Ontario Rett Syndrome
ASSOCIATION OF CANADA

Transitioning with HOPE

Quality of Life & Advanced Care Planning Handbook

Version 03/01/2025

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QUALITY OF LIFE & ADVANCED CARE PLANNING

What is Quality of Life & Advanced Care Planning?

Quality of life and Advanced Care Planning (QOL/ACP) is a patient and family-centered approach to medical care that focuses on quality of life by identifying goals for care, incorporating family values and beliefs and focusing on comfort management. A QOL/ACP perspective can be supportive for anyone living with a chronic lifelong condition and help identify physical, intellectual, emotional, social, and spiritual needs to facilitate patient/family decision making, provide access to information and support personal choice of treatment options.

QOL/ACP, services are available with, or independent of, curative or life-prolonging treatment. Patient and family's hope for peace and dignity are supported throughout the course of a chronic illness, during the dying process, and after death. It is important throughout this process that your primary care team continue to be involved, rather than be replaced to support improved care.

QOL/ACP cannot be done in isolation; this form of care is best provided by an interdisciplinary team. Also, patients, families, and health care providers must collaborate and communicate about care needs throughout the course of illness and beyond (i.e., into bereavement).

Benefits of Integrating Quality of Life and Advanced Care Planning Early

Effective integration can happen at many time-points during your journey including at initial diagnosis; when treatment strategies change; for comfort/symptom management or when the primary care team, family or patient needs further support.

Some of the benefits to early integration include:

- Offering patients and families more autonomy when actualizing their roles in decision making
- Providing the primary team with new team perspectives
- Enabling families to hold dual goals of care by providing aid during supportive therapy
- Preventing a disruptive transition to a new care team during more difficult times
- Allowing the full scope of support to be available for families. (When QOL/ACP occurs late in the trajectory, it is difficult for the team to establish rapport, build a trusting relationship and employ all of the resources at their disposal to enhance quality of life for families.)

Common Myths about Quality of Life & Advanced Care Planning

Myth #1: Patients must be terminally ill or at the end of life

QOL/ACP, both as a philosophy and subspecialty, is recommended at any point in the patient's journey as an extra layer of support. The teams can offer consultative support during a heightened time of need.

Myth #2: Quality of Life & Advanced Care Planning = giving up hope

Not only is advanced care planning not the same as hospice (or end-of-life care), it also is not associated with the loss of hope. For example, an important paper showed that disclosure of a poor prognosis by a physician can actually support hope. Resource below.

Myth #3: Patients must have a Do Not Resuscitate (DNR) to have Advanced Care Plan

While a DNR order/documentation is often in line with the goals of care of families when faced with a terminal illness, this is not always the case. In fact, resuscitation should be treated like any other intervention with regards to its benefits and burdens and is important to discuss with any healthcare provider.

Myth #4: Must abandon all treatments

Good QOL/ACP often includes illness directed therapies. These forms of treatment are not only useful for maximizing quantity of life, but they also have a role in maximizing quality as well.

Myth #5: Administering some medications for pain/comfort management could cause respiratory depression and quicken death

Pain and comfort management are an important and an essential component of improving quality of life. When titrated appropriately with your medical team, the risk related to medication toxicity causing significant respiratory depression and hastening death is significantly low. The team will partner with you at your comfort and focus on your goals for treatment. It is important should you see any early signs of toxicity with any new medication, such as drowsiness, confusion, difficulty breathing and/or loss of consciousness that you notify your medical team or seek medical attention immediately prior to any significant respiratory concern.

COMMUNICATION

Health care providers should communicate honestly with a seriously ill patient and his or her family about prognosis and expected illness trajectory is central to excellence in all care for individuals living with a chronic life limiting condition and especially for quality of life and advanced care planning and end-of-life care. Honest prognostic discussions, as difficult as they are, allow the patient and family to anticipate what they will likely experience and empower them to make effective decisions about their ongoing care. Engaging in these discussions also enables the medical provider to explore the family's goals, needs, hopes and fears. No caregiver enjoys talking about the possibility/likelihood that there is no further curative treatment available for their loved one, however research has taught us that caregivers want to have these honest discussions with their medical provider. At times, your non-verbal is more important than verbal communication. Silence, being present, accessible and approachable are all very important skills for effective communication in quality of life and advanced care planning.

Advanced Care Planning

Advanced care planning (ACP) is necessary for any individual with a neurological condition such as Rett syndrome. It requires effective communication to clarify the goals of care and establish agreement on appropriate interventions for the patient prognosis. Ideally, ACP discussions should happen early and in a non-urgent fashion to help caregivers digest complex decision-making. ACP should be implemented even though it is difficult to exactly predict the timing of a decline in health or death. Important topics to review in ACP include:

1. Seriousness of illness
2. Expected course, treatment options and risk/benefits to each.
3. Treatment options may include antibiotics, blood replacement products
4. How long to continue and when to limit certain aspects of the treatment play
5. Will treatment prolong life but at a cost to suffering? Will treatment prolong life and improve quality of life?

6. Benefits and impact of artificial nutrition and hydration at end of life
7. Reassurance that the patient will be offered fluids and foods by mouth for comfort providing ability
8. Focus on minimizing distress and easing suffering
9. Review of pain medications and comfort care
10. Family-centered care and the focus on siblings
11. Resuscitation
12. What does death look like: included in the section on End of Life (EOL) care

Resuscitation

Resuscitation status is a small but integral part of ACP. Discussions about resuscitation should be incorporated into the larger issue of goals of care, as the benefits of CPR when goals become focused on optimizing comfort are questionable. Caregivers typically obtain their information about resuscitation from the media. Some caregivers have expressed worry that “DNR” means “Do Not Treat”; they may have the misperception that if there is a DNR in place, their loved one will not have access to pain and symptom management and other aspects of supportive care, leading to increased suffering.

SETTING OF CARE

Most patients and their families prefer to be at home, if at all possible, but understand the need for outpatient visits and hospitalizations when necessary. However, as the patient's illness and care needs progress/increased, alternative options to support care can be helpful (respite, hospital or hospice). Any setting can be adapted to the individual's situation. Consider consultation with a quality of life and advanced care planning team when caregivers are familiar with caring for the individual but unfamiliar with provision of care to the medically complex, sick or dying, or where there is familiarity with provision of care for a condition but not for children or adult. This team can add experience in symptom management, communication and ethical issues which arise throughout a life span.

Home

Should you wish to have an end-of-life approach within your home a local team can help re-evaluation the physical set up of the home to accommodate the changing care needs of the individual and to seek supports to meet these needs (i.e., Quality of Life and Advanced Care Planning team, nursing, personal support workers, physiotherapy, occupational therapy, social work, interlink nurse). Regular contact with care providers in person, by phone or using technology will be helpful to ensure the family continues to feel supported. Clinician home visits and 24/7 access to telephone advice is often necessary for optimal comfort and symptom management.

Hospice

In some areas, care in a hospice setting may be available and may allow increased support for the family in a more home-like setting than a hospital. Discussion with a local hospice to discuss types of care available should include family members. Specialized hospices are available in some areas, and some individuals and families may already be familiar with

Hospital

Some families just prefer the additional support and reassurance that comes with the hospital setting for their loved one's end-of-life care.

END OF LIFE

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

Revisiting Goals of Care

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

1. Location of care (home, hospice, hospital) will be determined by the individual and family choice and may change over time. If hospital care is preferred, the individual room (if not already in place) allows the family more private time together. Decision about care at home includes interventions still desired as well as nursing and medical support available. Care in hospice may be preferred by some families to provide access to increased medical support in a home-like setting.

2. Review of interventions with discontinuation of those which are no longer desired. Interventions that may be discontinued include blood work, antibiotics, IV fluids and medications, oxygen (unless indicated for comfort), transfusions. Discussion about natural reductions in appetite and thirst at the end of life is essential. The suggestion of offering the individual food and drink but allowing the body to determine the need is often helpful to families.

3. Allow a natural death – confirm that cardiopulmonary resuscitation is no longer in individual's best interest, benefit and harms of oxygen and suctioning, complete care directive if indicated and provide DNR-C form.

DNR-C form is used by Health Care Facility Staff and Regulated Health Care Providers. It is a Provincial form used in situations where a plan of treatment has been developed where CPR is no longer medically indicated. Without this form, Emergency Medical Service Providers are required to perform CPR and for a death for a child under the age of 18 Emergency services are required to secure a home until a coroner can confirm a natural cause of death. When the family provides this form, it allows the responders to focus on providing comfort-based support including pain management, oxygen and comfort measures. This form also notifies emergency services that the individual had a life limiting condition, and a death was anticipated.

Physical changes which may be seen as end-of-life approaches include the following:
Changes in gastrointestinal functioning with failure to absorb drugs, food and fluid; diarrhea or constipation. Discussion of these changes may improve understanding of decreased appetite and thirst outlined above.

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

Care interventions which may improve comfort as death approaches:

1) Review of medication, with discontinuation of all non-essential medication. Oral medications should be converted to subcutaneous or rectal routes (or IV if central line is present).

2) Medications made available for symptoms which may occur and instructions on when these medications should be used. Symptoms may include pain, agitation, respiratory tract secretions, nausea and vomiting.
3) Positioning
    a) Individual to identify most comfortable position if able to do so, otherwise care givers should use their best judgment based on the individual's appearance
    b) Consider pressure relieving mattress to avoid or alleviate pressure wounds
4) Eyes may become dry if there is protrusion of the eye or if their eyelids don't close fully. Lubricating eye drops may increase comfort.
5) When fluid intake is minimal, attention to mouth care is essential. Lubricants can be provided or frequent moistening with water (still or carbonated soda water) is comforting.

Other Considerations:

1) Support is essential throughout the trajectory of disease but especially during the end of life. Maintaining connections with the Physician, Case Manager RN, clinic staff, Interlink RN, Social Workers and Spiritual Support caregivers can allow the family trusted people to provide emotional support and coping skills. If not already in place, referral to home Quality of life and advanced care planning is advised.
2) Memory making includes photographs, hand/footprints, plaster castings, memory box, scrap book etc.
3) Religious/spiritual needs discussed, and plans put in place.
4) Funeral planning may be done in advance or may be done after death is confirmed. Identify who will assist the family in this planning.
5) If death is to occur at home identify who to call (MD support, nursing support, spiritual support) including who can confirm death and who should be notified after death.
6) Autopsy – if medical need, family need, legal requirement
7) Bereavement resources available in the community for parents, siblings and extended family members should be provided.

TISSUE & ORGAN DONATION

The advancement of scientific discoveries towards treatments and a cure for Rett syndrome depend on the ability of researchers to study how mutations in the MECP2 gene affect growth and development. You can help researchers by donating your loved one's organs to research.

Brain Donation

If you decide to proceed with organ donation after death it is critical that you notify your medical team about your wishes prior to death or immediately after a death has occurred, as they require to medically prepare the body for organ donation to be successful.

For general organ donation your medical team can help support you with the process and discuss in more detail how this can occur after a death.

For Rett specific research organ donation, please have your medical team contact the Dr. Rastegar's Laboratory within 24 hours of a death for brain donation for Rett Syndrome Research before any preparations (cremation or embalming) occurs. Know that donation will not interfere with any funeral arrangements, including viewing. The kind and respectful staff at the Manitoba University Laboratory will handle all arrangements directly with the hospital, hospice nurse, coroner, or pathologist. Dr. Rastegar's available to answer any question you may have and support you during this process. In this package you will find an organ donation brochure with more information regarding the process, the formal consent form and wallet cards to keep in case of emergency.

The University of Manitoba
http://rastegar.biochem.umanitoba.ca/

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Organ Donation

Now in Ontario, you can register your consent to become an organ and tissue donor online. It only takes a few minutes to register but one day could save 8 lives and enhance 75 more. Visit BeADonor.ca to learn more about organ and tissue donation, watch stories of lives that have been changed by organ and tissue donation and to register your consent to donate

RESOURCES FOR FAMILIES

1) Canadian Mental Health Association: To find your local program go to ontario.cmha.ca; Website also provides literature to provide to families.
2) Local funeral homes often offer bereavement programs for adults and children
3) Local churches may offer support groups and counselling
4) Bereaved Families of Ontario: bereavedfamilies.net
5) centerforloss.com – another good resource for helping families who are mourning
6) afterloss.com – an excellent monthly newsletter for those wishing help at home
7) fernside.org – a club for kids and teens dealing with death
8) griefwords.com/index.cgi?action=page&page=articles%2Fmourners.html&site_id=5 –Mourner's Bill of Rights, Alan D. Wolfelt
9) centerforloss.com/who-are-you/someone-i-love-has-died/ – The Mourner's Six "Reconciliation Needs", Alan D. Wolfelt
10) speakupontario.ca/resources-for-individuals-and-families/
11) hamiltonhealthsciences.ca/mcmaster-childrens-hospital/areas-of-care/services/quality-of-life-advanced-care-program/
12) cheo.on.ca/en/clinics-services-programs/palliative-care.aspx
13) Grievingchildrenlighthouse.org
14) courageousparentsnetwork.org/topics/end-of-life-and-bereavement
15) complexchild.org/
16) sickkids.ca/en/care-services/support-services/grief-bereavement-resources/
17) Book: It's OK That You're NOT OK: Meeting Grief and Loss in a Culture That Doesn't Understand, by Megan Devine

RECONCILING YOUR GRIEF

You may have heard – indeed you may believe – that your grief journey's end will come when you resolve, or recover from, your grief. But your journey will never end. People do not "get over" grief.

Reconciliation is a term that may be more appropriate for what occurs as the mourner works to integrate the new reality of moving forward in life without the physical presence of the person who died. With reconciliation comes a renewed sense of energy and confidence, an ability to fully acknowledge the reality of the death and a capacity to become reinvolved in the activities of living.

In reconciliation, the sharp, ever-present pain of grief gives rise to a renewed sense of meaning and purpose. Your feelings of loss will not completely disappear, yet they will soften, and the intense pangs of grief will become less frequent. Hope for a continued life will emerge as you are able to make commitments to the future, realizing that the person who died will never be forgotten, yet knowing that your life can and will move forward.

FUNERAL ARRANGMENT CHECKLIST

Please call the funeral home of your choice as soon as possible to set up an appointment.

INFORMATION WHICH MAY BE REQUIRED BY THE FUNERAL HOME:

1. Necessary information regarding the deceased person:

   Name:

   Date of Birth:

   Place of Birth:

   Social Insurance #:

   Health Card #:

   Names & birthplaces of both parents:

   Father:

   Mother:

2. Do you own a cemetery plot?

   In which cemetery?

   Do you wish burial or cremation?

3. Call all family and friends in and outside of the city (you may wish to make a list and check them off one at a time).
4. Sit down as a family and decide:

What financial resources are available (bank accounts, insurance, pensions, etc.)

Approximate day and time you would like to hold the funeral:

Person you wish to conduct the funeral service:

Names of pallbearers as appropriate:

1. ___________________________________ 4. __________________________________

2. ___________________________________ 5. __________________________________

3. ___________________________________ 6. __________________________________

5. Prepare information for newspaper notice:

(Note: Your local newspaper may need the notice in by a certain time in order for it to be published the next day. The funeral home will usually contact the newspaper for details regarding Monday's publication).

Names of Parents:

Names of Brother(s) & Sister(s):

Names of Maternal Grandparents:

Names of Paternal Grandparents:

Others:

Other information you wish to include:

If you wish memorial donations, to which charities?

Appointment with the Funeral Director:

When you go to the appointment, please bring with you:

- The information contained in this pamphlet, Birth Certificate, and Social Insurance card (if applicable).
- All clothing.

- A recent photograph (if available).

The Funeral Director may:

- Contact the clergy of your choice and confirm the day and time for the service (if you haven’t already).
- Assist you with arrangements for cemetery plot(s).
- Make arrangements for a newspaper notice
- Provide you with copies of “*Statement of Death*” for insurance purposes, etc.

HELPING CHILDREN WHO GRIEVE

Children grieve when someone a loved dies – even though they may not seem old enough to understand. They need to be prepared for and included in the process. By being honest, open, and loving, adults can help children grieve in a healthy way. Some suggestions that may be of assistance:

- Tell your child what is happening in simple honest and clear language that they can understand. Give only the information requested. Use factual words like "die" rather than "gone away" or "asleep".
- Hold them. Let them cry. Don't be afraid to cry with them. Acknowledge the reality that grief hurts.
- With warm sensitivity, listen to the child – to their feelings as well as their words. Let them know that it is OK to be sad or angry – that all their feelings are normal. Assure them that nothing they thought, did or said caused the death. Don't hide or deny feelings.
- Ask the child if they have any questions. They may need to ask the same questions over and over. If you don't have all the answers, don't pretend you do. They need your listening presence, more than answers.
- Realize that grief causes difficulty in concentration. Schoolwork may be affected.
- Maintain a daily routine if possible.
- Encourage your child to decide what he or she needs and would like to do – e.g., visit a dying loved one. Prepare the children for what they will see, hear, smell and do.
- Value and share cherished memories. Honour your loved one through special rituals.
- Explore religious and spiritual beliefs. Don't worry if you don't have all the answers – just do your best to explain your beliefs in words children can understand.
- Talk about whether the child wishes to attend the funeral or not. Explain that the funeral is a time to honour and remember the life of the person who died. Consider the child's age, understanding of death and closeness to the deceased.
- Find age-appropriate ways for children to participate in the funeral: sharing a memory, reading a poem, or drawing a picture (it could be copied and used for the service folder).

Grief is a natural expression of love for someone who has died. How grief is expressed will vary from child to child. You know your child best and need to do what is best for him or her.

There are books on grief for your child to read or for you to read with your child. A list of resources is included in this package. Check with your local bookstore or public library.

Bibliography

- Saying Goodbye with Love, Sheila Martin, Crossroad Publishing 1999.
- Creating Meaningful Funeral Ceremonies, Alan D. Wolfelt, Ph.D.
- funeralplan.com/grief support

COPING WITH THE HOLIDAYS

For those who are grieving, coping with the holidays is no small task. These suggestions will help to make your grief a little easier and your holiday season a little lighter.

Be with those who comfort you:

Share your thoughts with someone you trust and are comfortable talking to. Trying to ignore the absence of a loved one can make you feel alone and depressed.

Acknowledge and accept your feelings:

The holiday magnifies our feelings of loneliness, bitterness, anger, frustration and depression. All the emotions you experience in grief are natural reactions to the death of a loved one. Don't feel pressured to be joyful and celebrate; these may not be the feelings you are experiencing. However, don't feel guilty if you do enjoy yourself.

Remember:

Include your loved one's name in conversation and share your memories. Remember the good times as well as the bad. Remembering is a very healthy and healing experience. You can laugh and cry as you remember times spent together.

Eliminate unnecessary stress:

Don't do anything that is extremely uncomfortable for you. If you don't feel like putting up decorations, buying presents, going to church, synagogue, mosque, then don't do it. Keeping busy only increases stress and postpones working through grief. Lower your expectations for the holidays and do what you can when you can.

Plan ahead:

Make plans for the holidays, even if the plans have to change. It is more beneficial to plan than to just let it happen. You may choose to celebrate as usual, or you may:

- Change the time of eating your traditional dinner.
- Change the room to eat dinner in.
- Go out for dinner to a restaurant or accept an invitation to someone's house
- Change the menu from the usual; cook ham instead of turkey.
- Go to church at a different time than you usually do or sit in a different location.
- Change the type and size of your tree and put it in a different spot in the house.
- Change the time that you usually open presents.

Tears are not a sign of weakness, foolishness or lack of faith. Tears are evidence of the capacity to care.

-Rev. Dale Turner

THE GRIEF EXPERICENCE

Because grief can be so painful and seem overwhelming, it frightens us. Many people worry if they are grieving in the "right" way and wonder if the feelings they have are normal. Instead of judging, it is more helpful to be patient and accept that every person's grief, including our own, is different.

Most people who suffer a loss experience one or more of the following:

Physical Responses:

- Tightness in the throat or heaviness in the chest. If these feelings persist, you should talk with your physician.
- An empty feeling in one's stomach
- A gain or loss of appetite or pleasure.
- Difficulty sleeping (may have nightmares)
- Over-sensitivity to noise
- A sense of depersonalization
- Breathlessness/sighing
- Nervousness, tension, agitation, irritability
- Dizziness
- Lack of energy; initiative motivation Dry mouth
- Decreased or increased sexual desire
- Heart palpitations, trembling, hot flashes and other indications of anxiety.

Emotional Responses:

- Restlessness and difficulty concentrating
- Feeling that the loss isn't real, that it didn't happen
- Sensing the person's presence; hearing their voice, seeing their face or expecting them to walk in the door at the usual time
- Forgetting and not finishing things you have started to do
- Preoccupation with the life of the deceased person

- Feelings of guilt or anger over things that happened or didn't happen in the relationship
- Mood swings over the slightest things
- Crying at unexpected time; feelings of sadness
- Feelings of anxiety over one's future or questions regarding one's own death
- Loneliness – emotional or social
- Fatigue
- Shock
- Yearning, searching
- Relief
- Numbness – overwhelmed with so many feeling

Interpersonal Responses:

- Feeling as though you need to take care of other people who seem uncomfortable and who refrain from talking about your own feelings of loss.
- Needing to tell and re-tell and remember things about the lost relationship.
- Social withdrawal or loss of interest in the outside world
- Avoiding reminders of the deceased

If your experiences become overwhelming causing you concern, do not hesitate to contact a support person such as:

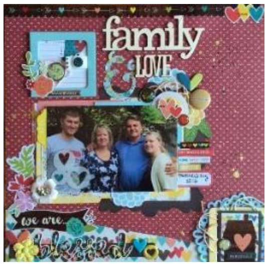
- your physician
- a clergy person
- a mental health professional
- a trusted friend or family member

LEGACY OF LOVE ACTIVITES

A Way for Families to Share Special Moments Together

These activities can provide an opportunity to reflect on the events and people that have made an impact on your or your loved one's life and can be a powerful coping tool for those who are ill as well as their family and friends.

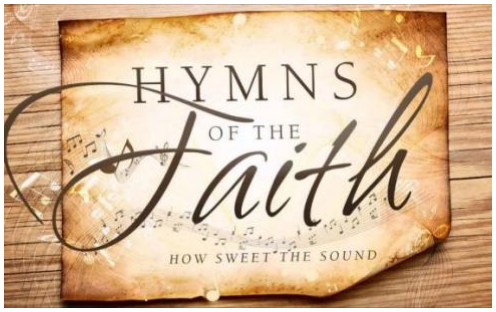
Create a scrapbook with pictures/keepsakes related to a particular time in your life, a loved one, a favorite vacation



Create a photo album of favourite photos with accompanying captions

Compile a binder of favourite recipes

Compile a collection of favourite songs or hymns



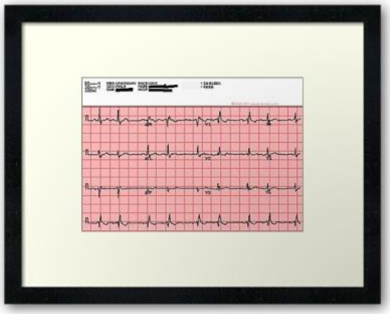
Create a quilt made from your favorite T-shirts or other fabric items

Handprints of you and/or your loved ones in plaster

Pay it forward, purchase someone else’s birthday cake in memory

Plant a tree in memory

Capture a heartbeat



Transcribe your feelings into poetry

REFERENCES

- Balfour Mount. 1973
- CAPC, Public Opinion Research on Palliative Care, 2011
- EPEC (education in palliative and end-of-life care) – Pediatrics. 2014
- Feudtner, C, Kang TI, Hexem KR, Friedrichsdorf, SJ, Osenga,, Siden, H, Friebert, SE, Hays, RM, Dussel, V, Wolfe, J. Pediatric palliative care patients: a prospective multicenter cohort study. 2011;127(6):1094-1101.
- Friedrichsdorf SJ. Pain management in children with advanced cancer and during end-of-life care. Pediatric HematolOncol. 2010;27(4):257-261
- http://www.nhpco.org/palliative-care-0
- Liben, S., Papadatou, D., & Wolfe, J. (2008). Paediatric palliative care: Challenges and emerging ideas.371(9615), 852-864. doi:10.1016/S0140- 6736(07)61203-3
- Mack JW, Wolfe J, Cook EF, Grier H, Cleary PD, Weeks JC, Hope and Prognostic Disclosure. Journal Of Clinical Oncology. 25:5636-5642. 2007
- Mattie Stepanek 1990-2004
- Pastrana et al, A matter of definition – key elements identified in a discourse analysis of palliative care, Palliative Medicine 2008; 22: 222–232
- Temel JS, Greer JA, Muzikansky A, Gallagher ER, Admane S, Jackson VA, Dahlin CM, Blinderman CD, Jacobsen J, Pirl WF, Billings JA, Lynch TJ. Early palliative care for patients with metastatic non-small-cell lung cancer. NEJM. 2010;363(8):733-742.
- Thorns A, Sykes N. Opioid use in last week of life and implications for end-of-life decision-making. Lancet. 2000;356(9227):398-399
- Wolfe J, Hinds PS, Sourkes BM, eds. Textbook of Interdisciplinary Pediatric Palliative Care. Philadelphia, PA: Elsevier; 2011
- Mack JW, Wolfe J, Grier HE, Cleary PD, Weeks JC. Communication about prognosis between parents and physicians of children with cancer: parent preferences and the impact of prognostic information. J. Clin. Oncol. Nov 20 2006;24(33):5265-5270.
- Editors in chief of Section 5.0 Palliative Care include Dr. Adam Rapaport, The Hospital for Sick Children, Toronto and Dr. Alisha Kassam, Southlake Regional Cancer Centre, Newmarket.