emotional support and physical contact with family, friends, and professional caregivers during the actual dying process. Families who have insisted on intensive treatment in the final hours and days often later regret the lost opportunity to be close to their child during this time and wonder whether their child felt alone at the end.<sup>67</sup> That said, intensive treatment and family intimacy are not mutually exclusive. With particular effort, this valuable support can be integrated into the provision of intensive care.

The clinician's desire to support the family's expressed wishes can lead to him/her having difficulty with: telling the family that their wishes cannot be met; knowing when or how to stop treatment, and whether to continue with a protracted resuscitation. Prognostic uncertainty and our inability to predict exactly how or when specific symptoms will arise or events occur makes advance decision-making about care during the last days and hours of life even more difficult. Planning for all of the "what if's" and "just in case's" requires careful consideration of the patient's wishes and/or best interests, values, beliefs, and goals, as well as those of the family. It also requires a full understanding of the patient's medical situation and all the possible events or decision points that might arise before death.

***Recording the patient's wishes: Advance directives, living wills, and other documentation***

Although not conventionally used in pediatric care, advance directives and living wills are frequently used by adults to express their wishes concerning end-of-life care and to appoint a substitute decision maker. Such documents have legal validity in several provinces (see Appendix D). They provide the patient with some assurance that his/her wishes concerning end-of-life care will be considered even if he/she is not competent at the time of the decisions. They also provide some guidance to family members and healthcare providers as they struggle to make decisions for a patient who can no longer speak for him/herself.

However, none of the various proposed formats and approaches to such documents completely address all issues that may arise between the time of writing and death. The best method of preparing for the unexpected is for the appointed substitute decision-maker to have detailed and open discussions with the patient, while he/she is still capable, about his/her wishes, values, and beliefs concerning the meaning of quality of life. It may also be useful to record the patient's wishes and thoughts about specific issues such as those relating to the use of hydration or ventilatory support.

Although not legally binding, having such documentation available and up-dated may help subsequent decision-making on the patient's behalf. This may help the substitute decision-maker in situations where the best interests of the patient do not appear to fit with the wishes expressed in the advance directive.<sup>87</sup> For example, a child with advanced cystic fibrosis may state that she does not want to receive any further antibiotics, with the intention of avoiding further intensive treatment and remaining at home. However, if she becomes unable to communicate and then develops a bladder or ear infection with pain-related behaviour, antibiotics intended to make her comfortable would appear to be indicated. If her substitute decision-maker knew that she valued being free of pain above all else, then it would be reasonable to make a decision that contravenes the written directive.

## VII.6. Decisions about the location of care

**Gina's** step-mother is unable to come back on the flight with Gina. Gina's wishes are that, if needed, she should be defibrillated until all her family are present. The following day, when all of Gina's family members are present, further discussion explores Gina's concerns and wishes. She wants to be home for care including end-of-life and to see her boy-friend. She voices great concern about the possibility of severe pain at the end-of-life.

### Reflective Questions:

1. What symptoms do you anticipate will be associated with Gina's progressive deterioration leading to death?
2. How would you prepare and reassure Gina and her family about how these would be managed?
3. What needs to be in place for this kind of care at home?

Gina leaves the PICU by ambulance to her home. She spends the next three weeks in her room, surrounded by friends and family. Her friends come over and play guitar, look at pictures, tell stories, and have nightly food feasts up in her bedroom.

Gina tends to store up her questions for the night, asking things like, "What do people think heaven is like? Will I be able to e-mail my friends or watch TV with my family from there when I am dead?" She asks what happens to the body and how long it takes to deteriorate. She asks about donating her body to science. Throughout this, Gina asks for her herbal tea, Essiac, widely used as an alternative/complementary anti-cancer treatment, to be made-up regularly and takes it like clockwork, asking when it is time for her next amount, often talking about how she hopes it is going to work for her.

### Reflective Questions:

1. How would you respond to Gina when she asks these questions? Consider your response when she expresses the hope to get better, to be cured?
2. Do you believe that Gina continuing to take Essiac tea means that she is denying that her advanced illness will lead to her death?

During the final stages of a prolonged illness, patients, their families, and health professionals often raise discussions about where the care will continue and where the death may occur. Options may include the hospital, home or a hospice/respite setting (obviously within the boundaries of control of such as decision).<sup>22, 56</sup> Children and families may express a preference based on a myriad of factors including; the child's physical needs and the ability of the family to care for him/her balanced with what help would be available in the home setting; past experience with home/hospital illness and death, family constellation; emotional functioning of individual family members and the family as a whole; socioeconomic and cultural factors. Whatever the decision the child/family comes to, the following overarching principles must be kept in mind at all times:

- There is no right setting for all families.
- Any choice that the child/family makes is reversible at any time. Thus, if a child goes home, and the situation becomes, for whatever reason, too onerous, readmission to the hospital can be done expeditiously.

Death in the home or in a hospice may be less traumatic for the patient and family than in a hospital space that can be intense and impersonal. The family and child can receive the full support of family

and community in their own home, and be fully involved in care throughout the dying process. If such a move is desired by the family and/or patient, and if the required care can be mobilized outside of hospital, then it should be arranged.<sup>17, 35, 34</sup> Most families will want continued contact with their primary care providers and may feel abandoned if the transition is too abrupt.

Some families and patients wish to remain in hospital. In this case, discussions and decisions should center on creating an environment that meets the needs of the family and patient.<sup>17</sup> This might include accommodating extra visitors, and finding creative ways to fulfill the child's final wishes and enable the family to conduct desired rituals. This may also mean finding a space where there is the option for minimal contact with patients and families who continue to receive intensive treatments.<sup>34</sup>

## VIII. How Do We Proceed?

### VIII.1. The basics of communication

#### ***Challenges and benefits of communication***

Good communication is essential to effective decision-making.<sup>14</sup> It is also difficult. Talking about death and dying with adults can be a challenge, but when these topics must be addressed with children, many people feel at a loss. In a recent survey, oncology physicians and nurses rated communication with terminally ill children and communication with the parents of such children as two of the most frequent challenges of their work.<sup>88</sup>

Traditionally, children were not involved in difficult discussions because they were believed to cause unfair anxiety and pain. This perspective has shifted over the last 25 years. It is now understood that children need to be offered opportunities to talk openly and honestly about their illness and impending death. This change in thinking is due to an increased recognition for the developing and/or actual autonomy of young people. Observational findings reveal that children figure out that they are seriously ill and possibly dying even when their families and healthcare providers have attempted to protect them from this information.<sup>89, 90, 91</sup> Given this insight, every child should be given the opportunity to discuss his/her situation and to receive further information, at their level, and emotional support.

Effective and ongoing communication can also help patients and families adapt to changes in care that occur as the patient progresses towards death. When not prepared for these changes, patients and families may be distressed and feel abandoned when the medical team stops ordering regular blood tests or other investigations or if the patient or family perceive that the healthcare team is withdrawing from contact and emotional attachment.<sup>14, 34, 46</sup> However, prior discussion about the changes in care that are likely to occur, the reasons for them, and reassurances that the patient and family will continue to be cared for by skilled and committed professionals can limit feelings of abandonment.<sup>34</sup> In addition, healthcare providers must guard against the tendency to decrease contact with patients for whom intensive treatment has been forgone and must work on improving their ability to interact comfortably and supportively with such patients and their families. Such contact can be amongst the most rewarding and therapeutic health care interactions.

Decisions made by patients and families can be influenced by verbal and non-verbal cues from healthcare professionals.<sup>17, 93</sup> Thus, excellent communication skills of all types are essential. Many of these are discussed in detail in the Ian Anderson Communications module. However, the essential task is to regard each family and patient as unique and to explore their perspectives and decision-making style with an open mind. What works for one family or patient is in no way guaranteed to work for the next.<sup>91</sup>

As well, apparent staff disregard for the deep distress felt by the child and/or family may be inadvertently conveyed by conversations they overhear. One example is the added distress experienced by a family in the pediatric ICU whose child has just died when they overhear staff discussing where to go for lunch.<sup>92</sup>

#### ***Laying the groundwork: Assessing family and patient communication***

The first step in establishing effective communication during decision-making is to assess the family's style of communication. This assessment may occur through observation of the family and/or by explicit discussion of these following topics:<sup>19, 93</sup>

- How does the family communicate currently?
- How much and in what format does the family/patient prefer to receive information?
- What information is shared between family members and with whom?

- ❑ What and how is information shared with the patient? siblings? larger family?
- ❑ How does the patient communicate with his/her family, both individually and as a whole?
- ❑ How are emotions and needs communicated?

Next, it is important to assess the patient and family's current understanding and perceptions concerning the illness, the care being provided, how they are coping, and their current needs.<sup>17, 93, 94</sup> With the family, these topics are better explored through explicit discussion than through observation (**Box 16**).

With the patient, various developmentally-appropriate methods of observation, discussion, and assessment are available (see **Box 15** and the section titled, "When children and adolescents are the decision-makers"). The use of symbolic play is a helpful method of communication often assessed by healthcare professionals with specialized training in meeting psychosocial needs.

#### **Box 15. Suggested questions for the child**

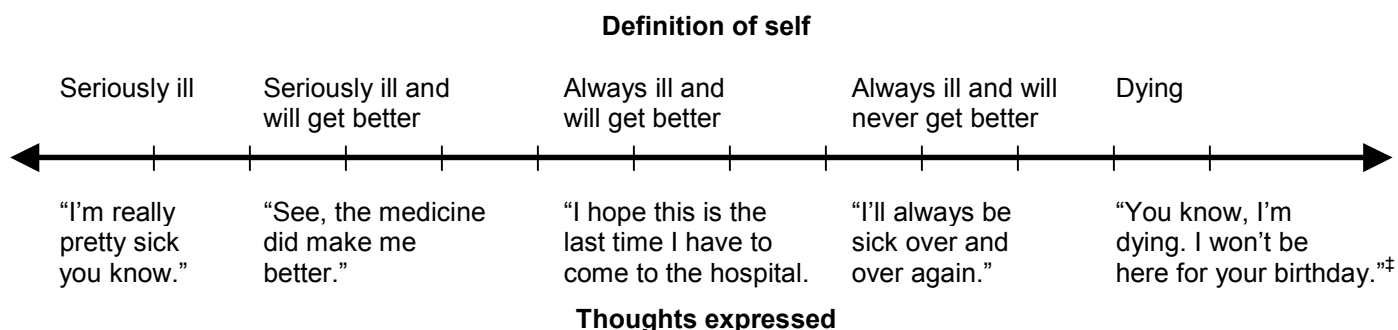
- ❑ Please tell me about the medicines and other treatments you're getting today/this week/at the moment.
- ❑ Why do you think you're getting these medicines and other treatments?
- ❑ How do these medicines or other treatments make you feel?
- ❑ When you first started getting these medicines or other treatments did anybody talk to you about what you thought about them? What do you remember about that?
- ❑ What's been the most difficult thing you had to go through since you got sick? What helped you get through that?
- ❑ What's the most difficult thing you're thinking about right now? Who or what do you think could help you with that?
- ❑ What are the most important things you want to do in the next day/week/month?
- ❑ If you had 3 wishes, could you tell me what you would wish for? If you had 3 wishes, and I could do magic to make them happen, what would you wish for? [The second wording is useful for stimulating the imagination of an older child or adolescent but should be avoided in a child who uses magical thinking to explain the illness.]

A child's concepts of illness and dying, as well as their ability to reflect on their own experience, evolve over time but cannot be directly correlated with age.<sup>64</sup> (Box 17) A child's understanding may be greatly influenced by his/her disease experience, prior experiences with the death of family or friends, religious or cultural beliefs, usual patterns of coping with pain, sadness, and other emotions of grief, and the way in which the child is expected to die.<sup>34, 64, 96</sup>

**Box 17. Proposed theoretical frameworks for a child's concepts of illness and dying**

**A child's understanding of illness and death is influenced by their experience of illness**

The child's awareness of the life-threatening implications of the illness can be conceptualized along a continuum [conceptual illustration below].<sup>95</sup> At one end, the child acknowledges being "very sick" or having a "bad disease"; however, there is no prognostic statement referring to life or death. In the middle, the child expresses some awareness that his or her life might be in jeopardy - uncertainty about *living* - but without a focus on death. At the other end of the continuum, the child is explicitly conscious that he or she could die of the illness. Awareness is gleaned from many sources. Primary is the "wisdom of the body": the child's irrefutable recognition of how sick he or she is. Other cues include the child's knowledge of the illness, the urgency and intensity of treatment, the emotions of family and caregivers, and encounters with other patients. Awareness is a fluid, not a static state. Thus, dependent on current medical status, or related to a significant life event, the child's comments and play will incorporate different elements at different times.<sup>†</sup>



**A child's understanding of death parallels standard developmental stages<sup>19</sup>:**

Stage of Development	Key Concepts
Infancy (0-2 yr)	Experience the world through sensory information
Early verbal childhood (2-6 yr)	See death as reversible, death is not personalized, have magical thinking
Middle childhood (7-12 yr)	Personalize death, aware that death is final Earlier stage: understand cause of death as being external to their bodies Later stage: understand cause of death as being inside their bodies
Adolescence (>12 yr)	Appreciate universality of death but may feel distanced from it

<sup>†</sup> Excerpt from *Armfuls of Time: The Psychological Experience of the Child with a Life-Threatening Illness* by Barbara M. Sourkes, © 1995. Reprinted by permission of the University of Pittsburgh Press.

<sup>‡</sup> Adapted from Bluebond-Langner, Myra; *The Private Worlds of Dying Children*, Copyright 1978 by Princeton University Press. Reprinted by permission of Princeton University Press.

Using open-ended questions with patients and families can lead to discussions that touch on many topics, emotions, values, and perceptions. The clinician should respond to these with empathy, using the language chosen by the patient and family.<sup>94</sup> In addition to being therapeutic for the patient and family, such discussions and responses open the door for the correction of misperceptions, provision of small parcels of additional information, and the evaluation or re-evaluation of priorities and decision options.

### ***Laying the groundwork: Assessing healthcare professionals' communication***

Patients and families will closely observe the explicit and implicit messages communicated to them by healthcare professionals. They may benefit from an open discussion about communication patterns amongst healthcare professionals and between healthcare professionals and patients/families. Topics might include how medical rounds and charting systems work, how potential care decisions are discussed, the chain of responsibility and reporting within the medical team, and the given system of sharing responsibility for patients amongst multiple staff people.

Difficulties often arise when patients and families are receiving information from multiple healthcare providers. Different people use different words to communicate the same thing but sometimes the resulting messages are perceived differently. Patients and families should be encouraged to point out differences in the messages they are receiving and to ask for additional clarification.

Healthcare professionals, as a group, have beliefs, fears, practices, and expectations regarding confidentiality, truth-telling, emotional involvement, admitting uncertainty, the ethic of “do no harm”, the definition of futility, time constraints, and resource management that create a culture that is not innately known to patients and families.<sup>52, 12, 93</sup> Clinicians should recognize and accept that their values may differ from those of the patient or family, and that this culture shapes what and how information is communicated to patients and families and how they are involved in decision-making.<sup>52, 73</sup>

Open discussion of this culture with patients and families is very important, especially when decision-making concerning end-of-life treatment is going to be needed. It is also important to clearly state the expectations and responsibilities held by the healthcare professional, family, and patient in order to make decisions effectively and ensure high quality care (**Box 18**).

#### **Box 18. Responsibilities and expectations**

The healthcare professional is responsible for:

- Providing frequently updated information and consulting with the patient/family concerning all decisions.
- Briefing the patient/family about what to expect.
- Listening to and addressing the wishes and concerns of the patient/family.

The patient and/or family is responsible for:

- Letting their clinician know how the treatment is making them feel, if it is having the desired effect, and if they are having any adverse effects.
- Asking questions about anything they are confused or concerned about.
- Expressing their thoughts and feelings.
- Speaking up when they are feeling overwhelmed, in need of a break, or otherwise in need of support.

### ***Ethnicity, spirituality, and culture***

As in any healthcare relationship it is essential to explore, acknowledge, and work with the cultural, spiritual, and ethnic beliefs and values of the family and the individuals within the family (**Box 19**). Although certain ethnic and religious groups tend to have a shared sense of meaning and traditions surrounding death and dying, the variability between individuals may be greater than the variability between groups. Avoiding stereotypes and gently inquiring about the beliefs and values of each individual is the best approach (**Box 20**).<sup>36</sup>



Your healthcare centre's translation service (or the equivalent) can be an excellent resource for information and advice in this area. The need for privacy and the principles of confidentiality form the rules of engagement and must be clarified with all involved parties. Sometimes, undue reliance is placed upon the individual doing the translating. If this role is assumed by a family member it can further complicate the discussion.

It is also important to explore, acknowledge, and work with the culture and values of the healthcare system and its individual professionals. These factors help shape all healthcare decisions but are of particular importance when the decisions are related to death and dying.<sup>97</sup>

### **Box 19. Culture and pediatric palliative care decision-making**

A family's cultural context can have a tremendous effect on their perceptions concerning such things as:

- the child's role in decision making
- who the key decision-maker is (it may not be the same person as the primary caregiver)
- the degree of authority granted to the clinician in terms of decision-making
- the involvement of extended or geographically distant family members in decision making
- the relative importance of quality of life concerns versus chances for cure or extension of life
- the acceptability of options such as forgoing potentially life-sustaining interventions including ventilation, and artificial nutrition and hydration
- the use of analgesics and other interventions
- the desire to have the child cared for in hospital or at home during the last period of life

### **Box 20. Approaches to discussing cultural issues with families**

- Each time I meet a new family I try to find out as much as I can about how they make decisions. It is really helpful for me to understand things such as... when do you want Leeza to be present for discussions, and who would you say is the person in your family whom everyone looks to for very important decisions? It would be really useful to know these things when planning Leeza's care.
- Different people have different beliefs about medical treatments such as pain medications like morphine, and ventilator machines that help someone breathe. I would like to find out your thoughts on such things, just in case your son gets to the point where we start thinking about using them. It can be very helpful if we know about your beliefs ahead of time so that we can all work together.
- Some families need to consult with people in their community before making important decisions. It may be with a leader within their religious community or a respected elder or someone who is a healer in their community. These consultations can be very helpful for some families. Is there anyone special that you may want to talk with about these decisions?

## VIII.2. Strategies for helping families to communicate



The parents of **Derrick**, the 12-year-old with relapsed lymphoma and immune deficiency whom you met earlier, have decided to talk with him about options for lung biopsy and ventilation in the setting of progressive respiratory symptoms.

Derrick's family usually does not spend much time on talking – they are more action-oriented, “living in the moment”, having fun, and often sharing affection by “horsing around.” Before this time, they had responded to Derrick expressed concerns about dying by focusing on the positive and on getting through by being courageous and “fighting”.

This time is different. Derrick's step-father, George, is encouraged to start a new conversation by saying to Derrick, “We are very worried about you. We are worried about how sick you are.” Derrick responds immediately by saying he knows how sick he is, that he is tired of fighting and that he is ready to die. They all speak of their love for one another and Derrick says he worries that he may not be remembered. Derrick loves cats and has a very good cat-friend, Rocky. He asks his mother to look out for stray cats and open the door to them because “I'm going to come back as a cat.”

After crying together and acknowledging Derrick's struggle and concerns, Derrick rallies and says “Okay, I'm going to fight.” His parents decide to go ahead with the lung biopsy, appreciating how difficult it is for Derrick but wanting to ensure that all reversible parts of his illness are investigated and treated.

Derrick is placed on ventilatory support that night and has a lung biopsy the following day. It shows inflammatory cells and intra-alveolar hemorrhages with no evidence of fungal, bacterial, or viral involvement. There is also no evidence of malignancy. Two days later, while still ventilated, Derrick goes into renal failure. Dialysis is offered and his parents decide not to pursue further interventions, appreciating that Derrick's deterioration involves many systems and that he is not expected to recover. He dies the following day.

### Reflective questions

1. What do you think the child with a life-limiting or life-threatening illness wants to hear from his/her family?
2. What do you think the parents of a child with a life-limiting or life-threatening illness wants to hear from the child?
3. What do you think the parents of a child with a life-limiting or life-threatening illness wants to hear from their friends and larger family?

### **Communicating with children**

There are many things that healthcare providers can do to help families communicate. Some families need help communicating with the young patient and his/her siblings. They struggle to tell their child about his/her illness and possible death, and do not know how to help an older child or adolescent find their own information about the illness and treatments. Possible techniques and strategies in these situations include:

- Reading stories or books that deal with the topics of illness and/or death in ways that appropriate to the patient's or sibling's level of development. See **Box 21** and **Box 22**.
- Asking questions about how the child and his/her siblings usually communicate and like to receive information. Do they usually like to hear lots of detail or just the basics? What do the siblings understand about how ill their brother or sister is? How do the parents share information about the ill child with their other children? What kinds of questions are the child's brothers and sisters asking about him?
- Use this information to provide guidance to the family about their discussions with the child.
- Providing parents and other family members with age-appropriate language to use with the child when talking about illness and death.
- Providing guidance about what type of questions and reactions to expect from the patient, siblings, and other family members.
- Discuss creative methods of communicating, such as through play, with the family.
- Provide opportunities for the parents to talk to other parents of children with similar illnesses.
- Inform families about peer groups and internet sites that are designed for children and adolescents with chronic or life-threatening illnesses. For example:
  - [www.mdausa.org/](http://www.mdausa.org/)
  - [www.faculty.fairfield.edu/fleitas/contents.html](http://www.faculty.fairfield.edu/fleitas/contents.html)
  - [www.familyvillage.wisc.edu/index.html](http://www.familyvillage.wisc.edu/index.html)
  - [www.rarediseases.org](http://www.rarediseases.org)
  - [childendoflifecare.org/](http://childendoflifecare.org/)
  - [www.growthhouse.org/](http://www.growthhouse.org/)

#### **Box 21. Communicating with a child when a family member is seriously ill or dying**

When a child has a sibling or parent who is dying, they need many of the same things that a seriously ill child needs – accurate age-appropriate information, encouragement to express their fears and feelings, support and love, and the freedom to ask questions.

Such children may be involved in discussions about healthcare decisions for their ill sibling or parent. For instance, a healthy child may be very uncomfortable with the idea of a sibling or parent receiving end-of-life care and dying at home. This perspective should be heard and considered when decisions are being made about the location of care.

While these children and adolescents may be involved in discussions about healthcare for their ill sibling or parent, too often they are excluded from any decision-making, particularly concerning the place of death. They rarely have any say in the rationale and implications for whatever choice is made, and often only hear about the decision once it has already been made. While home care may permit children greater access to their ill relative, it often does not provide them with sufficient respite from the relentlessness of dying; the safety of the home may be lost for the child during the present circumstances and even into the future.<sup>98</sup>

There are some excellent resources available to help with this process. Several of them are listed in **Box 22**.

## Box 22. Books about serious illness, decision-making and death

See Appendix B for full citations.

### **For children and adolescents:**

- American Cancer Society, *Why Charlie Brown, Why?* [Video cartoon].
- Breebart J and Breebart P. *When I Die, Will I Get Better?*
- Buscaglia L. *The Fall of Freddy the Leaf*. [The story of a leaf's life including his discussions with neighbouring leaves about what it's like to die and his fear about dying and the unknown.]
- Heegaard M. *When Someone Very Special Dies*. [a workbook for children]
- Josephson KB and Sourkes BM. *My Life is Feelings. Starring Poly Polar Bear*. [Teddy bear discusses his feelings during serious illness.]
- Lazar L and Crawford B. *In My World: Official Life Journal*. [Structured and open spaces for writing and creative projects by teenagers facing life-threatening illness.]
- Mellonie B and Ingpen R. *Lifetimes: A Beautiful Way to Explain Death to Children*. [Simple language and pictures to describe the way all living things have a beginning, and ending, and "life in between." Progresses from animals and plants to people; from natural life-spans to those made shorter by illness or injury.]
- Mills J. *The Gentle Willow*. [A willow tree is very sick. Despite the love of her friends and knowledge of the tree wizards, she is not able to keep living.]
- Miner JC. *This Day is Mine: Living with Leukemia*. [A 16-year-old girl talks about coming to terms with her diagnosis and treatment.]
- Munroe J. *The Facts About Leukemia*.
- White EB. *Charlotte's Web*.
- Wiener L. *Be a Friend: Children Who Live with HIV Speak*.

### **For adults:**

- Adams DW and Deveau EJ. *Coping with Childhood Cancer – Where do we go from here?*
- Davis D. *Fly Away Home*. [Support and guidance for parents who decide to forgo continued intensive treatment for their child.]
- Davis D. *Loving and Letting Go*. [Guidance for parents of critically ill newborns.]
- Fitzgerald H. *The Grieving Child*.
- Frantz TT. *When Your Child has a Life-Threatening Illness*. [Practical guidance for parents about coping with emotions, medical information, decisions, impending death, and talking with the ill child and siblings about death and decision-making.]
- Grollman E. *Talking About Death: A Dialogue Between Parent & Child*.
- Hamilton J. *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*. [Valuable resource concerning language and developmental considerations to be used when talking with children about illness and death.]
- Hilden JM, Tobin DR, Lindsey K. *Shelter From the Storm: Caring for a Child with a Life-threatening Condition*. [Resource for parents or health professionals addressing decision-making and other components of caring for children during serious illness. Includes children's stories as helpful examples.]
- Lee SA. *Choices: When Your Child is Dying*. [Includes guidance for parents about end-of-life issues: advance planning, talking with the dying child about his/her wishes, deciding about location of care (home vs. hospital), autopsies. Each section includes personal stories written by parents.]
- Minnick MA, et al. *A Time to Decide, A Time to Heal: For Parents Making Difficult Decisions about Babies They Love*. [Parents tell their stories about facing the news of fetal anomaly, making decisions, and grieving.]
- Nussbaum N. *Preparing the Children: Information and Ideas for Families Facing Terminal Illness and Death*. [Information and practical suggestions for parents when they have to prepare a child for death. Could be applied for use with the dying child or siblings.]
- Why Mine?* [Supportive and informative resource for parents of seriously ill children.]
- Zagdanski D. *Something I've Never Felt Before – How Teenagers Cope with Grief*.

## Communicating with family and friends



**Monica** is a young girl from a rural community. After being diagnosed with cancer, Monica's home community actively fundraises to assist her and her family in their multiple trips to the regional tertiary care centre for treatment. She also has to travel to the treatment centre for regular re-evaluations. Whenever she has good results from such an evaluation, her grandparents turn on the Christmas tree lights in their yard to signal these good tidings to their neighbours and the closely connected social community.

### Reflective Question

1. In the event of a child's death, what practical strategies would you suggest in a close-knit community to help people express their distress and find support?

Communities can provide wonderful support for ill children and their families. However, maintaining lines of communication with a wide group of people can be difficult for patients and parents. They may need help with telling their wider family and friends about their healthcare decisions, particularly if those decisions involve forgoing potentially life-sustaining interventions following recognition that such interventions would not change the course of the child's illness and may contribute further to the child's burden of illness.<sup>47</sup> In general, the larger the number of family members and friends who understand the situation, the greater the support network available to the patient and parents. However, the burden of communicating with all of these people can be great. Useful techniques and strategies include:

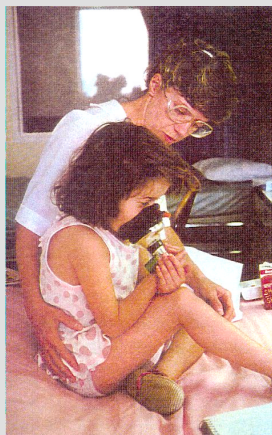
- Convening a meeting with as many of the family and friends as possible so that the healthcare providers can provide the same information to everyone and answer questions. When family and friends are at a distance, they can be included with the use of teleconferencing or by making a videotape of the meeting that can be shown to them later.
- With the permission of the child and family, organizing a meeting at the patient's school or some other place where his/her friends and their families can gather to learn about the child's illness, the decisions that have been made about his/her care, what they can do to support the ill child and his/her family, and where they themselves can go for help in dealing with their friend's illness and death.
- Telling the patient or parents about easily accessible and accurate internet sites, to which they can refer family and friends for more detailed information.
- Providing the patient or parents with "info sheets" that contain concise but informative written descriptions of the illness, its prognosis and treatments, possible genetic implications, etc. These are useful to give to family and friends so that the patient or parents do not need to repeatedly communicate all of this information.
- Having a designated "communicator" for the family who receives update reports from the family and transmits these to community members.

### VIII.3. Speaking the unspeakable: earlier rather than later



**Jennifer** is a 13-year-old with advanced lung disease from a complicated course of cystic fibrosis. She is currently not eligible for lung transplantation. Although the prognosis for patients with cystic fibrosis has improved greatly

in recent decades, with many patients living well into adulthood, the course can vary greatly and young patients can develop severe disease. The degree of lung disease is the main predictor of life expectancy.<sup>99</sup>



Jennifer's early course was a difficult one, with frequent infections involving many hospitalizations. She required a jejunostomy tube for supplemental nutrition from 3-5 years of age.

On several occasions Jennifer has expressed vague anxieties about her illness and the pediatric palliative care service is asked to see Jennifer to discuss these anxieties.

#### Reflective questions

1. Do you believe that discussions relating to end-of-life rob the child and family of the hope of getting better?
2. Do you believe it possible to take away a family's hope for a miracle?

The discussion between Jennifer and the pediatric palliative care professional proceeds:

Clinician: After introducing herself, "Do you know why I've been asked to see you?"

Jennifer: "You s'posed to help me not worry so much. I'm not worried. It's everybody else that's worried."

P: What do you think everybody else might be worried about?

J: They're all worried 'cause they think I'm going to die.

P: Oh! They all think that you're going to die. What do you think about that?

J: I'm too young to die. I want to live long enough to do more stuff. I want to live long enough to become a marine biologist. I want to live long enough to have my own children. I want to live long enough to do some bad stuff. I'm only 13 and I haven't done any really bad stuff yet.

P: I really hope that you get to live long enough to do all those things. I also know that everyone here wants that for you too. I know that your doctors and everyone here is working really hard on getting you better and getting you through this. I wonder, though, just-in-case that is not possible, if you have any worries about that.

J: I'm not worried about dying. I know I won't have any pain, or anything. I wonder about whether I'll

see my parents in heaven.

P: I wonder if you might have any ideas about what you might like to have happen, in case we can't get you through this.

J: Well, maybe next week, if I felt better I could hold a baby and feed it.

P: I think that's possible but I wonder if we shouldn't have that happen sooner rather than later, not 'cause I think anything is going to happen. It is more just-in-case. So we could have that happen, say, tomorrow, and if you felt better next week, we could have it happen again, and in a month from now, again. But, maybe, just-in-case, we should see about doing this sooner.

J: OK. Yes, let's do that.



It is arranged to have an infant visit Jennifer the next day. She holds and feeds this child while a staff member takes pictures.

Over the next few days, Jennifer, her parents, and her sister share intimate thoughts and important moments together, lead by the shared theme of "We're working on getting you better but just in case, I want you to know..." This occurs at a time when Jennifer is able to express her concerns and wishes relating to end-of-life care while continuing to maintain hope. At time, Jennifer says, "I would know. My body would know if I was dying."

Jennifer and her parents, with the support of a spiritual care clinician, discuss Jennifer's concerns about seeing her parents in heaven. Jennifer becomes unresponsive within several days and dies within a week of her initial conversation about possibly not being able to recover.

### Reflective Questions

1. Have your previous perceptions about hope and illness been altered by hearing about Jennifer. In what way?
2. Have you ever had a similar conversation about "hoping for the best but preparing for the worst"? What about it went well? What would you like to change?
3. Imagine yourself having such a conversation and try out the language you would use with a colleague.

Finding the right time to introduce discussions concerning end-of-life care can be very difficult. Waiting for the "optimal" moment can result in delaying discussions until decisions are imminent. A better approach is to introduce the topic as soon as possible after diagnosis of any illness that could result in premature death, but preferably not during the same meeting where the diagnosis is disclosed.<sup>20, 100</sup> **Box 23** contains some suggested language for introducing this topic.

The intensity of this introductory discussion should be guided by both the child's clinical situation and the child and family's reaction to the introduction of the topic. Some young patients and their families, especially those who have been living with a chronic illness for some time, have thought about these issues and may have talked about them amongst themselves. They may want to discuss their

thoughts and wishes with a healthcare professional but are fearful of broaching the topic because this may make the possibility of death more real, or seem to infer that they have given up hope for a cure. Other patients and/or families may not be ready to talk about these issues at the time of the introductory discussion. For these families, early mention of palliative care treatment options can reduce the fear associated with such discussions, allow plenty of time for thought, plant the seeds for later discussions and decisions without eroding hope, and enable decisions to be made over time.<sup>67</sup>

There remains a myth that the introduction of such topics can remove a patient/family's hope for cure or improvement. Discussing probable death with parents who have not yet recognized that there is no realistic chance for cure usually

does not reduce the parents' ability to hope.<sup>46, 101</sup> The majority of parents who recognize that their child is likely to die are able to maintain hope for extended life. At the same time, they are able to discuss their concerns and wishes about preparations for that death and acknowledge that the lessening of suffering should be the primary goal of treatment. Thus, the discussion and integration of palliative care measures does not need to erode hope.

Earlier recognition of the probability of a child's death by physicians and parents has been associated with earlier integration of palliative care interventions and improved quality of life for children during the palliative phase.<sup>101</sup> Early discussions are also important because they may allow the patient an opportunity to express his/her wishes concerning palliative care options and to achieve goals, such as taking a meaningful trip, saying goodbye to friends and family, and preparing special mementoes, while still physically and mentally capable.

One of the primary fears of a dying child is that they will be forgotten. Children need to be continually reassured that they will not be abandoned and will always be remembered. Early discussions concerning palliative care can provide an opportunity for the child's family and friends to show him/her affection and support, and provide time for creating some concrete memories together and the means to record them.

### **Box 23. Suggestions for opening discussions.**

- ❑ I would like to take a few minutes to talk about some decisions about treatment for Maia that may come up in the future. As you know, it is possible that Maia's condition will get worse and that she may die. If that time comes, you and Maia may want to change the way she is being treated. [Pause for response]... For instance you may want her to reduce the number of procedures and time in the hospital, and you may chose for her to go home with you and receive care to make her comfortable there. Maybe you are ready to talk about these kind of things today, but maybe it will take some time before you're ready... [Pause for response]... That's okay. I just want to let you know that I'm ready to talk about those kind of things whenever you feel ready.
- ❑ Other families have told me that it can be very difficult to think and talk about decisions related to dying when they're still hoping for a cure. But the families whose children have died tell me that, when the time came, they were very glad they had taken the time to think and talk about those decisions beforehand.
- ❑ We can start talking now about the issues that may come up if Ryan's condition gets worse but we don't have to make any of the decisions right now. You can think about it all, talk with your family, friends, spiritual advisor, family doctor, or whoever else you want. Then we can make the decisions bit by bit, as we go along.
- ❑ At any point as we go along it's really important that you ask whatever questions you have on your mind. Even if you think they might be obvious or very difficult to ask. Just to give you an example, some parents who are thinking about taking their child home for care at the end of his life want to know who they are supposed to call at the time of death. It's very difficult for them to ask about that but it's very important information for them to know. So whenever you have questions, about anything, please just ask them. We will do our best to answer them.



Once such discussions are broached, periodic revisiting of the questions, initiated by the patient, family, or clinician, may make later definitive discussions and decisions easier. This ongoing discussion not only ensures that the patient and family are informed about all of the possible treatment options at all points in illness progression, but also contributes to the building of a trusting and collaborative relationship.<sup>47, 100</sup> It allows patients and families to digest information concerning palliative care options, combining it with their values, beliefs, and expectations to reach a personal understanding of what they wish to occur should they later face decisions regarding end-of-life care.

When the time arrives for definitive discussions and decisions, the setting and timing of conversations should be as conducive as possible. Try to find a setting that is private, quiet and uninterrupted. Ensure that all key people, as defined by the patient or designated decision-maker(s) and the healthcare team, are present.<sup>100</sup> At the same time, try not to overwhelm the patient and family with a large number of healthcare professionals. Within the constraints of the clinical situation, allow as much time as possible for these discussions. There is great variation in the amount of time required by clinicians and families to agree on a course of action when the patient's illness is progressing towards death.<sup>78, 79, 102</sup>

### ***Antenatal palliative care discussions***

Ultrasound, amniocentesis, and other diagnostic techniques employed during pregnancy enable clinicians to diagnose potentially life-threatening conditions well before birth. Consequently, it is now possible to have early prenatal discussions about terminating a pregnancy, providing palliative care and limiting medical treatment at the time of birth, or pursuing life-sustaining or potentially curative treatment at the time of delivery.

Factors in such decisions may include: the gestational age when the diagnosis is made; the nature of the abnormality detected; the nature and extent of any accompanying abnormalities (eg., chromosomal or severe cardiac anomalies); the degree of certainty concerning the diagnosis; parental wishes.

Discussions between health professionals and parents who are carrying a pregnancy with a compromised fetus are not dissimilar to those that occur once a child has been born. Early discussions can clarify expectations, explore the range of options with a view to reducing subsequent and potentially life-long guilt and remorse about the decisions made, and prevent the need for urgent decision-making in the delivery room.



**Ku'an** and **Lin** are a young couple recently immigrated from China and having their first antenatal visit at 32-weeks gestation. During this visit, you learn that they have been married for 4 years and have come to Canada from China for Ku'an to complete his PhD in biochemistry. Lin was also trained as a scientist but is intending to stay at home with this, their first child.

Both Ku'an and Lin speak some English but seem to search for their words. Both were raised in homes where multiple generations of the family resided together. Both consider themselves to be Buddhist but

neither is actively practicing any religion. Following your assessment, an ultrasound is arranged.

The radiologist calls you to report the ultrasound findings of a gross anomaly of the abdominal wall, probably an omphalocele with liver involvement. Many fetuses with omphalocele also have other defects and/or chromosomal abnormalities.

Mortality rates vary between 20% and 60% across the antenatal and perinatal period. Amongst infants who survive long enough to undergo surgical and medical treatment of their anomaly, survival to discharge is about 80%. However, these interventions carry significant risks of morbidity (sepsis, intestinal necrosis, and organ failure) and can have profound implications for quality of life, both during the period of intensive treatment and for years afterwards.<sup>103, 104, 105, 106</sup>

You call Ku'an and Lin and ask that they come in to see you tomorrow to discuss the ultrasound findings and the treatment options available once the baby is born.

#### **Reflective questions:**

1. Given what you know about this family, how would you go about disclosing your findings and the possible outcomes for the baby?
2. How would you frame your discussions with them about the decisions that they will need to make once the baby is born?
3. How could you help the parents prepare questions for discussion with their clinicians at the time of birth?

How could you most effectively communicate the parents preferences to your clinical colleagues?

In the event of a fetal or early neonatal death, parents are sometimes given the impression that their grief and distress is not equivalent to that of the parents of a child who lived for months or years. This is an erroneous assumption as all parents anticipate a child's life and plan for their future. Their profound grief may largely go unrecognized. Bereavement follow-up for the family including brothers, sisters and grandparents as well as the parents is integral to comprehensive care.

#### VIII.4. Framing decisions and building consensus



Born at 41 weeks gestation, **Emily** is apneic at birth with Apgars of 4, 5, and 5, and requires immediate and continuous assisted ventilation. She is intubated and transferred in the early morning hours to a tertiary pediatric care center.

Detailed examination shows severe hypotonia with ineffective respiratory effort, no spontaneous movement of the limbs, complete absence of all reflexes including the gag reflex, some flexion contractures of the limbs with markedly decreased muscle bulk, some facial and spontaneous eye movements, right club foot, and bilaterally dislocated hips. The pregnancy had been remarkable for an abnormal maternal serum screen and third-trimester polyhydramnios. Ultrasound examination had been normal and amniocentesis had shown a normal female karyotype.

Neonatal investigations include a muscle biopsy that suggests congenital muscular dystrophy, a normal serum creatine kinase level, an unremarkable CT scan of the head, and normal EEG findings. Detailed pathology reports on the biopsy will not be available for some time. Given her severe respiratory involvement and the fact that there are no curative

treatments for any of the congenital muscular dystrophies or myopathies, Emily's prognosis is extremely guarded.<sup>107</sup>

These findings are discussed with Emily's parents, as well as the difficult reality that Emily would not survive without mechanical ventilation and that continued ventilatory support is not a feasible choice in the long term. They come to understand this reality and agree to meet with the palliative care specialist to discuss topics including options for the timing and location of the withdrawal of ventilatory support.

##### Reflective Question

1. Write out or say aloud the words you would use to elicit the family's preferences about how, when, and where ventilatory support is withdrawn?

This meeting occurs when Emily is 7 days old. Discussions focus on the hopes, wishes, and concerns of Emily's parents about her remaining time alive and her death. They both want Emily to experience life in as many different capacities as possible, such as rocking in the car seat and feeling the breeze around her. Her mom says, "Emily came here in the middle of the night on Tuesday, she has seen the moon. I want her to see the sun, to blink like she would if we were taking her home at 4 days of life. It's not for her. It's for us as parents to know we have provided her with all the possible experiences." These wishes and hopes lead to Emily being maintained on ventilatory support for a week while being baptized with family present, spending time with her 4 year old sister, rooming-in with her parents who provide daily care including bathing, cuddling, diaper changes and comfort care. Emily spends time outside with her parents and sister in the sunshine and breezes of the play garden.

##### Reflective Question

2. How would you address the concern of a healthcare team member that this time will only increase the family's subsequent distress by increasing their attachment to Emily?

In terms of the actual withdrawal of ventilatory support, Emily's mom wants specific information about how the ventilator would be turned off and her dad wants the withdrawal to be as free of monitors, tubing, and other technology as possible. At 15 days of life, Emily is pre-medicated for possible symptom distress and then has her ventilator discontinued. She passes away in the arms of her parents, 2½ hours later, in the midst of the play garden.

### **Challenges to building consensus**

Building consensus between the patient, parents or other substitute decision-makers, and the healthcare team can be a difficult task.<sup>15, 40</sup> This is due in part to the value-laden nature of pediatric palliative care decisions, as well as the associated emotions, consequences, and frequent time constraints. It is made easier when those involved are:

- willing to be involved in an open discussion
- well informed about the potential benefits, burdens, and risks of the available options
- aware of their own values and beliefs that may influence their weighing of the options
- emotionally and mentally capable of participating.<sup>17, 15, 13</sup>

Several researchers have investigated and compared the factors used by parents and physicians to make decisions about palliative care options. In general, the findings suggest that physicians and parents differ in the weight they place on different factors. Physicians tend to be most influenced by:

- expressed patient and/or family wishes
- the probability of survival and predicted quality of life if the patient survives
- the current functional and neurological status of the patient
- the availability of potentially effective treatments
- information provided by other members of the healthcare team
- the presence of unrelenting pain or other symptoms.<sup>47, 41, 42, 68, 69, 102, 111</sup>

Parents, on the other hand, tend to be most influenced by:

- recommendations and information received from healthcare professionals
- the child's current quality of life including pain and discomfort
- the child's expressed wishes concerning continuing or not continuing treatment
- the child's chance of improvement or survival
- concerns about the adverse effects of treatment options.<sup>47, 53</sup>

Consideration of these differences in perspective can help clinicians in their framing of discussions and decisions. Appropriate framing can make it easier for the family and patient to understand the information presented, integrate it into their view of the situation, feel supported and face the necessary decisions.<sup>17, 14, 47, 68</sup> Although it may not prevent differences of opinion concerning the best path of treatment, it may help prevent conflict by fostering mutual respect and understanding.<sup>76, 110, 108</sup> Approaches to dealing with disagreements that do arise are discussed in a later section of this module titled, "How do we work through conflict?"

### **Framing the decisions**

When framing decisions for families and patients, clinicians must sensitively present the options within the reality of the disease process.<sup>54</sup> This may be important in preventing later doubts and guilt regarding the decision taken. The pattern and rapidity of disease progression can make certain intensive or invasive treatments unrealistic. Legal or ethical issues, or resource inavailability may make other options less appropriate or feasible. Thus, the aim is to present a balanced and realistic picture of the feasible options.

Without such appropriate framing of the decision, parents may pursue unrealistic or unfeasible treatments because they feel that not doing so would be equivalent to abandoning their child. If parents understand that certain options have been made unrealistic by the disease process itself, its

implications, or the child's readiness, they may be better able to make realistic decisions, feel that they are not abandoning their child, and avoid later doubts and guilt concerning these decisions.<sup>75</sup> **Box 24** provides one suggested way of framing decisions in this way.

**Box 24. Example of framing decisions when options are limited**

I think sometimes we believe we have decisions to make, that we truly have choices, that by deciding one way or the other we can make something happen or not. I sometimes wish that we really had such choices. However, I think Sara's illness is actually deciding for us and Sara is telling us that, in her own way. Because she is so sick, we have few if any options that would make her better. What we do have options and choices about your wishes for where Sara is cared for, who you would like present, and things like that.

**Evaluating options**

Once the realistic options have been presented, it is useful to have a structure for systematically discussing and evaluating each of them in turn. One such structure is a series of questions used to evaluate the likely benefits, burdens, and risks of each option (**Box 25**).

**Box 25. Evaluating treatment options<sup>19</sup>**

1. How realistic is it that the intervention will cure the disease?
2. If not able to cure the disease, will it prevent progression of the disease?
3. Will the intervention improve the way the child feels?
4. Could the intervention make the child feel worse? If so, for how long?
5. What will it be like for this child to go through this treatment?
6. What is likely to happen without the intervention?
7. Will the intervention change the outcome for the child?
8. What is the likely impact of this decision on us as a family?

Decision-making

through the weighing of pros and cons is a process that is familiar and comfortable for many people. It is also the primary basis for ethical and legal decision-making and should be applied to all decisions, even those that appear straightforward on the surface.<sup>17, 40, 42, 13, 67</sup>

Proceeding through such a process helps each of the participants to fully understand their own perspectives, as well as those of the other participants, on each of the available options.<sup>17</sup> Hopefully this mutual understanding will lead to agreement about the preferred option and the decision will be made without disagreement. However, if disagreement exists, this process will clarify exactly what that disagreement involves. It may lead to a compromise or an agreement to disagree on that particular point but to proceed on the basis of consensus achieved in other areas.<sup>13</sup> In the most difficult scenario, participants will identify an area or areas of unresolved disagreement that block the formulation of any consensus decision. This situation is addressed in more detail in a later section of this module titled, "How we work through conflict?"

**Parental perspectives on their involvement in decision-making**

There is great variation in parental expectations concerning decision-making. Some parents view the decision-making process as a collaboration and are dissatisfied when the physician proposes a formulated plan of care without welcoming discussion; while others want physicians to provide strong recommendations and effectively make the decisions for them.<sup>15, 50, 76</sup> It is also a process that can be easily and subtly manipulated by those involved, particularly the participant with the most power, the physician.<sup>17</sup> Although many parents are satisfied with their involvement in decision-making and the information provided by physicians, several studies have found dissatisfaction amongst a significant number of parents concerning the level of information received and their sense of feeling constrained and not fully engaged in decision-making.<sup>46, 52, 76, 109, 110</sup>

The majority of parents want to play an active role in decision-making about their child's care, want honest information about the even the most difficult of topics, and with adequate explanation and support are able to comprehend and work with complex medical information.<sup>46, 76, 110, 111</sup> Two additional perceptions expressed by physicians, and supported by the literature, are that patients and families want to defer decisions to the physician, and/or will be overly burdened with the responsibility of decision-making.<sup>43, 50, 52, 110</sup> Some parents feel an extra burden of guilt and regret if their decisions do not have a beneficial outcome and they prefer the physician to make decisions for them.<sup>15, 50, 53, 76</sup>

### **Obligations of clinicians to the decision-maker**

Clinicians have an ethical obligation to involve the patient or his/her designated substitute decision-maker in all decisions.<sup>42, 12</sup> This obligation is based on the principle of respect for autonomy and is made all the more important by the serious consequences of some palliative care decisions. However, respect for this principle should not lead to patients and families being left to make decisions without the support and carefully considered recommendations of their clinicians. Clinicians should approach

disclosure and discussion of palliative care options with sensitivity and compassion.<sup>112</sup> They should frame decisions in such a way that the decision-makers feel fully informed yet also secure and trusting of the process. They should share their recommendations about the available options and be prepared to respond to a family and/or patient who want the decision to be made by the

clinician (**Box 26**). Finally, they should consider the family's long-term comfort with the decisions made – they will think back on these discussions for the rest of their lifetime.

**Box 26. Suggested responses when a patient or family says, "Please give us some direction." or "We can't live with the responsibility. We want you to make the decision." or asks, "What would you do?"**

- Let's go through the pros and cons of each choice and see how they balance when everything is on the table.
- From what I know of you, there are two choices that seem to make sense at this time. They are ...
- We have talked about many different options for Theresa's treatment at this time. It can sometimes be very difficult for parents to make these kind of decisions for their child. They feel that the responsibility is too much. I am willing to tell you what I think would be the best choice for Theresa and you can tell me your thoughts. Please tell me what you think and we will work together to find the best solution.

### **Framing urgent decisions**



**Tony** is an 8-year-old with known progressive pulmonary compromise secondary to an inoperable cardiac defect. For the past 5 days he has been at a camp for people with medically complex conditions. Tony developed a mild flu-like illness with a runny nose and low-grade fever. He was improving until his cabin-mate found him this morning, unresponsive and in significant respiratory distress. He is accompanied to hospital by his mother, who was called at work and met the ambulance at the hospital.

There are multiple points of communication and decision-making during his initial assessment and emergent hospitalization.

Within a few hours, Tony is breathing on his own with oxygen saturations of 82% on supplemental oxygen by face mask. He looks obviously ill with central cyanosis and tachypnea. He is using extensive accessory muscles for respiration and grunting with expiration. You are now able to spend some time talking with Tony's mother.

### Reflective Questions

1. What would you do in the next 10 minutes to best support Tony's family through this difficult time?
2. What information do you need as you arrange to meet with Tony's mother?

The preceding discussion has addressed general concepts concerning communication and decision-making. Special attention is warranted in the situation of urgent decision-making. Such situations arise in the lives of previously healthy children (eg., when a child experiences traumatic injury) or in children who have been chronically ill but develop acute exacerbations requiring rapid and complex decision-making.

Parents in these situations are often disoriented, sleep-deprived, far from their usual support system, dealing with the shock of the acute event, and feeling a mix of anger and denial. When combined with the time pressures experienced by clinicians caring for multiple critically ill patients this can lead to misunderstandings, anxiety, and increased difficulty during urgent decision-making.<sup>100</sup> Although extreme care must always be taken to listen and speak with sensitivity and clarity, this is even more important when the

clinician and family are not well known to each other and/or decisions must be made quickly. There is little time to foster rapport and build trust. (**Box 27**).

The same principles apply in this situation as in all

others – attend to the informational, emotional, and practical needs of the family and encourage discussion of options as early as possible.<sup>100</sup> One strategy is to assign one member of the healthcare team to be the caregiver for the family. Taking care of the simple needs of the family – providing private space with a telephone, food and other creature comforts – can make an enormous difference in their capacity

to absorb information and make decisions. The assigned caregiver can also be the primary source of updated information and the initiator of discussions concerning imminent or upcoming decision points, thus increasing the consistency of messages

#### Box 27: A parent's perspective on unclear communication

"No one ever told me the baby could die. I never understood what was happening medically. The doctor came out during the operation and asked my wife if they should stop or continue the operation. I didn't understand that the baby would die either way at that point."<sup>31</sup>

#### Box 28. Suggestions for framing urgent decisions

- We normally would not be asking you to make these decisions so quickly and we recognize that it must be very difficult for you to face all of this at once.
- We are trying to give you as much time as possible but we don't have a lot of time and we need to decide soon what we are going to do.
- Is there someone who could help you sort through all of this information? Your family physician? Your pediatrician? Some other healthcare professional? Someone in your family? A friend? A spiritual support person?
- Is there anyone you would like to be here to support you during this time?
- Although many of the things that we're discussing are very difficult to talk about, the situation with your child may change very quickly. If the decision comes up very suddenly, we might not have enough time to talk it through properly. It's better for us to know your worries and wishes before we actually need to make a decision.

being transmitted from the healthcare team to the family, and vice-versa.<sup>100</sup> **Box 28** contains some suggested questions and strategies for framing discussions with such families.

### VIII.5. Documenting discussions and decisions

Substantive discussions and all decisions concerning the care of a child with a life-threatening or life-limiting illness should be explicitly documented in the form of clear orders and explanatory progress notes.<sup>40</sup> This is essential for effective communication within the healthcare team and continuity of care.

Orders describing the forgoing of treatments should be specific and detailed. The physician writing the order is responsible for ensuring that all those involved in its implementation understand it fully. Orders for appropriate management of anticipated and ongoing pain, and other symptoms, should always be present in a patient's chart, including when a DNR or other order concerning potentially life-sustaining treatment is in effect.<sup>9</sup>

### VIII.6. Continuity

#### *Barriers to achieving continuity*

Continuity within the healthcare team, involving the effective and ongoing communication of decisions and clear definition of responsibilities, is a prerequisite for high quality care and decision-making.

Several authors have commented on the lack of continuity or overall coordination of care provided during the palliative care phase (**Box 29**).<sup>31, 35, 46, 66, 88, 114</sup>

Obstacles to achievement of these goals include time and resource constraints, on-call schedules and resident rotations, poor communication skills, and differences in attitudes and

practices concerning palliative care measures. Patients and families are often left feeling abandoned, misunderstood, and unsupported at a point in time when their burden of uncertainty and emotional distress may be at its peak.<sup>114, 115</sup>

During the transition from restorative care towards care aimed at relieving symptoms and preparing for death, there are often changes in the location and/or service(s) involved in providing care.

Maintaining continuity through these changes requires communication of the full historical perspective about the patient and family. The team receiving the patient must work to establish open and trusting relationships to replace those lost with the out-going team.

#### **Box 29: A clinician reflects on barriers to continuity**

"Increasing numbers of children with life-threatening illnesses are receiving all their medical care in regional centres, which may be many miles from home. Treatment often lasts for several years, and the parents and children become completely dependent on the regional center for medical care and emotional support, during which time the district pediatrician and family doctor become strangers to the child, the family, and the illness."<sup>113</sup>

**Jody** is the 15-year-old with severe cerebral palsy (CP) whose care is shared between tertiary and community caregivers. The goals of care and a detailed plan of care are established over the course of several discussions with Jody's foster parents, her biological parents, Children's Services, and her team of healthcare professionals and volunteer caregivers.



There is consensus that if Jody has further cardio-respiratory compromise, the priority of care should be on comfort and resuscitative attempts should not be pursued. The list of who to contact at the time of such a deterioration is drawn up and made readily available at Jody's foster home, school, local emergency department, physician's office, tertiary care centre, and Children's Services. Jody has a card describing the emergency measures to be taken in a side pouch of her wheelchair and the paramedic service has this information in a protocol database that is readily available to them from any location.

### ***Achieving continuity: Practical suggestions for healthcare providers***

Healthcare providers can use several practical methods to increase the sense of continuity experienced by patients and families. During times of transition between teams of caregivers, a meeting involving the key people from both teams, the patient, and/or the family may facilitate introductions and ease the transfer of care. Clarifying the healthcare team's methods of working and maintaining continuity (e.g., explaining the on-service and on-call schedules, timing of medical and family rounds, methods of communication between team members, and collective care arrangements) can help a patient and/or family feel more comfortable with the wide range of professionals with whom they are likely to have contact.<sup>49</sup> It may also help them to build a schedule that allows family members to be present during rounds or at other times when communication with the healthcare team is easiest.

Families have repeatedly emphasized the importance of receiving consistent information and perspectives from all members of the healthcare team. A lack of such consistency can cause great anguish, doubt, difficulty during decision-making, and complicated grief, even years later.<sup>31, 75</sup> Several authors have noted the importance to families of a single continuous professional as the key information source and arbitrator of care, especially when the prognosis is poor.<sup>31, 41, 49, 52, 75, 108, 114</sup> However, this is not always possible and there are often multiple clinicians and other allied health professionals providing the patient and family with information and opinions. Thus, multidisciplinary meetings to achieve consensus on the prognosis and care plan are essential to ensure the consistency and continuity of information provided.<sup>52, 75</sup> As mentioned previously, discussions with the patient and family about the communication methods and "culture" of the healthcare team may help families feel more comfortable with multiple caregivers.

Finally, clinicians can enhance continuity by encouraging the patient and/or family to initiate conversations about past, present, and future care decisions whenever they feel the need. Clinicians, patients, and families can also make explicit agreements about when to revisit or review discussions and decisions regarding palliative care. This encourages all parties to continue thinking about such options and decisions, and to continuously evaluate the relative benefits, burdens, and risks of the treatment being provided.

### ***Achieving continuity: Practical suggestions for patients and families***

Patients and families can also contribute greatly to the maintenance of continuity between themselves and the healthcare team. For instance, they can:

- Keep a log book of symptoms, lab results, treatments, side effects, decisions taken, etc. that can be used by the patient and/or family members during meetings with healthcare professionals.
- Remind various healthcare professionals to send reports and update each other on the child's condition.
- Designate one individual to collect information. He/she can then be the coordinator when information or up-dates are needed by the healthcare providers.
- Use email or other means to maintain continuity with important caregivers who are not available to meet face-to-face.

- ❑ Tape record meetings or important conversations with clinicians or other professionals so that patients and families can listen to them again later for clarification and additional information.
- ❑ Videotape unusual or questionable symptoms or events that occur when a healthcare professional is not present.

## IX. How Do We Work Through Conflict?

**Katharine** is a 19-year-old, reflecting back on the decision she made at age 16 to have limb preserving surgery and resection instead of an amputation for osteogenic sarcoma<sup>†</sup>

*Clinician:* You wrote a poem about the issue of quality of life.

*Katharine:* The last assignment in my creative writing class was to describe the event that most affected you during your high school years. For me it was easy. It was getting cancer and having problems with my legs. I used a metaphor. Without even thinking about it, I just wrote down a comparison that I use all the time. It describes a lot of what I've felt, and I'm sure that other kids would identify with it. The poem doesn't have a title:

They say the fox will gnaw off his  
     own limb to save his life if  
     he gets caught in a trap,  
 but I have yet to see a three-legged  
     fox lazily browsing through an  
     apple orchard in late fall.  
 If his need for survival so greatly  
     exceeds his sense to maintain  
     the quality of his life, I hail the fox.  
 I could not make such a sacrifice as he.  
 He will never run at full speed through  
     the yawning fields of the countryside again.  
 Every time I see a fox so beautiful and free,  
 I wonder how the chains of man's  
     insensitivity can bind him so snugly  
     that he forgets what it is to be a fox.  
 And I feel sorry that the fox has  
     to make such a decision for  
     reasons, like mine,  
     which are beyond our control.

The poem just about sums up this experience: something beyond my control. It's like the fox who runs around and gets into a trap. What does he have to say about it? Nothing. He can't sit around asking why it's he. He must make the choice: either I cut my leg off or I die. I've heard that if foxes are physically able and not weakened, they will cut off their leg. You can't lose perspective on what you are. The way I look at it, your leg is part of your body. That's how I was brought into this world, that's what it is to be me-to have both of my legs. If I had had my leg cut off without thinking, or without any choice, I know that I would have changed totally. But since I did have the option, I couldn't have it cut off. So you have to control what controls you to a certain extent. You know, your independence, your self-respect: these are within your own control... It's such an individualized experience which people handle in many different ways. The way I deal with it is to remember that I have a life of my own.

**Reflective Questions** (Please note: these are theoretical questions)

This is a powerful description by a young woman facing amputation or a limb salvage procedure for

osteogenic sarcoma. Imagine that Katherine required an amputation as a life-saving measure and limb salvage was not an option.

1. What strategies might you use if Katherine and her parents disagreed with the treatment approach recommended by the health care professionals caring for her?
2. If Katherine had wishes in relation to her care that were in opposition to her parents' wishes, what strategies would you suggest for helping the parent or child to re-examine their strongly held beliefs and views.
3. Do you believe parents always think they are truly acting in the "best interests" of their child?
4. How do you address the concern that challenging parents about their beliefs and decisions may cause the child to be inadequately supported by their parents through this difficult time?

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† Excerpt from *The Deepening Shade: Psychological Aspects of Life-Threatening Illness* by Barbara M. Sourkes, ©1982. Reprinted by permission of the University of Pittsburgh Press.

Disagreements are inevitable during decision-making about pediatric palliative care. This is understandable given the large role values and beliefs play in such decisions, as well as the high level of uncertainty that is often involved.<sup>17, 43, 13</sup> The risk factors for the development of disagreements are not yet well characterized but may include<sup>17, 31, 41, 43, 10, 13, 62, 75, 64, 97, 108, 116,</sup>

- critical illness or an unexpected or severe event
- lack of prognostic certainty
- involvement of a large number of primary and specialist healthcare providers
- previous experience involving others who were cured or died from the same or a similar illness
- patient or family perceptions of insufficient or ineffective communication with healthcare providers
- patient or family perceptions of unprofessional behaviour by healthcare providers
- patient perceptions that decisions are being discussed or made without their input
- healthcare providers' perceptions about the patient or family's "unrealistic expectations for cure"
- certain religious beliefs
- differences in cultural beliefs and values
- lack of a shared language and/or available translators
- lack of parental knowledge concerning the legal rights of adolescents and mature minors
- families with other ill members, internal conflict, geographical separation, or which are divided by parental separation or divorce
- public perceptions about the chances of recovery from certain illnesses
- inadequate or incorrect information gleaned from the Internet.

However, disagreement does not necessarily lead to conflict. Open and respectful communication can prevent many disagreements from escalating. When the clinical situation allows it, taking time away from discussions and returning at an agreed-upon time can help diffuse conflict and allow fresh perspectives. Discussions should be approached carefully and all efforts at mediation and negotiation attempted before recourse is taken to the courts.<sup>17, 10</sup>

When conflict does occur it can create anger and resentment for all those involved and can have erosive and distressing effects on family and healthcare professionals alike.<sup>15, 47, 53, 6</sup> Even if the underlying disagreement is not resolvable, it is essential that the emotional distress be both named and reduced. A systematic approach should be used for dealing with any conflict. Such an approach helps all those involved to be open to all perspectives and to understand the rationale for those perspectives, as well as ensuring that all possible factors in the decision are discussed. The details of such approaches differ between authors, but the essential components are similar:<sup>17, 33, 40, 11, 13, 75, 93</sup>

- ❑ Express a genuine interest in resolving the conflict and a willingness to be accepting of differences of opinion.
- ❑ Allow expression of the emotional components of the conflict and respond to them empathetically; then seek an agreement to focus on the discussions and decisions at hand rather than the emotions.
- ❑ Seek a detailed understanding and agreement concerning the root of a conflict, focusing on each party's understanding of the facts of the situation, the level of uncertainty involved, and the values or beliefs that are shaping his/her perspective on the issue.
- ❑ If there is lack of agreement on how to proceed, the process needs to be broken down into smaller steps, providing the opportunity for agreement on a smaller, initial step.
- ❑ If appropriate, seek agreement to a second opinion or to a time- or outcome-limited trial of the proposed treatment or change in care.
- ❑ Involve other professionals, such as ethics consultants, psychiatrists, social workers, spiritual advisers, and trained mediators, to help resolve disputes or facilitate a compromise.
- ❑ If the conflict cannot be resolved through the involvement of ethics consultants or others, and no compromise decision can be reached, the treating physician has four options:
  1. transfer care to another physician who will provide the care about which there is conflict or who may be able to reach a consensus with the patient and/or family
  2. treat the patient according to the wishes of the patient and/or family but against the objections of the healthcare team
  3. initiate legal proceedings to resolve the dispute
  4. treat the patient according to the physician's understanding of what is best, against the wishes of the family, and place the burden on the patient or family to begin legal proceedings.

## X. How Do We Train And Support Clinicians For Decision-Making In Pediatric Palliative Care?

### *Training*

There are a wide range of techniques and strategies used to train clinicians for decision-making in pediatric palliative care. Most clinicians currently practicing in this field have learned their skills through informal methods such as trial and error, and observing colleagues and role models. A minority have taken formal courses or had structured clinical training in pediatric palliative care. Many physicians consider informal methods of training more useful than formal ones when it comes to teaching communication, negotiation, and other skills needed during decision-making.<sup>41, 117</sup> Most of these methods do not require the development of new curriculum, but rather require the purposeful involvement of trainees in on-going care-giving activities.<sup>5</sup> Particular training techniques include:<sup>5, 67, 118</sup>

- ❑ Role plays and simulated patients can help trainees learn how to probe difficult subjects and respond to challenging situations such as when a family blames the healthcare team for their child's worsening status.
- ❑ Discussion groups and/or personal writing exercises can help clinicians and trainees to reflect on their practice, professional roles, ethical dilemmas, and the emotional aspects of caring for a dying child, leading to improved insight, job satisfaction, and quality of care.
- ❑ Actively involving trainees in case management conferences, family meetings, and decision-making can help them develop skills in collaborative decision-making. Involving them in discussions with children and adolescents prepares them for the types of questions that these patients ask and how to respond to them in a developmentally-appropriate manner.
- ❑ Exposing trainees to the various settings for palliative care – in-patient wards, hospices, home-care – can widen their skills around continuity of care and working with patients and families when imminent death is openly acknowledged.
- ❑ Debriefing sessions involving all members of the team, including trainees, provide an excellent opportunity for training and ongoing education.

A list of useful resources for clinicians is included in **Box 30**. Other resources are listed in the references to this module.

### **Box 30: Useful resources for clinicians**

#### **Books and articles**

- Field MJ, Behrman RE, eds, Committee on Palliative and End-of-Life Care for Children and Their Families, Board on Health Sciences Policy, Institute of Medicine. *When Children Die: Improving Palliative Care and End-of-Life Care for Children and Their Families*. Washington, DC: National Academy of Sciences, 2002.
- Hilden J, Tobin DR, Lindsey K. *Shelter From the Storm: Caring for the Child with a Life-threatening Condition*. Cambridge, MA: Perseus. 2003. *Helpful for clinicians and families.*
- Kuhl D, Wilensky P. Decision making at the end of life: A model using an ethical grid and principles of group process. *Journal of Palliative Medicine* 1999; 2(1):75-86.
- Sourkes B. *Armfuls of Time: The Psychological Experience of the Child with a Life-threatening Illness*. Pittsburgh: University of Pittsburgh Press. 1995

#### **Websites and organizations**

- The Canadian Pediatric Society at [www.cps.ca](http://www.cps.ca) and the American Academy of Pediatrics at [www.aap.org/policy/pprgtoc.cfm](http://www.aap.org/policy/pprgtoc.cfm) *Useful sources for guidelines including statements on bioethics, palliative care and decision-making.*
- Canadian Network for Palliative Care for Children at [www.cnpcc.ca](http://www.cnpcc.ca) *Has excellent materials and links relating to palliative and ed-of-life care for children, including posting of protocols, relevant conferences*
- Children's International Project on Palliative/Hospice Services (ChIPPS), a project of the National Hospice Palliative Care Organization – Ethics and Decision-making Bibliography. Website: [www.nhpco.org/public/articles/index.cfm?cat=89](http://www.nhpco.org/public/articles/index.cfm?cat=89) *An exhaustive bibliography of materials pertaining to decision-making and ethics in pediatric palliative care.*
- End of Life / Palliative Education Resource Center (EPERC), Medical College of Wisconsin. Website: [www.eperc.mcw.edu/start.cfm](http://www.eperc.mcw.edu/start.cfm) *General education for clinicians interested in palliative care.*
- Growth House, "The Internet's leading portal for end of life care." Website: [www.growthhouse.org/](http://www.growthhouse.org/) *An internet portal for access to a wealth of resources concerning palliative care.*
- The Children's Pain Assessment Project at [www.ich.ucl.ac.uk/cpap](http://www.ich.ucl.ac.uk/cpap) *A comprehensive UK-based pediatric initiative with links to other internet and paper-based resources, and access to a list-serv.*
- Initiative for Pediatric Palliative Care. Website: [www.ippcweb.org/](http://www.ippcweb.org/) *An educational resource currently under development, including "trigger" video tapes, case studies, and downloadable slide presentations.*
- Lucille Packard Children's Hospital, Stanford University Medical Center: Care of the Terminally Ill Child. Website: [www.lpch.org/DiseaseHealthInfo/HealthLibrary/terminallyill/index.html](http://www.lpch.org/DiseaseHealthInfo/HealthLibrary/terminallyill/index.html) *An overview of decision-making and other topics pertinent to pediatric palliative care.*
- Palliative Care Council of South Australia, Inc., Multicultural Palliative Care Guidelines. Website: [www.pallcare.asn.au/mc/mccontents.html](http://www.pallcare.asn.au/mc/mccontents.html) *An online guide to multicultural issues in palliative care.*
- Royal Society of Physicians and Surgeons of Canada, The Good Pediatrician: An Ethics Curriculum for Use in Canadian Pediatrics Residency Programs. Website: [rcpsc.medical.org/english/ethics/pedethnet\\_e.php3](http://rcpsc.medical.org/english/ethics/pedethnet_e.php3) *A useful resource for clinicians and educators concerning ethics in the care of children.*
- Texas Children's Cancer Center, Texas Children's Hospital: End-of-Life Care for Children. Website: [http://childendoflifecare.org/frame\\_dyn.html?about/](http://childendoflifecare.org/frame_dyn.html?about/) *Educational site for clinicians, including a section dedicated to decision-making with videos of suggested approaches to difficult issues.*
- The University of Toronto Joint Centre on Bioethics. Website: [www.utoronto.ca/jcb/main.html](http://www.utoronto.ca/jcb/main.html) *Ethical and legal information about advanced care planning in Canada.*

## **Support**

Caring for children with life-limiting or life-threatening illnesses, and their families, can be professionally and personally challenging, exhausting, and emotion-filled.<sup>100</sup> To ensure that clinicians in this field are able to continue their work, their colleagues and institutions need to provide various personal and professional support options. These may include:<sup>17, 19, 34, 5, 67, 88, 97, 118</sup>

- ❑ Group discussions, either amongst members of the same profession, multidisciplinary, or both, can be used to address problems and to provide positive feedback, emotional support, and an opportunity for grieving to all involved. Some authors suggest that such discussions should occur on a regular basis to avoid the accumulation of stress and tension.<sup>88</sup>
- ❑ Confidential one-on-one counselling should be available to clinicians who require it.
- ❑ Journal writing and other reflective exercises can help clinicians become more aware of how their own values, beliefs, emotional reactions, and past experiences shape their care for dying patients and their families. Such reflection can improve care and help clinicians deal with their own dilemmas, inner conflicts, and emotions.
- ❑ Sports, hobbies, relaxation techniques, music or art therapy exercises, and other creative methods can be used by clinicians, either on personal time or as part of structured sessions, to reduce stress levels and to deal with emotions and other difficulties.
- ❑ Encouragement for clinicians to take time off or request patient assignments that do not involve end-of-life care discussions when they feel they are becoming overloaded with the burden of this type of care.
- ❑ Supportive policies that can be implemented by the institution include calling in extra staff when a patient's death is imminent, providing funeral leave, routine counselling, regular memorial services or other forms of remembrance, and encouragement of ongoing follow-up with grieving families by a designated member of the healthcare team who was closely involved with the family.
- ❑ Identification of several supportive colleagues with whom to review concerns and reactions.

## XI. Detailed Case Scenario and Workshop Materials

Daniel is a 3<sup>1</sup>/<sub>2</sub>-year-old who presents with a 5-week history of weight loss, anorexia, limping, and intermittent abdominal pain. He has always been a “picky” eater and had a preceding history of “failure to thrive”, having fallen off his growth curves.

Daniel lives about 1 hour’s drive away from the tertiary care center where he receives his care. He lives with his 6-month-old sister, Maria, and his parents, Keith and Teresa. Daniel loves books. He is able to describe his pain as an “owie” and will tell his parents when he is hurting. He had been sleeping poorly and was irritable. These symptoms resolved with regular doses of acetaminophen and codeine.



Investigation of an abdominal mass confirms neuroblastoma (a cancer originating in the neuro-endocrine cells above the adrenal gland, typically presenting in early childhood at an advanced stage). A metastatic work-up shows stage IV disease with involvement of parietal bones, pelvis, right hip, eighth rib, multiple vertebral bodies, and bone marrow. In children older than 1 year with advanced stage neuroblastoma, the average long-term survival rate is 15-25%. For those who survive to undergo bone marrow transplant, there is a 40-50% survival rate. Treatment is associated with significant short-term morbidity and can be associated with long-term morbidity.<sup>1, 2, 3</sup>

Daniel receives treatment with chemotherapy, radiation, and surgery. This is followed by a bone marrow transplant (BMT) when he is 4 years old. He requires hospitalization for neutropenia-related infections, nausea and vomiting, and mucositis. He requires artificial nutritional support with nasogastric feeds and hearing aids.

In the year following his BMT, Daniel enjoys going to the petting zoo, picking strawberries, bird-watching, doing crafts, and working on his computer.

At 5 years of age, he returns to the hospital on Christmas Eve with increasing hip pain. Work-up shows a recurrence of his cancer. At this point, Daniel’s parents decide to shift the goals of his care, knowing that cure is no longer attainable. They wish to pursue measures that are intended to help Daniel live as long as possible with a good quality of life.

Escalating pain is managed with opioids, focal radiotherapy, and multiple co-analgesics. With progression of his disease, Daniel has nausea controlled with a variety of medications. He continues to enjoy eating small amounts of his favourite foods.

Daniel’s mom, Teresa, modifies his stroller, enabling him to be quite mobile. It has a steering wheel and horn attached to it within Daniel’s reach, so he seems very much in control. He dislikes being in the hospital for any extended period of time although he visits happily enough.

With quality of life as their main goal, Daniel’s oncologist and parents discuss treatments that may be life prolonging but do not have significant toxicity. They also consider his previous treatment, his response to it, and his current tumor burden. One option is oral daily chemotherapy that does not involve swallowing large numbers of pills and does not generally cause severe neutropenia, so that hospitalization for febrile neutropenia would not be expected. Another option is to travel to another province for systemic radiotherapy. The radiopharmaceutical MIBG is used for scans but with higher



doses can kill neuroblastoma cells. This option is better established outside of Daniel's home province and would require a 9-day outpatient stay in the treatment region. The possibility of not pursuing either of these treatments is also included as an equally reasonable option.

Daniel's parents opt for palliative focal radiotherapy and therapeutic MIBG. This treatment is generally well tolerated. However, in children like Daniel, who have already received extensive myelosuppressive treatments, protracted myelosuppression, particularly of platelets, may be an inadvertent consequence.

Daniel's family embraces the trip for treatment as an opportunity to spend some time together. They incorporate fun, family time into the travel, visiting special places, swimming in the wave pool, and buying some special treats, like a cowboy hat for Daniel and a special gift for his sister, Maria.

Over the 6 months following MIBG treatment, Daniel enjoys doing crafts and watching the family cat have her kittens. He then develops shortness of breath due to a large pleural effusion, compounded by anemia. His parents and health care providers must decide whether to use thoracentesis to drain the effusion while implementing other measures to ensure Daniel's comfort. This option is not pursued.

Daniel is transfused because his anemia could be contributing to the dyspnea. His sensation of breathlessness is relieved with systemic opioids and anxiolytics, and he is positioned to ensure maximal comfort. Daniel dies at home 1 week later.

### **Teaching Instructions for Opinion Leaders**

1. Distribute the case scenario. Allow participants a couple of minutes to read the information or have one of the participants read the scenario.
2. Ask participants to identify the issues and questions about decision-making in pediatric palliative care that are raised by this case scenario. Write these up on a flip chart or overhead. These issues and questions may include (but are not limited to):
  - decision-making on behalf of young children when the options are limited
  - involving young children in decision making
  - the effect of remitting-relapsing illnesses on family and child functioning and decision-making
  - discussing new therapeutic options with limited supporting data
  - changing discussions and decisions when the goals of care change
  - involvement of sibling children
3. Participants may have personal or professional experiences of dealing with decision-making for and with children. Ask participants to reflect on these experiences and discuss what skills and methods are useful to health care professionals when faced with such situations.
4. Ask participants to discuss how they would have approached this case differently if Daniel had been 14 years old at the time of presentation.
5. Ask participants to write down, and then share with the group, the wording they would use to tell Daniel's parents that there are no further treatment options that could be hoped to extend his life.
6. Ask participants to write down, and then share with the group, the wording or methods they would use to tell Daniel that there are no further treatment options that could be hoped to extend his life.
7. Daniel's parents may have preferred to him not to undergo BMT during the early course of his illness. Given the survival statistics with and without BMT, this preference could well create disagreement between the medical staff and Daniel's parents. Ask participants to discuss what their approach to this situation would be.

8. Review the issues and questions generated by the group and address any that have not yet been discussed.

## **XII. Appendices**

### **XII.1. Appendix A: Legislated age of majority and age of consent for medical treatment**

As presented below\*, Canadian provinces and territories have different legislated definitions of the age of majority and age of consent for medical treatment. These definitions do not alter the need for assessment of capacity given that a person under the age of majority or consent may be judged capable and designated a mature minor for the purposes of making a particular decision. Likewise, a person over the age of majority (an adult) or the age of consent may be judged incapable of making a given decision.

<b>Jurisdiction</b>	<b>Legislated age of majority<sup>119</sup></b>	<b>Legislated age of consent for medical treatment<sup>120, 121</sup></b>
Alberta	18 years	Not legislated
British Columbia	19 years	16 years
Manitoba	18 years	Not legislated
New Brunswick	19 years	16 years
Newfoundland	19 years	Not legislated
Nova Scotia	19 years	Not legislated
Northwest Territories	19 years	Not legislated
Nunavut	19 years	Not legislated
Ontario	18 years	Not legislated
Prince Edward Island	18 years	For surgery, 18 years
Quebec	18 years	14 years
Saskatchewan	18 years	For surgery, 18 years
Yukon	19 years	Not legislated

\* As of January 2002.

## **XII.2. Appendix B: Assessment of Capacity – An Example**

The following approach to assessing capacity is presented as an example. The details may differ between jurisdictions and institutions, and may change with time.

### **Assessment of Capacity<sup>†</sup>**

#### **First consider if the individual:<sup>i</sup>**

- understands the condition for which the treatment is proposed
- understands the nature and purpose of the treatment
- understands the potential benefits and harms in undergoing the treatment
- understands the potential benefits and harms of alternatives to the treatment (including no treatment)

#### **The following components must be included in the assessment.<sup>ii</sup>**

- \$ medical history
- \$ medical evaluation
- \$ course and severity of the patient's condition
- \$ appearance and affect
- \$ mood
- \$ behaviour (from clinical history and observations of friends, family, and others)
- \$ intelligence (includes such qualities as insight, judgement, abstract ability)
- \$ memory
- \$ sensorium
- \$ thought content (such as the absence of paranoid ideation, etc)
- \$ thought process (flow of thought, coherence, etc)
- \$ language ability (may be non-verbal but needs to be able to communicate ideas)
- \$ awareness of current health status
- \$ learning

#### **He or she must:**

##### **1. Be able to receive and appreciate information necessary for making a decision, and about the issues that must be decided.**

For this to be successful the person must know that there is a decision to be made, and must be able to tell the assessor what the decision is.

##### **2. Be willing to make a decision**

The person must want to make the decision.

##### **3. Be able in some way to communicate (or implement) the decision**

Any mode of communication is acceptable as long as their choice is able to be conveyed.

##### **4. Be able to manipulate the information in some way to produce the decision.** This requires:

- Memory sufficient to retain relevant information long enough to make a decision
- The ability to assess or recognize facts (not opinions), and in some instances, the ability to obtain factual data independently;
- The ability for functional logic or basic reasoning.<sup>iii</sup>

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<sup>†</sup> Modified from IWK Health Centre. *Policy on Consent and Assent – Draft*. 2003. Halifax: IWK Health Centre.

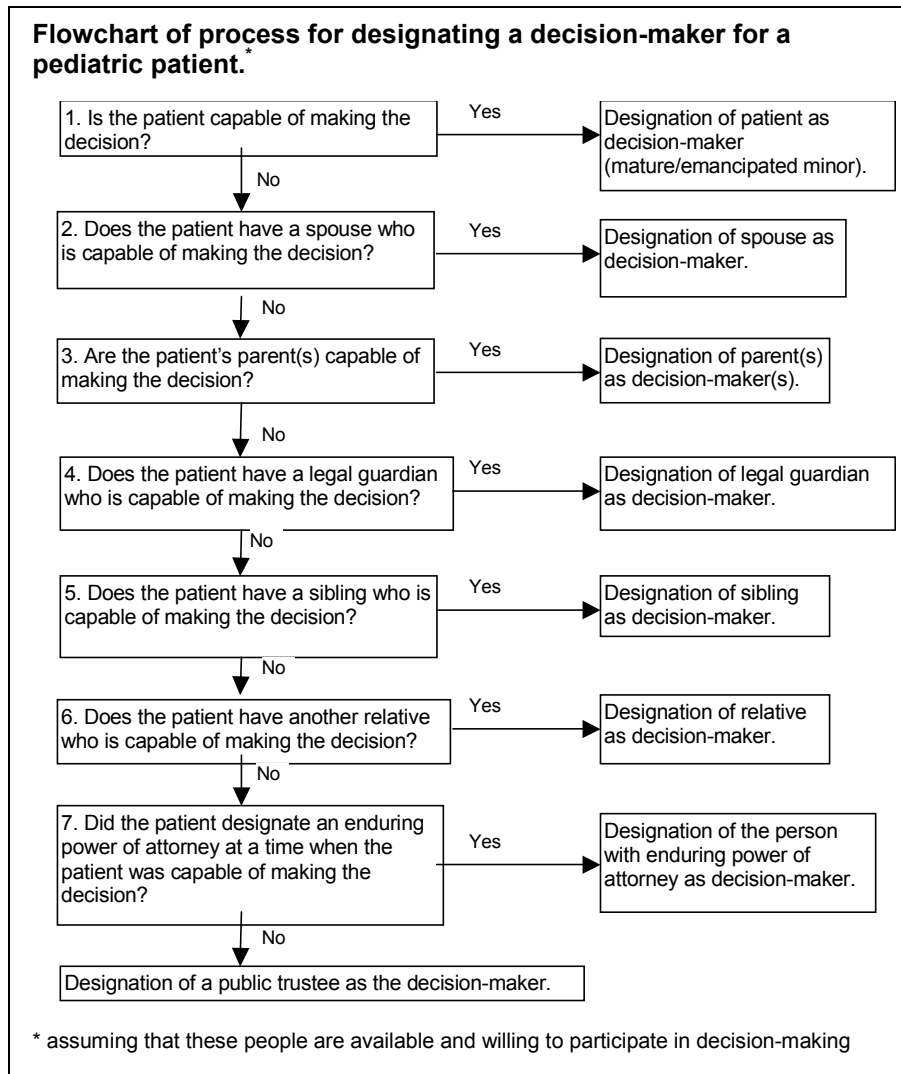
i. Hospitals Act. Chapter 208 of the Revised Statues, 1989. Amended 1994-95, c. 7, 29-37, 150

ii. Enquiry on Mental Competency (Final Report). Chairman: David Weisstub. Ontario Government. 1990:242

iii. Manitoba Law Reform Commission. Informal Assessment of Competence. 1999:53-6

### XII.3. Appendix C: Designation of a Substitute Decision-maker

The following flowchart is presented as an example of the process used to designate a decision-maker for a patient who is judged not capable of making a healthcare decision for themselves. Although arranged in a step-wise fashion, the order in which people are considered may differ between jurisdictions and institutions, and may change with time.



## **XII.4. Appendix D: Provincial legislation concerning advance directives and living wills**

The following provinces have enacted legislation concerning advance directives or living wills. Other provinces and territories may soon develop similar laws.<sup>122</sup> Provinces may vary in terms of the age or other criteria used to determine who can have an advance directive or living will.

Alberta	A “personal directive” may be used to appoint a proxy decision-maker or give instructions about health care or personal matters.
BC	Legislation concerning living wills recently came into effect but is complex so consultation with a lawyer is recommended.
Manitoba	A “health care directive” may be used to appoint a proxy decision-maker for health care decisions but the proxy cannot make decisions about personal matters.
Newfoundland	“Advance health care directives” may be used to appoint a proxy decision-maker for healthcare decisions, but the proxy cannot make decisions about personal matters.
Nova Scotia	A legal will may be used to appoint a proxy or a substitute decision-maker for healthcare decisions but the proxy cannot make decisions about personal matters.
Ontario	A “power of attorney for personal care” must involve appointment of a proxy and may include instructions concerning healthcare decisions.
PEI	A “health care directive” may appoint a proxy for healthcare decisions and/or stipulate circumstances in which the person wants to be permitted to die a natural death, and/or give directions concerning specific treatments and/or broader healthcare decisions.
Quebec	A “mandate in anticipation of incapacity” may name a proxy decision-maker for healthcare and personal decisions. Court approval is required for the mandate to take effect and consultation with a notary is recommended.
Saskatchewan	A “directive” may be used to appoint a proxy decision-maker for healthcare decisions, but the proxy cannot make decisions about personal matters.

A helpful website relating to advance health care planning and appointing proxy or substitute decision-makers is The End of Life Project from Dalhousie’s Health Law Institute at: [www.dal.ca/hli/endoflife](http://www.dal.ca/hli/endoflife)

## **XII.5. Appendix E: Books about illness, decision-making, and death – Full citations**

### ***For children and adolescents:***

- American Cancer Society, *Why Charlie Brown, Why?* [Video cartoon].
- Breebart J and Breebart P. *When I Die, Will I Get Better?* New York: Peter Bedrick Books, 1993.
- Buscaglia L. *The Fall of Freddy the Leaf*. Torofare, NJ: Slack Publishing, 1982. Available from: Fitzhenry & Whiteside, Ltd., 91 Granton Dr., Richmond Hill, Ontario, L4B 2N5
- Heegaard M. *When Someone Very Special Dies*. [a workbook] Minneapolis: Woodland Press, 1988. Available from Centering Corporation, PO Box 4600, Omaha, NE 68104 Tel: 402-553-1200 Internet: [www.centering.org](http://www.centering.org)
- Josephson KB and Sourkes BM. *My Life is Feelings. Starring Poly Polar Bear*. Pittsburgh: University of Pittsburgh Press, 1995. Available from The Montreal Children's Hospital Foundation, 1 Place Alexis Nihon, 3400 boul. de Maisonneuve Ouest, bureau 1420, Montreal, Quebec, H3Z 3B8 Tel: 514-934-4846 Internet: [www.childrenfoundation.com](http://www.childrenfoundation.com)
- Lazar L and Crawford B. *In My World: Official Life Journal*. Available from Centering Corporation, PO Box 4600, Omaha, NE 68104 Tel: 402-553-1200 Internet: [www.centering.org](http://www.centering.org)
- Mellonie B and Ingpen R. *Lifetimes: A Beautiful Way to Explain Death to Children*. Toronto: Bantam Books, 1983. Available from Centering Corporation, PO Box 4600, Omaha, NE 68104 Tel: 402-553-1200 Internet: [www.centering.org](http://www.centering.org)
- Mills J. *The Gentle Willow*. Washington, DC: Magination Press, 1993. Available from: Compassion Books, 477 Hannah Branch Rd., Burnsville NC 28714 Tel: 828-675-5090
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- White EB. *Charlotte's Web*. New York: Harper & Row, 1952.
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### ***For adults:***

- Adams DW and Deveau EJ. *Coping with Childhood Cancer – Where do we go from here?* 3<sup>rd</sup> edition. Hamilton, Ont.: Kinbridge, 1993.
- Davis D. *Fly Away Home*. Available from Centering Corporation, PO Box 4600, Omaha, NE 68104 Tel: 402-553-1200 Internet: [www.centering.org](http://www.centering.org)
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- Frantz TT. *When Your Child has a Life-Threatening Illness*. Available from: Association for the Care of Children's Health, 7910 Woodmont Av. #300, Bethesda MD 20814, Tel: 301-654-6549
- Grollman E. *Talking About Death: A Dialogue Between Parent & Child*. Boston: Beacon Press, 1990.
- Hamilton J. *When a Parent is Sick: Helping Parents Explain Serious Illness to Children*. Halifax: Joan Hamilton, 1998. Available from: Joan Hamilton, Queen Elizabeth II Health Sciences Centre, Victoria

General Hospital Site, 1278 Tower Rd., Halifax, NS B3H 2Y9. Tel: 902-473-5407 Email: [joanh@istar.ca](mailto:joanh@istar.ca)

Hilden JM, Tobin DR, Lindsey K. *Shelter From the Storm: Caring for a Child with a Life-threatening Condition*. Cambridge, MA: Perseus Books, 2003. Available from: Perseus Books Group, 11 Cambridge Center, Cambridge MA 02142 Tel: 800-255-1514 Email: [j.mccrary@perseusbooks.com](mailto:j.mccrary@perseusbooks.com)

Lee SA. *Choices: When Your Child is Dying*. Calgary: Script Publishing, 1995. Available from: Script Publishing Inc., 839-5<sup>th</sup> Ave. SW, Suite 200, Calgary, Alberta T2P 3L8 Tel: 403-290-0800

Minnick MA, et al. *A Time to Decide, A Time to Heal: For Parents Making Difficult Decisions about Babies They Love*. 4<sup>th</sup> edition. St. John's, Michigan: Pineapple Press, 2000. Available from Centering Corporation, PO Box 4600, Omaha, NE 68104 Tel: 402-553-1200 Internet: [www.centering.org](http://www.centering.org)

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*Why Mine?* Available from Centering Corporation, PO Box 4600, Omaha, NE 68104 Tel: 402-553-1200 Internet: [www.centering.org](http://www.centering.org)

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