

## **Annotated Professional Resources Part B**

### **Communicating with Families About Severe and Terminal Illness in Their Children: Annotated Resources**

#### **WEBSITES**

##### **Center to Advance Palliative Care**

[www.capc.org](http://www.capc.org)

The Center to Advance Palliative Care (CAPC) is a national organization dedicated to increasing the availability of quality palliative care services for people facing serious illness. It is the nation's leading resource for palliative care development and growth. As a national, member-based organization, they provide hospitals, health systems, hospices, payers and other healthcare organizations with the tools, training, technical assistance and metrics needed to support successful implementation and integration of palliative care.

##### **British Columbia Children's Hospital Patient & Family Resource Center**

<http://www.bcchildrens.ca/grief-and-loss>

People of all ages can feel the emotions of grief. Sadness, anger, frustration, fear, guilt, anxiety, a sense of injustice, remorse, despair, relief, longing, rage, apprehension and so many others make up the feelings of grief. It is said that if a child is old enough to love, they are old enough to grieve. The BC Children's Hospital offers materials to support children, teens, and adults who are experiencing grief and loss.

##### **Study Guides and Strategies: Actively Listening**

<http://www.studygs.net/listening.htm>

Since 1996 the Study Guides and Strategies Website has been researched, authored, maintained and supported as an international, learner-centric, educational public service. Users can find resources, tools, and scenarios based on building active listening skills. Active listening intentionally focuses on who you are listening to, whether in a group or one-on-one, in order to understand what he or she is saying.

#### **PRINT PROFESSIONAL RESOURCES**

##### **Buckley, L. Critical Moments- Doctors and Patients. *NEJM* 2011; 365:1270-1.**

<http://www.nejm.org/doi/full/10.1056/NEJMp1106647>

This perspective article by Dr. Buckley MD, MPH discussed her experience communicating bad news and treatment options with a teenage patient newly diagnoses with Crohn's disease.

##### **Wolfe, L. Should Parents Speak with a Dying Child about Impending Death?**

***NEJM* 2004; 351:1251-1253.**

<http://www.nejm.org/doi/full/10.1056/NEJMe048183>

This editorial discusses the presence of the physician at patient funerals and honoring the struggle of the family. Participating in these observances serves as a reminder of the importance of helping families deal with the death of a child and to try to piece together a constructive outcome from an event without purpose.

### **When Things go Wrong Responding to Adverse Events: A Consensus Statement of the Harvard Hospitals March 2006**

<http://www.macoalition.org/documents/respondingToAdverseEvents.pdf>

The concepts and principles in this final document are supported by all of the Harvard teaching hospitals, which use them to develop specific policies and practices to implement the recommendations. The paper is organized into three major divisions: The Patient and Family Experience (Sections II–IV), The Caregiver Experience (Sections V, VI), and Management of the event (Sections VII–XI). Each of the major sections is organized into three parts: a brief summary of expert consensus about the issue; the reasoning and evidence behind the Consensus; recommendations.

### **MULTIMEDIA RESOURCES**

#### **Communication Skills in Clinical Practice Part 4**

<https://www.youtube.com/watch?v=ftgNapAfV6Q>

See Dr. Robert Buckman demonstrate how to break bad news using the SPIKES (setting, perception, invitation, knowledge, exploring emotions, strategy \* summary) six point protocol.

#### **Breaking Bad News: When a Child is Seriously Ill**

[https://www.youtube.com/watch?v=KBrmMW9c8\\_g](https://www.youtube.com/watch?v=KBrmMW9c8_g)

Stephen Liben MD, Associate Professor in the Faculty of Medicine of McGill University, Director of the Montreal Children's Hospital Pediatric Palliative Care Program shares strategies for telling parents their child has a life-limiting illness.

#### **At the End of a Child's Life, Parents at a Loss for Words: ABC news 3/5/12**

<http://abcnews.go.com/Health/childs-end-life-talking-death/story?id=15841183>

Few parents can imagine having to tell their child that his or her life will be cut short. Parents faced with the task are often reluctant to speak candidly about death, fearing that the news will spark fear or sap the child's will to live. A conversation about death happens differently, depending on the age of the child and the cultural background and customs of the family. But experts say it's important for all parents to be as honest as they can about their child's condition and what the future holds. This article covers the story of two families and their struggle to have this conversation with their own child.

### **Three Minute Breathing Space**

<http://cdn.franticworld.com/wp-content/uploads/2013/12/08-Three-Minute-Breathing-Space.mp3>

This mini-meditation exercise can introduce the practice of mindfulness into your daily routine. It can be a useful tool to find calm in a hectic environment. This abbreviated exercise acts as a bridge between the longer, formal meditations detailed in the book *Mindfulness for Health*.

### **How to Break Bad News: Doc Gurley Posts from an Insane Healthcare System**

<http://www.docgurley.com/2008/01/how-to-break-bad-news/#sthash.Mm7msKa1.dpbs>

Dr. Gurley recalls an experience as a medical student learning how to break bad news to patients and families.

### **The Oncology Nurse Community: Interview with Dr. James Tulsky on the ‘Ask-Tell-Ask Model**

[http://www.theonc.org/video.asp?section\\_id=1687&doc\\_id=253192](http://www.theonc.org/video.asp?section_id=1687&doc_id=253192)

Dr. James Tulsky, Director of the Duke Center for Palliative Care at Duke University, discusses the power of the ‘Ask-Tell-Ask’ model in palliative care.

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