

Faculty of Medicine

This Changed My Practice (UBC CPD)

Preparing children for the medically assisted death of a loved one

By [Dr. Susan Woolhouse](https://thischangedmypractice.com/author/susan-woolhouse/) (https://thischangedmypractice.com/author/susan-woolhouse/) on February 26, 2020

Receive 0.25 Mainpro+ or MOC Section 2* study credits per article, click on the link below, between votes and comments. Credits directly uploaded to CFPC and RCPSC!

By Susan Woolhouse, MD, MCISc, CCFP, FCFP ([biography and disclosures](#) - <http://thischangedmypractice.com/bios/#suwoolhouse>.)

Disclosure: Co-Chair of the Ontario College of Family Physicians Palliative/End of Life Care and MAID Collaborative Mentoring Network. Medical advisor on the Behaviour Protocols Committee at L'Arche Community (volunteer). No conflicts of interest. Mitigating Potential Bias: Recommendations are consistent with the evidence-based literature about and practice standards on how to support grieving children and their families. Given that MAID is so new, tips are extrapolations from this literature.

What care gaps or frequently asked questions I have noticed

There is a prevailing assumption from health care providers and families alike that children should not be present at the medically assisted death of a loved one.

I have had the privilege of being involved in over 70 assisted deaths, either as an assessor or provider. The average age of individuals receiving medical assistance in dying (MAID) is 72 (1). In my experience, they die surrounded by their adult children and, occasionally, by their grown grandchildren. One day I received a referral for a 40-year old man, and I realized how ill prepared I was to support a family with young children through MAID. Yet, instinct told me that involving children in the MAID process of their loved one was possibly one of the most important and therapeutic experiences for a child. My past experiences during my palliative care rotations reassured me that children could benefit from bearing witness to a loved one's death. Why would MAID be any different? I set out to learn more about how children grieve and ways in which I could support children through the dying of a loved one seeking MAID.

What I recommend

TIP 1: Consider having children present.

In my experience, involving children during the dying of loved one is not even a consideration for either the families involved in a MAID death or the majority of clinicians who provide MAID.

TIP 2: If you are involved in caring for a dying person, ask if there are children who will be affected by the death of the individual.

Just under 7,000 people received an assisted death in Canada between December 2015 to October 31, 2018 (1). Approximately six to seven percent of people receiving MAID are under the age of 55 (1). MAID provisions are expected to rise in number as more and more Canadians gain awareness of this as an option, as thus, the number of younger people seeking MAID will also presumably rise. This will result in more children being impacted by the assisted death of a loved one.

TIP 3: Arm yourself with a few helpful "facts" to discuss with adults/caregivers.

This is what I tell parents/caregivers:

Contrary to our instinct to protect children, children who have more end-of-life information have less anxiety, better trust in health care professionals and better psychological well-being. (2-4)

A Swedish study that explored parents talking to their dying children about death found that no parent regretted speaking candidly to their children, but that one third of parents who did not have these frank discussions regretted not having done so. (5)

We can care better for children by preparing them for life's hard stuff.

Assuming that children are given honest, compassionate and non-judgmental information about MAID, there is no reason to think that witnessing a medically assisted death cannot be integrate as a normal part of the end of life journey for their loved one. If the adults surrounding them normalize MAID, so will the children.

TIP 4: Offer the family the option of involving children in the MAID process.

You can ask: "Can I provide you with some information about how you might talk with your children about MAID?" In order to do this, parents/caregivers will need some tools about how to approach this difficult conversation. Here are some of the suggestions that I give families:

Have the adult initiate the conversation about death and dying and then let the child take the lead about how much information they want. You can try starting the conversation with: "I'm wondering if you can tell me what you understand about what is happening to [their loved one]?"

Make sure to name and explain the disease using correct language. Be honest about what you don't know. There are many great resources directed at helping to explain dying and terminal illnesses to children. (Resources #1-4).

When explaining MAID to children, reinforcing that dying is not due to lack of effort is important. Their loved one wants to live and watch them grow up. But their disease makes this impossible. You can also explain that the disease does not have a cure and that despite trying different treatments their loved one is going to die. Here is a suggested way to explain MAID:

"In Canada, when someone has an illness that will cause their body to die, they can wait for this to happen or they can ask a doctor help. The doctor or nurse uses a medication that stops the body from working and causes the body to die. This is done in a way that isn't painful".

There are great resources to help guide these conversations (Resource #5,6).

TIP 5: Ask the child!

Each child is unique and a child's interest in being involved is more dependent on temperament than on age. Offer to have an "Ask the Doctor" session with any children affected by the death when children can meet with the MAID provider and have their questions answered (6). These conversations can easily be had with children as young as 4.

Ideas about how to support children during MAID:

TIP 6: Explain exactly what you are going to do and why.

Offer to show your equipment (syringes, stethoscope, IV supplies). For example:

"I have a tray with the things that I will use to help your loved one die. These include medications and syringes. I am going to leave them on this table and if you would like to take a look you can. I will stand beside the table and you can ask me any questions."

TIP 7: Explain what they will see/hear/feel when the body dies.

Use clear language and avoid euphemisms. Remember, children are literal thinkers. Use the terms death, dying, dead and died. If you tell them that their mother is asleep, they might expect her to wake up. Here is what I say: *"I am going to give your [loved one] medication over a period of about ten minutes. This medication will make her very look very tired and then she will very quickly go into a coma. This means that she will no longer be able to hear, see or feel any pain. You might hear strange breathing sounds, however these do not cause her any pain. Her skin will get colder and maybe even change colour. She will stop moving her body. Her heart will eventually stop beating and this means that her body has died. When a body dies, it can no longer see, feel pain, or hear. It can't ever be fixed."* Note that once a person has died, I do not use the loved one's name when referring to the body so as to help children understand that their loved one is no longer alive. For example: *"Your mom was really special to you. I know you are sad that your mom died. Would you like to spend more time with the body?"*

TIP 8: Give children choice and control about being involved.

I often walk children into the room where the MAID procedure will happen and talk about where they might want to sit. If possible, assign a designated adult to support the child in case they wish to leave as it may not be realistic that the spouse of the dying parent leave the bedside. It is a good idea to have an activity ready in another room (especially for younger children). Regardless of whether or not they have been present for MAID, children can be given the option of having time with the body after their loved one has died. Seeing and feeling that their loved one is not breathing and there is no heartbeat can be helpful in order to understand the permanence of death, especially for young children. Children also appreciate being given the opportunity to have ways to say goodbye, and can make crafts for their loved ones to have with them during their assisted death. A great idea given to me by Andrea Warnick, a national leader on children's grief, was to make a "Hug" to wrap around their loved one as they die. Some families choose to have their loved ones buried with their "Hug" or may take it back as a memento. See below for directions on how to make a "Hug" ([see Handout \(http://med-fom-tcmp_sites.olt.ubc.ca/files/2020/01/Make-a-Hug.pdf\)](http://med-fom-tcmp_sites.olt.ubc.ca/files/2020/01/Make-a-Hug.pdf)).

Acknowledgements:

My experience in supporting children through the dying and death of a loved one comes from my own MAID practice, volunteer work at Camp Keaton (a camp for bereaved children), continuing professional development and mentorship from staff at the Bob Kemp Hospice and Andrea Warnick Consulting. I owe special thanks to Andrea Warnick, Sue Repa, Nicola Elbro and Lisa Robinson for sharing their wealth of knowledge with me. Much of my writing today are tips I have learned from them.

References:

1. Health Canada. Fourth Interim Report on Medical Assistance in Dying in Canada. Published April 2019. Accessed January 17 2020. ([View \(https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019/medical-assistance-dying-interim-report-april-2019-eng.pdf\)](https://www.canada.ca/content/dam/hc-sc/documents/services/publications/health-system-services/medical-assistance-dying-interim-report-april-2019/medical-assistance-dying-interim-report-april-2019-eng.pdf).)
2. Dalton L, Rapa E, Ziebland S, et al. Communication with children and adolescents about the diagnosis of a life-threatening condition in their parent. *Lancet*. 2019;393(10176):1164-1176. DOI: 10.1016/S0140-6736(18)33202-1. (View with [CPSBC \(https://www.cpsbc.ca/user/login\)](https://www.cpsbc.ca/user/login) or [UBC \(http://ezproxy.library.ubc.ca/login?url=http://dx.doi.org/10.1016/S0140-6736\(18\)33202-1\)](http://ezproxy.library.ubc.ca/login?url=http://dx.doi.org/10.1016/S0140-6736(18)33202-1).)
3. Raveis V, Siegel K, Karus D. Children's psychological distress following the death of a parent. *J Youth Adolesc*. 1999;28(2):165-180. DOI: 10.1023/A:1021697230387. (Request with [CPSBC \(https://www.cpsbc.ca/article\)](https://www.cpsbc.ca/article).)

requests), or view with UBC (<http://ezproxy.library.ubc.ca/login?url=http://dx.doi.org/10.1023/A:1021697230387>.)

4. Grenklo T, Kreicbergs U, Valdimarsdóttir U, et al. Communication and trust in the care provided to a dying parent: a nationwide study of cancer-bereaved youths. *J Clin Oncol*. 2013;31(23):2886-94. DOI: 10.1200/JCO.2012.46.6102. (Request with CPSBC (<https://www.cpsbc.ca/article-requests>), or view with UBC (<http://ezproxy.library.ubc.ca/login?url=http://dx.doi.org/10.1200/JCO.2012.46.6102>).
5. Prchal A, Graf A, Bergstraesser E, et al. A two session psychological intervention for siblings of pediatric cancer patients: a randomized control trial. *Child Adolesc Psychiatry Ment Health*. 2012;6(3):1-9. DOI: 10.1186/1753-2000-6-3. (View (<https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3398278/pdf/1753-2000-6-3.pdf>).
6. Warnick A. This changed my practice: The unvoiced questions of children experiencing an illness, dying, or death in their family. April 2015. (View (<http://thischangedmypractice.com/unvoiced-questions-of-children-grief/>)). Accessed January 21 2020.

Resources:

1. Warnick, A. When to Tell the Children: Preparing Children for the Death of Someone Close to Them. Canadian Virtual Hospice. (View (http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Topics/Topics/Communication/When+to+Tell+the+Children+_Preparing+Children+for+the+Death+of+Someone+Close+to+Them.aspx)). Published May 2019. Accessed January 21 2020.
2. Makri, A. Explaining to the kids: Telling teenagers about a dementia diagnosis. Alzheimer's Society. (View (<https://www.alzheimers.org.uk/dementia-together-magazine/oct-nov-19/explaining-kids-telling-teenagers-about-dementia-diagnosis>)). Published September 2019. Accessed January 21 2020.
3. Delisle, R. How to tell your kids a loved one has cancer. How to tell your kids a loved one has cancer. Today's Parent. (View (<https://www.todayparent.com/family/parenting/how-to-tell-your-kids-a-loved-one-has-cancer/>)). Published February 2018. Accessed January 21 2020.
4. Als411. ALS Society of Canada. <http://www.als411.ca/> (<http://www.als411.ca/>). Published 2008. Accessed January 21 2020.
5. Explaining Medical Assistance in Dying (MAID). Canadian Virtual Hospice. (View (<https://kidsgrief.ca/mod/lesson/view.php?id=281&pageid=621&startlastseen=yes>)). Published 2017. Accessed January 21 2020.
6. Medical Assistance in Dying. Dr. Jay Children's Grief Centre. (View (<https://drjaychildrensgriefcentre.ca/programs/medical-assistance-in-dying/>)). Published 2017. Accessed January 21 2020.
7. Consultation resource from <https://kidsgrief.ca> (<https://kidsgrief.ca>). Accessed February 26, 2020. Email: KidsGriefQA@virtualhospice.ca (<mailto:KidsGriefQA@virtualhospice.ca>) and free online Q&A every month.
8. Canadian Virtual Hospice "Ask A Professional": pose a question and get a response from one of their team members (View (http://www.virtualhospice.ca/en_US/Main+Site+Navigation/Home/Support/Support/Ask+a+Professional.aspx)). Accessed February 26, 2020.

HANDOUT "MAKE A HUG" (<http://med-fom-tcmp.sites.olt.ubc.ca/files/2020/01/Make-a-Hug.pdf>)

Preparing children for the medically assisted death of a loved one

By Susan Woolhouse, MD, MCISc, CCFP, FCFP

View: <http://med-fom-tcmp.sites.olt.ubc.ca/files/2020/01/Make-a-Hug.pdf> (<http://med-fom-tcmp.sites.olt.ubc.ca/files/2020/01/Make-a-Hug.pdf>).

1. take an light coloured bed sheet
2. lie it on the floor
3. lie down on top of it with your arms outstretched (like a snow angel)
4. trace out the arms with a thick marker
5. get up and you will be left with an outline of two arms that are not attached
6. use the marker to attach the two arms making one really long arm with hands at each end
7. this is now a "hug" that can be wrapped around your loved one as they are dying
8. you can decorate each "hug" with drawings, writing, poems, etc
9. some people take their hug back after their loved one dies and some people have their loved one buried/cremated wearing their hug

Acknowledgement:

"Make A Hug" was a bereavement tool presented by Facilitator Andrea Warnick, RP, RN, to students attending the "Certificate in Children's Grief and Bereavement: Module 1 – Preparing Children for the Death of Someone Close to Them" on May 6, 2019 at the SickKids Centre for Community Mental Health Learning Institute; Toronto, Ontario.

Please indicate how this article will change your practice:

Preparing children for the medically assisted death of a loved one

- I disagree with this approach
 I will consider changing my practice, but need more information/time
 I will likely change my practice
 I will definitely change my practice
 I already do this

[Vote](#)

[View Results](#)

6 responses to “Preparing children for the medically assisted death of a loved one”

Jill

[Permalink](#)

February 27, 2020 (Thursday, February 27th, 2020, 1:25 pm) at 1:25 pm (Thursday, February 27th, 2020, 1:25 pm)

This a beautiful, thoughtful piece. Thank you

Heather

[Permalink](#)

February 27, 2020 (Thursday, February 27th, 2020, 2:50 pm) at 2:50 pm (Thursday, February 27th, 2020, 2:50 pm)

Thank you for this insightful approach. It helps to enter into discussion about death with children.

Michelle

[Permalink](#)

February 27, 2020 (Thursday, February 27th, 2020, 9:55 pm) at 9:55 pm (Thursday, February 27th, 2020, 9:55 pm)

I am saddened that you think that we should be involving children in MAiD.

Christopher

[Permalink](#)

March 1, 2020 (Sunday, March 1st, 2020, 12:15 pm) at 12:15 pm (Sunday, March 1st, 2020, 12:15 pm)

Very thoughtful and sensitive article.

Michelle Korvemaker

[Permalink](#)

March 2, 2020 (Monday, March 2nd, 2020, 10:16 am) at 10:16 am (Monday, March 2nd, 2020, 10:16 am)

I don't think we should encourage children to be involved in MAiD as they don't have the maturity to deal with it. They think concretely and aren't able to abstract yet. I see children coming into the ER who are suicidal. I am concerned that MAiD is contributing to the increase in suicidal thoughts in children.

Steve Wong

[Permalink](#)

March 2, 2020 (Monday, March 2nd, 2020, 2:51 pm) at 2:51 pm (Monday, March 2nd, 2020, 2:51 pm)

Note from the editor:

We've received several comments from readers, many about medical assistance in dying (MAiD) in general, which are beyond scope of this article or outside of our posting guidelines (thus not posted above). As expected, the topic of MAiD remains controversial and deeply personal, and even more so when introducing children to the conversation. Our site is not the forum to discuss MAiD as an overall topic, however we have posted this article because availability of MAiD is the reality of practice today, and children will eventually be part of the discussion (even if the decision is to not involve them in any way). Much of the advice in this article is applicable in situations (even outside the context of MAiD) where one would need to prepare children for death of a loved one.

Steve Wong, MD, FRCPC

Medical Director, This Changed My Practice, UBC CPD