



# **END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME**

**Maria Rugg, RN, MN, ACNP, CHPCN(c)  
Hospital For Sick Children  
Toronto, Ontario**

Original event air date - 25 August 2005

Post-production running time - 59 minutes, 41 seconds

Companion written transcript for a post-event MP3 Podcast (Individual Web License)

Use of the content contained herein and the companion MP3 file is  
subject to the Terms of Use document appearing on Page 2 of this electronic PDF file.

## Terms of Use

The Pallium Project, as represented by its Administrative Hosting Authority\* is the rightful owner, copyright holder and licensor of this digital object and the companion MP3 file. It is important that you read and agree to these Terms of Use prior to using these digital objects. Use of these digital objects is considered by the Pallium Project as constituting agreement with the Terms of Use by you, or your organization, as the case may be:

1. These digital objects are licensed for individual continuing professional development (CPD)/self-directed learning by individuals in Canada<sup>1</sup>. Provided and for so long as you meet these qualifications for use, you are entitled to a license to use, copy without alteration and publicly or privately exhibit the contents of this digital object.
2. The Pallium Project retains all property, right, title and interest in and to the digital objects, including all trademarks, trade names, copyrights and other intellectual property rights.
3. The digital objects provided through this license are made available to you in Canada as a duly-qualified end-user “as is, as available” without warranty of any kind, either expressed or implied, including, but not limited to the implied warranties of merchantability, fitness for a particular purpose, or non-infringement. The Pallium Project or its agents assume no liability for or relating to the delay, failure, interruption or corruption of any data or information embedded in the electronic media associated with the digital objects.
4. The Pallium Project, its agents, employees, participants and funders shall not be liable for any injury, loss or damage of any nature whatsoever suffered by you or any of your agents, employees, contractors or voluntary workers resulting from use or exhibiting of the digital objects.
5. You agree to indemnify and save harmless the Pallium Project, its agents, employees, participants and funders from any and all losses, damages, expenses, actions and claims, including third party claims, that may be made, sustained or brought for any injury, loss or damage whatsoever arising from any willful misconduct, negligence or omission on the part of yourself, your employees or agents.
6. You agree with the following statements: (a) the digital objects are not a substitute for, and do not provide, medical advice; (b) the material contained in the digital objects is for educational and informational purposes only and is not be used for the direction of care of individual patients; (c) the material contained in the digital objects is general in nature and is not intended in any way to be a substitute for a medical exam or professional medical advice, diagnosis or treatment; and (d) a user should never disregard or delay seeking consultative advice because of something they have read, heard or viewed as a result of use of these digital objects.
7. These digital objects or any of their component elements shall not be used to develop or derive any additional continuing professional development (CPD) or educational/training product or service for distribution or commercial sale without the written consent of the Pallium Project.
8. If the Pallium Project objects to the manner in which you are using, exhibiting or broadcasting the digital objects, the Pallium Project may revoke this License Agreement upon written notice to you.
9. If you breach these Terms of Use, this license may be revoked immediately by written notice to you from the Pallium Project. In the event of termination, you must immediately return the digital object to the Pallium Project, or destroy it and certify this destruction in writing to the Pallium Project.
10. Inquiries regarding this license agreement can be made in writing to Pallium Project Development Office, Box 60639, University of Alberta RPO, Edmonton, Alberta T6G-2S8.

Effective 04 July 2006

\*The Alberta Cancer Board through its Medical Affairs and Community Oncology (MACO) Division is the Administrative Hosting Authority for the Pallium Project – Phase II. The Pallium Project is an intersectoral community of academic, health services delivery, voluntary sector, government leaders and citizens working together to build hospice palliative care capacity as part of Primary Health Care Renewal in Canada. Major funding for Phase II is from Health Canada through the Primary Health Care Transition Fund (PHCTF).

<sup>1</sup>. A companion kit entitled *Conversations on Caring – Volume 1* is available through the CHPCA Marketplace ([www.chpca.net](http://www.chpca.net)) for use in Canada in staff development, continuing professional development (CPD) and health sciences education.

**Suggested Process and Learning Objectives for Problem-based, Small Group Learning and Local Staff/Professional Development Learning Circles**

**INTRODUCTION**

This transcript is a web-based version for use with a companion MP3 professional development podcast. This MP3 session is also part of a larger set of digital audio recordings forming a resource entitled *Conversations on Caring, Volume 1 (CoC)*. CoC is a learning resource which has been prepared from previous Pallium Project professional development events. These events are the *Monthly Continuing Professional Development (CPD) Audio-conference Program* series. The *Monthly CPD Audio-conference Program* series was supported in 2005 and 2006 through a contribution from Health Canada's, Primary Health Care Transition Fund (PHCTF) as part of Primary Health Care Renewal in Canada. The views expressed in these sessions do not necessarily reflect the official policies of Health Canada or the employing organizations of members of the Pallium Project's, Community of Practice. These materials have been prepared as "reminder resources" for participants of the original CPD sessions and as learning resources to help support improved access and enhanced quality for provision of Hospice Palliative Care in Canada.

- I. The MP3 audio files and this PDF of the written transcript have been post-produced from the original event in order to provide essential information and enable use, generally within 1 hour time blocks. Each of the sessions has been based on topics which practicing Registered Nurses have identified as important to improving practice and service locally as part of a 2005-2006 audio-conference series entitled *Improving Care in Our Communities*. While program-developed and organized principally from a nursing process and case-management perspective, sessions reflect the inter-professional and trans-disciplinary perspectives of both the Guest Resources/Invited Panelists and the local participants, many whom reflect a diversity of perspectives of social workers, spiritual care providers, primary-care physicians, hospice/palliative program volunteers and others.

**SUGGESTED LEARNING OBJECTIVES FOR THIS SESSION**

By the end of the session the participant should be able to discuss all or part of the following:

- Common circumstances in which children may be referred to/indicated for hospice palliative care interventions.
- Key considerations in age and developmental stage for approaches to hospice palliative care in children and adolescents.
- Strategies for breaking bad news and discussing dying and death with children/adolescents and families.
- Strategies for supporting families (including parents and siblings) during a life-limiting illness of a child/adolescent.
- Issues in assessing and managing pain and common symptoms with pediatric clients.
- Issues in supporting psychosocial and spiritual aspects of care with pediatric clients.
- Sources of additional resources and support in Canada.

## END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME

Guest Resource

**Maria Rugg, RN, MN, ACNP, CHPCN(c)**  
Palliative and Bereavement Care Program  
Hospital For Sick Children  
Toronto, Ontario

Moderator

**Jacquie Peden, RN, MN**

**Original Air Date – August 25, 2005**

### **JACQUIE PEDEN**

Can you tell me, what children are referred to hospice palliative care?

### **MARIA RUGG**

In general, if we look at where children are dying and, in particular in Canada, but across North America, what we are seeing is that the majority of children are actually dying from diseases other than cancer. As a result, what we are beginning to understand when we talk about what type of children are referred to hospice palliative care – we know that the majority of those children, and six thousand die in Canada each year, are dying in a neonatal and critical care unit in hospitals and a small percentage are dying at home, but the trend is increasing. The types of children that are generally seen in the pediatric palliative care population can be divided up into four groups.

The first group being the group that curative treatments are available, but possibly might fail so you would generally see cancer or irreversible organ failure.

The next group we talk about are children where conditions have long periods of intensive treatment that is generally aimed at providing good quality of life but oftentimes premature death does occur. You can think of a diagnosis such as cystic fibrosis being one of the diagnoses that fit into that category.

The next group would be children with progressive conditions where treatment is generally exclusively palliative from the time of diagnosis, but may extend over many years and they have sickness that waxes and wanes and what we mean by that is that they can hit periods of crisis all along their illness but they generally will hit a crisis and, at some point come back to health, but then don't do very well. Children with metabolic diseases or neurologic diseases tend to fall into this group.

The final group is a group that has children that are born with a severe disability and oftentimes it can be a neurologic disability, and may not necessarily be progressive but they are extremely vulnerable to health complications and we generally anticipate a premature death. We talk about those four groups being part of the groups of children that we would see generally in pediatric palliative care. In fact, when you look at palliative care programs across the country who specialize in pediatrics, the majority of children that they are seeing fall in groups three and four. One of the myths is that

the majority of children that would be considered palliative are those children with cancer. In fact, that makes up the smallest number of the children who are often seen.

### **JACQUIE PEDEN**

I am surprised because I believed that myth that it was cancer.

### **MARIA RUGG**

Yes and in fact that would be the smallest number of children that we do see. It is, in fact, the children that make up groups three and four with these progressive neurodegenerative type diseases or oftentimes undiagnosed diseases that make up the majority of groups that we see.

### **JACQUIE PEDEN**

Does that mean that these children are being cured (leukemia comes to mind)?

### **MARIA RUGG**

Well, yes. In fact, these children are surviving and being cured. What we are starting to see, and I don't have any confirmed data on this trend but this is certainly by experts in pediatric oncology is that we are starting to see that some of those children becoming adults and suffering late effects and being diagnosed later in their disease in their lives with other diseases as affects from the cancer. In fact, children with leukemia are being cured and doing quite well.

### **JACQUIE PEDEN**

That is very good to hear!

### **MARIA RUGG**

I think the only other thing we wanted to highlight is the idea that when we are looking at children in this population, there is a number of things we need to remember but mainly that children aren't "little adults". They have very unique needs in terms of illness and understanding around communication, their pain and symptom management, their experiences are quite different and their families' experiences are quite different when considering what the children are going through as compared to adults with a palliative care type of diagnosis.

### **JACQUIE PEDEN**

OK, I think that leads us into my next question – how does the child's age and developmental stage impact how you provide care?

### **MARIA RUGG**

Generally, when we think of care within age groups, what we have to remember is that not all children are equal. When we think of pediatric palliative care we go right from infants through to adolescents and depending on the area of which you work that can range from zero to nineteen plus. It is important to understand that children develop both physically and emotionally in stages.

One of the basic things we try to reinforce and remind people is that in that development, their understanding of both their illness and death will change as time goes on, which affects not just themselves – children who are dying – but also their siblings. When we talk about death, we talk about understanding that there are four concepts. Even in terms of not necessarily death, but in terms of life threatening illness, there are four concepts that we need to consider – universality, irreversibility, non-functionality and causality. What do we mean by these things?

Generally, universality is the idea that death is universal and inevitable. It includes an awareness that the child will die themselves at some point in their lives. The idea of irreversibility talks about how a child's ability to conceptualize that people who are dead, do not return to life in a physical form as we know it. Non-functionality talks about a child's ability to conceptualize that everything biological, sensational, emotional and cognitive cease to function with a person who has died. Finally causality is that child's ability to understand that the factors that lead to death, both internal and external causes. The reason why it is important to understand this is that as child moves through birth to adolescence, their issues will change, how we deal with them will need to be altered and changed, explanations and how we communicate changes.

When you think of birth to two years the issues that are important to consider or remember are things such as trust and attachment. Those are the big things that are important with an infant and to keep in mind or guidelines to remember are the importance of consistency with caregivers, the use of distraction and giving simple choices to children of this age.

The next age would be three to five year olds. In this age group, oftentimes we need to remember that they want to be autonomous, but feel very constrained by it. They have increasing amounts of attachments. They have a sense of precocious maturity. They are subject to wide emotional flings and lots of behavioral range changes. The things to remind yourself in terms of guidelines are to encourage verbalization (encouraging them to talk things through as much as possible), preparing them for what to expect and providing choices that maximize their own involvement with what is happening.

In the six to eleven year olds, the issues are often social isolation, loss of a sense of competence (they are not feeling as competent as they would be because they are at a tricky stage in terms of intellect as well as developmentally physically [they can be clumsy], they often have

misunderstanding of disease origin and the ways of treatment so if you think about the idea that oftentimes children at this age think that you can catch a cancer and anything that my brother or sister has or "How did I catch this? I must have gotten it by not washing my hands"). The important guidelines to remember here is to educate about the facts and give a lot of opportunity for open dialogue where they are encouraged at any time to ask any issues that are of their concern.

Finally, with the adolescents I think that what we understand is the big issues are the change in self esteem and the idea of dependency and loss of privacy. They will oftentimes feel they are falling behind their peer group if they have an illness and the idea of social isolation and not wanting to be that way. I think what we need to do is what we often do with adults and that is helping provide assistance in searching for meaning (what does this illness mean for them), giving them a sense of privacy, giving them lots of opportunities for control (in terms of controlling their situation and what's happening within their treatment or end of life care), encouraging dialogue and back to the issues of privacy.

### **JACQUIE PEDEN**

Some of the ideas that you have about giving them control and encouraging dialogue is even something you do with adults. I want to move along because we are coming close to the time when we need to have a discussion. I am going to combine the next 2 questions. How do you break bad news and talk about death and dying with the child?

### **MARIA RUGG**

I think the important things to remember, Jacquie, are to think about the developmental stages. What we do know is that it is oftentimes a process. This is not going to be a one time occasion. We are going to have the conversation and they have accepted it and they understand it. I think it is important to look at the idea and what we do know and there has been some research in this that the acquisition of information happens in stages.

In particular, with a child that has the serious illness themselves, they probably acquire information much sooner than we are actually giving them information. Often that comes as a result of changes in what is happening to their body, changes in how they are dealing with the medications that they are having and so it is important to understand that the internal process is probably moving a lot faster than the external process. What I mean by that is what is happening inside of them, inside their brains and how they are acquiring this information, "Oh goodness, well I am actually not that well and I am not getting better" is happening much faster than they are letting us know and what we think is happening. Some of the things to think about and remind yourself is to remember nonverbal communication and cues. Children often learn about their condition from things that have been said, how things have been said, what is not said but was understood by body language, facial expressions and mood

## END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME

change. Children are notorious for overhearing things and what they imagine. That is a very important key thing to think about is imagination, especially in the early childhood through to the late adolescence can run rampant. In terms of the number of things that children can have and are impressionable on and especially in today's society with computers and television and everything, it is important to understand that idea of what they can imagine.

There is also the idea of popular notions and what I mean by that is religion and culture and realizing the impact that has on what a child understands and what a child doesn't understand, the idea of superstition, the idea that we want to protect children's innocence and well being and that we feel we have failed somehow when we aren't able to do that and we try to protect that and are we really communicating and doing what is in the best interest of our children.

In terms of being able to understand that communication should be developmentally appropriate and you should address common developmental fears, so the idea of understanding that isolation or fear of attachment is an important for a five to eight year old is extremely important to remember that when we are thinking about "How do I communicate this bad news to this child?" Beginning early versus late so that it is a process and it is not just a verbalization overload for a child. Also, using augmentative communication strategies if vocalization is a challenge, so again understanding that children with disabilities still need that opportunity to communicate and know things, so giving them alternatives to communication verbally is really important.

### **JACQUIE PEDEN**

For instance, give me an example.

### **MARIA RUGG**

An example would be, we here at the hospital, have opportunity with speech language pathologists who use tables which use words tables, so a child can point to words versus having to speak the words. Certainly, there have been computer programs at this point that can provide all sorts of opportunities for communicating alternatively and, again, that idea of allowing the child ways to communicate to you other ways other than just having to verbalize because children oftentimes don't verbalize as well.

Finally, some of the things I think are important as they would be with adults is the idea of maintaining hope while being honest. Understanding that evolution of meaning over the disease process. It is important that if you start off being honest at the beginning you are able to not have to go back and say, "I am sorry I didn't quite tell you everything". It is ideal to start at the beginning and slowly – that way it isn't a huge burden on the child. It is important to acknowledge hopes and wishes. It is important to acknowledge the loss of hope and despair, depression and sadness. Those are all common things in children, but oftentimes I think we don't

look at them because of our own fear of not knowing how to handle those. Those are all important things when we are talking about communicating with children.

Think it through and be ready for the conversation to be different than what you think. Don't try to project into the conversation because it may end up in a very different place. Begin early, use appropriate but clear and accurate language. Try to avoid metaphors but relate to concepts that they understand (metaphors can oftentimes be a little bit too big of a tangent for children to understand intellectually, especially at certain developmental ages to kind of comprehend), repeat and support multiple ways of communication (books, play, art, music, many different things – the more you have at your disposal, the more the child feels that idea of being able to control when, how, and how much).

Clarify questions before answering them because oftentimes what you think they are asking is something very different (an example I can use is a child who just really wanted to know what a body looks like when it is dead and I thought, "Gosh, what are you asking?". I didn't know what they were asking me so I started describing gory details and they were like, "No, no, no... Is it cold? Are you pale?" They wanted very simple things and I was getting into very deep things and very graphic because I thought that was what they were asking, but in fact they just wanted some basic things. "Can you talk? Can you walk?"

It is important to clarify before answering what you think they are asking, also address developmental anxieties and fears (in this I want to remind people that culturally and in society to remember where children are from in terms of their backgrounds because we have children in a multicultural society from many different places, so it is important to understand that you may be dealing with children who are already subject to post-traumatic stress syndrome from the lives they have already lived). It is important to understand developmentally and culturally what are their anxieties and fears and address those to the best that you are able to in terms of the situation.

### **JACQUIE PEDEN**

How do you support the family which I think would include both parents and siblings in this whole process?

### **MARIA RUGG**

I think when we talk about families we remember what we have talked about with children, but remember that each family has its way of communicating. This includes what they will talk about and how they will talk about it, and what they won't talk about, what all the members can know and what some members may never know.

We understand that each society and each culture has their own way of communication. Families are a culture within themselves and just because we have preconceived ideas of a

## END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME

way a family should do this may not necessarily be a way the family can do it, so it is important to understand all those nuances. Families often can provide caregivers directly or indirectly with expectations.

It is important to remember that there are many ethical and professional challenges when you are dealing with families. What we mean by that is the idea that what we believe is important for a child to know, in particular that child who is dying or siblings, may not be the way that family understands communication or information to be shared, so we need to be able to work within the family context as well as maintaining what we believe ourselves - our appropriate standards of care for a child. It is a balance between family, expectations and what they are also expecting from us as professionals. Part of that is making sure that, back to the idea of communication, making sure that you talk about what are some of the popular notions about talking with children about death, understanding and helping to make families understand that while you may have heard this and this is maybe what you think, this is what we know.

Oftentimes I have many families who are very inhibited about talking to their children about the actual death. When you find out from them why this is and what this is about, you can often dispel some of the myths. Giving them the tools of understanding what cognitive development and communicative ability of their child and helping them to understand those things. Making sure that you understand as a professional caregiver, what are the family rules, what are the expectations, what are the patterns of behavior and try to work with the family in those – making sure you keep account for non-verbal communication and cues.

Recently we have done a study at Sick Kids and I know there have been a number of studies in the adult world about that idea of maintaining hope and the importance of that, but being honest. It is a very fine line that we walk within palliative care and it is just as important in pediatrics, but we found the families that felt they got great care felt that, “You didn’t rob me of my hope but you were honest with me”. I think that they need to also gain those tools in being able to communicate with their children. I think that is it.

### **JACQUIE PEDEN**

Okay, great. Can we move on to more of the physical aspects? How do you actually assess and manage pain in a child?

### **MARIA RUGG**

The important things in terms of managing pain in a child are making sure that we understand about six key concepts. I call them the six key principles.

The first is that patients and parents are the experts because oftentimes when we are dealing with children they can’t give us those direct reports that we understand that parents or primary caregivers for a child are the ones who are the

experts. They are the ones who understand their child. They understand the nuances. We need to use them in the best capacity that we can.

The same thing goes in terms of adults – that a comprehensive pain assessment includes detail about intensity, location, quality, patterns of radiation, character, onset, alleviating, aggravating factors, knowing current treatments they are using and their effectiveness. Pain management history is critical when you are dealing with children, one of the key things is what are this child’s manner of expressing this pain? How does that child say it? How do the parents know that this child is in pain? I think it is important that even with children, pain assessment should identify all the factors, both physiological and non-physiological that contribute to a child’s pain and suffering. When we talk about pain measurement tools we should be using those that have been consistently demonstrated as developmentally appropriate for a child’s age and stage and we certainly can talk about some of those tools and pain must be reassessed continually for children just as it is in adults – evaluation, reassessment and reimplementation.

### **JACQUIE PEDEN**

I know there would be a lot of differences with the management of pain – for instance, the medications and doses are going to be. Are the medications the same?

### **MARIA RUGG**

The medications are the same. When we talk about our gold standard, we use the same models as in adults – which is the WHO model (*Editorial note: WHO Analgesic Ladder background at [http://www.whocancerpain.wisc.edu/eng/19\\_1/19\\_1.html](http://www.whocancerpain.wisc.edu/eng/19_1/19_1.html)*) with your first, second and third steps. I think what is important to remember when we are dealing with pediatrics is that the doses might change and I am not going to go through dosages because those are things looked at easily in terms of readily accessible resources and reviewed.

It is important to understand that, certainly, in terms of the myths that exist for adults, there are myths for children as well and oftentimes are tenfold. People are very inhibited in terms of use of opioids and strong analgesia with children. Our drugs are the same. What we are struggling with is just in terms of dosages and oftentimes starting dosages. For instance, when we look at the fentanyl patch the starting dose is quite high when you are looking at a child and their body mass. Trying to find creative ways is key when we are dealing with pediatrics. We certainly try to look and scan the literature for creative ways of the administration of drugs.

We try to stick to the oral route as much as possible and oftentimes if it is not the oral route, then by gastronomy, nasal gastric tube, or continuous IV access. Certainly some of the sublingual or buccal methods have been used quite well with children. We have less experience with subcutaneous infusion only because generally what we have found is children who need to go through some sort of venous route

have already a permanent line put in by this time, but certainly we have used the subcutaneous route and again back to the idea that you have less of a body mass so you tend to run out of sites a little more quickly just because of the lack of more fatty areas to try and initiate some subcutaneous infusions.

### **JACQUIE PEDEN**

So, besides pain, what are some of the other common symptoms?

### **MARIA RUGG**

Some of the other symptoms that we tend to deal with in terms of children are seizures and I divide them into six categories, so under neurologic, we certainly look at seizures being the number one of the symptoms we often deal with as well as sleep problems. Respiratory-wise, certainly dyspnea is one but oftentimes ongoing pneumonia. Secretions are a large one, especially in groups with neurodegenerative type diseases. G.I. symptoms sometimes are things we deal with such as feeding intolerances as well as nausea and vomiting from treatment. Oftentimes, when we look at feeding intolerances, we look at alternative methods of feeding and often can become ethical challenges with children because we may look at alternative or nasal gastric or gastrostomy tubes, but oftentimes children with severe neurologic or neurodegenerative type diseases even have feeding intolerances despite mechanical intervention. Those are some of the symptoms we deal with in G.I.

Children with hematological diagnoses within the cancer population... you oftentimes see the active bleeding and the platelet issue. Generalizing such as fatigue is common with children and again lack of sleep. Psychological goes back to the developmental issues but we generally see that within children, we see the same types of things – depression, sadness, fear and oftentimes one of the things that gets dismissed is spiritual distress. We are not very good at addressing that in children. When we look at the management of any of these types of symptoms, we try not to look at the idea of being terminal. Oftentimes, we find that if we identify these children as terminal, it limits their care but if we talk about them having a life threatening illness and we say that some of the management may seem aggressive but at the same time, it actually helps improve the quality of life, it is important to weigh the costs and benefits.

### **JACQUIE PEDEN**

I think that is quite similar to adults as well.

### **MARIA RUGG**

We try to limit the diagnostic tests to as little as possible, going based on what symptoms are they showing and how can we manage them versus how can we investigate every possibility?

### **JACQUIE PEDEN**

How do you support the psychosocial and spiritual aspects of a child?

### **MARIA RUGG**

I think it goes back to some of the things we talked about from the beginning. That idea of trying to talk about hope and beginning to talk about beliefs and what happens to a child after death can often bring comfort to a child and parent. Trying to understand what their belief system is and engaging them in that discussion is extremely important.

Looking at legacy building and that has become a really big part of what we do with children and families – engaging them in that idea of meaning and what has brought meaning to life to this child and family and engaging them in that.

Identifying support systems and beyond because we do understand that families don't exist in a vacuum as well and they exist within a community (whatever that community may be, whether it is extended family or within their social community) and working within to engage those things that a family finds supportive and helpful are very important and really working within those.

### **JACQUIE PEDEN**

What about the grieving family? How would you actually support the parents and the siblings?

### **MARIA RUGG**

I think some of the things we try to do with families is really look at identifying the support systems that they have close by that are within reach because it is great to identify lots of bereavement support but if it is out of reach for a family, it makes it practical, so looking at what is close by and what is in their community what we found was that the technological world has really been able to help out family outreach much farther and much easier than they have in the past (looking at internet sites and chat rooms for families who have had children who have died of similar disease and whatnot have been extremely helpful with the families we are involved with).

Trying to normalize and individualize the grieving process. Oftentimes you will hear in the literature talking about the idea of complicated grief and what we are finding more and more is, in fact, grief is so very individualized that while, yes, there is some very complicated grief, oftentimes this is a process that a family or an individual must go through. I think that part of this is understanding that others are going through this and that they are not alone in that process. Certainly actualizing the loss and facilitating the living without the physical presence of the child is part of what we talk about legacy building – helping a family figure out, “How do I normalize that when my child is not here physically? How does my child continue to be present in my life?” Those are some of the key things that we try to address – sharing of information, sharing of resources in literature, internet and as many modalities as possible, listening, reassuring, and validating feelings.

## END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME

Certainly in terms of siblings and children who are left behind when their siblings die, encouraging parents and caregivers who are with them to continue to make them involved, continue with a routine and try to support some of those ongoing normalcy issues. Some of the other things that parents have told us that have helped in terms of grief and bereavement is talking about tissue and organ donation which certainly is a topic that many families have said that they wish people had talked more about when we talked to them about what we would like to see and improve upon in terms of care and certainly those options not be discussed and why they make us quite uncomfortable as professionals give some comfort and relief to families – some families anyway because it makes them feel like there was a purpose in all of this.

Certainly the idea of autopsy and that is a big topic in terms of pediatrics especially when we talked about groups three and four – those two groups where oftentimes you have children who are born with congenital anomalies in general or are born with diagnoses or diseases that they were unable to diagnose. Having some sort of closure in terms of autopsy and the feeling that they might get some answers – they like that option or choice and oftentimes we shy away from giving those choices to families because we feel as though it is not an appropriate thing to do at this time.

Other things parents have told us in terms of the research that has been very helpful in terms of their bereavement is follow up by the child's doctor. They really see that as a gesture of extreme kindness and they feel like they are important and that remembrance was extremely important for them. The ability for a physician to follow up with the family has rated among one of the number one things that they appreciated and the follow up phone calls, letters, emails, newsletters certainly there are all sorts of methods that we have tried with follow up and the more different methods a family has in terms of being able to connect, the more they feel they had choice and that certainly has been highlighted as one of the primary things that they have really appreciated is the choice.

### **JACQUIE PEDEN**

I think we are going to move along. We have two questions that were actually sent by participants when they registered about resources and I know we did send out a resource list before, but we will talk about these questions anyway. The first one is from Elaine Marrington in Interior Health. She is asking if there are any internet resources for child caregivers to access for support in rural communities and actually Joy Graham from Internal Health also wants to know about strategies in rural areas. So maybe we can kind of combine that idea?

### **MARIA RUGG**

Sure. Certainly rural areas have been a struggle even in terms of our tertiary care centre making sure that we reach out to our rural partners. The one website that I would recommend for people is the Canadian Network for Palliative

Care for Children and that is [www.cnpcc.ca](http://www.cnpcc.ca) and, in fact, it has numerous links to a variety of resources specifically related to pediatrics around the world. One of those resources certainly is a website called ACT – the Association for Children with life threatening or Terminal conditions and their families which is a UK resource, but again, in terms of easy access, it is very easy to access and it is an excellent resource in terms of literature on different pain and symptoms on a variety of topics, both for professional caregivers and for families themselves because the website is divided into a couple of different areas and, certainly, it is a great connection in terms of parents and families living with children with life threatening illness to connect and also for professional caregivers to have the most up to date information when it comes to pediatrics in terms of pain and symptom management, grief and bereavement resources. They also have a bulletin board that you can sign up for which is free called PAED PAL. Any questions or comments or anything you want to put out there in terms of wanting to ask a huge variety of people who are specializing in pediatric palliative care. It is one of the best websites I have been to.

### **JACQUIE PEDEN**

Can you give those addresses again?

### **MARIA RUGG**

The Canadian Network for Palliative Care for Children is [www.cnpcc.ca](http://www.cnpcc.ca). ACT is [www.act.org.uk](http://www.act.org.uk). It is all lowercase.

### **JACQUIE PEDEN**

Thank you very much. I think we are ready now for questions from the participants.

### **LYNN CUMMINGS – VICTORIA, BRITISH COLUMBIA**

Thank you very much. It is actually Lynn Cummings asking the question. We're a program that has all age groups. We primarily deal with adults because that is the mortality rate. What suggestions do you have for staff support when we do have a child on program?

I think just to narrow it down we are a program that has a registration of all ages, so sometimes we have neonates right up to 100 year old patients. We are predominantly an adult program but when we have children, I think our skill sets are good but we need staff support. What would you suggest for staff support and dealing with the issues of identification and families losing children? I am just looking at your suggestions for staff support that you may have with you pediatric department.

### **MARIA RUGG**

I think in terms of staff support what we try to do is, in particular, meet frequently and often, make sure that it is multidisciplinary, ensure that there is never just one team member doing the majority of work with the family (that it is a shared care type of agreement because we realize that the multiple stressors that a dying child can put on a staff member individually), making sure that there is lots of

opportunity to bounce concerns and ideas, in a very open, non-judgmental forum and lots of opportunities to do that in multiple ways, so throughout our hospital oftentimes we have opportunities for staff to email or drop comments in an anonymous way because sometimes some of the ethical issues and challenges oftentimes that do occur with pediatrics make people feel extremely vulnerable in terms of bringing them forward, so we try to provide lots of opportunity for dialogue in non-judgmental ways that can remove any sort of stigmatization of that individual. Does that answer the question?

### **LYNN CUMMINGS – VICTORIA, BRITISH COLUMBIA**

Yes, thank you.

### **SIMONE STENEKES – HALIFAX, NOVA SCOTIA**

I have just a couple of comments in terms of cancer and being low in numbers, but I guess is our centre is comparable to those across Canada? Cancer forms the single largest group but is still very low in number, so it is only 1/3 of the children we see and 2/3 is made up of that entire consolation that you were describing. Children with oncologic diseases form the single one largest group of the 1/3 bulk.

The other thing that I was going to highlight that was kind of unique about pediatrics was that it is coming more in the form of anti-natal consultation, so even before birth and the involvement and capacity to be involved on that level is coming and changing.

### **MARIA RUGG**

Yes and I think that is becoming a whole new field of care – anti-natal hospice palliative care and field palliative care is certainly coming out in the recent few years in terms of the literature. Thank you Gerri (i.e., Dr. Gerri Frager) and Simone for bringing those comments forward because certainly when we talk about the spectrum of life threatening illness in children, we talk about diagnosis even before children are born that we are seeing now families needing that support and that kind of forethought and thinking forward.

### **SIMONE STENEKES – HALIFAX, NOVA SCOTIA**

Maria, I just have one more comment as well. In terms of resources, not necessarily for the kids themselves, but for the parents, the Canadian Virtual Hospice would also be something that would be quite helpful to health care professionals, parents and family members. It is [www.virtualhospice.ca](http://www.virtualhospice.ca).

### **MARIA RUGG**

That link is on the CNPCC website as well. Another great opportunity with the (Canadian) Virtual Hospice is you would be able to bring your questions forward as caregivers and have them answered by other professional caregivers.

### **SIMONE STENEKES – HALIFAX, NOVA SCOTIA**

Thanks. You knew I had to put a plug in for that.

### **OPERATOR**

Thank you. Your next question comes from Gary Paquin. He is calling from Edmonton, Alberta. Please go ahead.

### **GARY PAQUIN – EDMONTON, ALBERTA**

Yes. Hello. I am very interested in the way that life challenging illnesses affect the psychosocial development of the children in your hospital and ways in which the true psychosocial development of the child is assessed versus the place that they should be at given their chronological age. I was wondering if you could go through the process and some of the tools that you may use such as kinetic family drawings, play therapy or sandbox therapy to make a determination as to where the child is truly developmentally and whether or not development is impacted more by the severity of the disease or there is a point where the severity of the disease no longer has a greater impact at least linearly with regards to the child's developments?

### **MARIA RUGG**

So, I can very briefly say that that is not my area of expertise per se. We have a fantastic social worker who works on our team and quite actively with children as well as our child life therapist who are much in tune with those more intricacies of assessment in terms of development. Again, in terms of references, I could mail you out some of the references that they have and they use. I know from my perspective, we try to use a multiple and variety of ways of assessing where a child is at and in terms of illness and understanding of illness.

Developmentally, what we have found, at least anecdotally, and I certainly believe that some of the literature that I have read, that we have found that children as we would say are very wise beyond their years and in fact children who have had the opportunity to have open communication and be able to work through their feelings tend to have a greater ability to understand and communicate to us and feel, I hate to use the words, at peace, but feel they have the support and access that support from their family or the key people that they have noted in their lives that provide that support. I am sorry that I cannot answer your question more specifically, but it is just not my area of expertise and that is why it is fantastic to work with a great team of people. Certainly, I would be happy to refer you to any of the team members in terms of answering something like that more specifically.

### **GARY PAQUIN – EDMONTON, ALBERTA**

Well, thank you very much. I think that you have done a much better job than you are giving yourself credit for. If I may ask one brief addendum to that... Most of your talk has dealt with children who are members of family who are grief stricken, but essentially intact and able to give large amounts of support, love and attention. If a child were to come from a non-nurturing family environment, perhaps they may be under crown ward ship or something like that due to child abuse and their support system is simply non-existent or not good enough. Does this happen with any sort of regularity in your hospice practice and I assume the steps would be interdisciplinary to build a support system for this child if one doesn't exist already?

## END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME

### **MARIA RUGG**

Absolutely! We have worked with a number of children in foster care and certainly the challenges as you said very eloquently and are unique in that they present complicating features that would require, as I said back to the idea of using experts who can support them more specifically. What we try to do is funnel more resources to these children and their surrogate support systems because they will need more of that kind of support and help in working through some of these challenges.

I would have to say that what we have found in terms of the Children's AIDS Society (because that is how it is described in Ontario) and foster care and surrogate families is that they have been able to rally with these children and do phenomenal jobs in supporting them and each other in the work and the social workers and professional caregivers within these organizations have done quite a bit, at least in Ontario, in making sure they are educated in the principles of getting them up to speed and being able to be a support to these children and families.

My advice or only comment would be that it is important to collaborate with all sorts of community organizations because they will be key to supporting these children that don't fall within the normal family context and certainly we have tried to outreach in our palliative care service to even organizations that support homeless youths and those types of organizations as well in recognizing that there are children who come from a variety backgrounds and needs that we need to be able to address those unique features.

### **GARY PAQUIN- EDMONTON, ALBERTA**

Thank you very much Ms. Rugg. Best wishes.

### **MARIA RUGG**

Thank you.

### **AUDREY FINDLAY- WHITEROCK, BRITISH COLUMBIA**

Hello. This is Janet Furkt from the Hospice Society in Whiterock. I know in the greater New York area they are dealing with a brand new situation of children born with HIV/AIDS who are now living into their teen years and their early twenties and dealing with that matter. Is there any particular program at Sick Kids for that or any research being planned to exploring what these needs are?

### **MARIA RUGG**

Certainly, we have a team that deals with the HIV/AIDS children – a whole program in service and there are some studies (I am not sure where they are at in terms of long term effects, but certainly in terms of our contact with them we don't have a lot of contact with them because very few of these children are seen as children, but are living into young adulthood). What has developed out into the community is a hospice that works with children affected or infected with HIV/AIDS. They work with the families, parents, caregivers and children so they are either affected or infected. Their

specialty has become the support of these children on the long term. I think we will see more literature coming out in that. It is still fairly new. These children are still quite well and they haven't moved into the long term chronic phases of their illness.

**AUDREY FINDLAY- WHITEROCK, BRITISH COLUMBIA**  
OK. Thank you very much.

### **VICKY McEWAN – CHURCHILL, MANITOBA**

Hi. I am Vicky McEwan from Churchill Regional Health Authority. The question our group has this afternoon is if a sibling is dying, would it be appropriate to bring the other siblings to the bedside?

### **MARIA RUGG**

I am going to just repeat the question to make sure that I heard it correctly. If the sibling is dying, would it be appropriate to bring any of the other siblings to the bedside? Is that correct? ... (response was yes).

Again, I go back to what I talked about is really working within the family and again I will try to get away from talking about parents because we have families of all different kinds of constitutions, but finding out how does this family cope with information, how much does the child themselves know, how much do the siblings understand. Certainly we have the range of experience where we have had families who have said absolutely in no uncertain terms will the siblings be involved at this stage of the dying process. We have had other families who have had decided differently.

I can give one example because I know that this family has said feel free to use us because it is a teaching tool where they all climbed into bed and this child died at home. They all climbed into bed with this child as he was dying, including the youngest sibling (a seven year old and the dying child being thirteen). As a family, they were together at those moments and they spent his dying moments all together in the bed. I think whatever works goes in terms of is there any literature or research? I have not found any that talks about whether this is a good thing or a bad thing. I can only speak to you to anecdotal reports of families who have chosen to and who have chosen not to. One study that came out in the New England Journal last year talked about families who did talk to their dying children about their deaths and the majority of them did not regret having done so whereas the ones who didn't, a majority regretted having not spoken to them. That is really all that I can speak to and I am certainly ready to give that reference if anyone would like it and if they want to email me about that reference.

I think it is important to understand that we have to look in a context of a family and their life history and life story and how all this information has come about in order to make this a planned and helpful intervention.

## END-OF-LIFE CARE FOR CHILDREN: ADDING LIFE TO A CHILD'S TIME

### **JACQUIE PEDEN**

I would like to thank Maria for joining us today and sharing with us ways to support children and their families during end of life care. I would also like to read to you three take home messages that Maria has sent to me about this topic:

1. For children with progressive life threatening illness in their families, there are numerous compromises to be made when balancing between treatment and quality of life.
2. The burden of chronic illness and the care it demands can exhaust a family financially, physically and emotionally.
3. Lastly, as disease progresses the health care team and family must weigh the cost of unproposed treatment and the impact the treatment will have on the child's comfort and quality of life.