

Post-death Care at Home as Extended Caregiving

AfterWards

*Take her not from me,
Let it be this hand
Who wipes the folds of her flesh —
A final encore to fading days.*

*With each tender stroke,
May her seasoned soul unwind its threads
from this mortal coil.*

*With each grieving caress,
May her enduring love weave more tightly
into the whole of my being.*

*Take her not from me,
Until the last essence of who she was is truly gone,
And I have captured only what she left for me —
In this hand and heart.*

Pashta MaryMoon

"Ask people where they want to die and 90 per cent will respond **at home**..... [Yet] sixty per cent of Canadians die in hospital, and an additional ten per cent die in nursing homes.... Dying at home helps not just the dying patient, but society as a whole, emphasizes [Donna] Wilson."¹

Although dying at home is not yet possible for everyone who chooses it, the development of the hospice/palliative care movement in Canada is making it a viable option for many families. What most Canadians (except in some rural areas) don't know is that it is *their legal right* to continue caring for their loved one at home *after the death*. In fact, caring for the loved one's body at home can become an extension of caregiving beyond death.

During the 20th century, the Western world developed a **death taboo** — a reluctance to even talk about it (which has fortunately been reversing over the past decade). Perhaps because of the history about the Black Plague, cholera, etc., we came to believe that handling a dead body was dangerous — even when we had been caring for that person until the moment of death. In reality, a recently-dead body is somewhat less infectious than a living one²; and caregiving after death is not much different than before death, except that we don't need to worry about hurting our loved one anymore.

We also came to believe that, by law, we had to send the body to a funeral home after death — this is simply not the case. Less than a century ago, it was commonplace for families to carry out their loved one's 'pan-death'³ care in their own homes (and lay them out in the 'parlour'); and families in the 20th/21th century have lost many of the advantages of doing so.

One of the critical losses is that — while the hospice/palliative-care team may have come to know the family's needs very well over the months of the pre-death process — the team has no connection whatsoever with the funeral home. As a result, right at the time when the family is dealing with the reality of the death and the immediate grief, they need to switch to an entirely separate service provider — who has a very different mandate from hospice, and little knowledge about the family.

This, in itself, can cause stress (despite our assumption that the purpose of funeral homes is to relieve stress) — never mind the stress that often comes from being strongly encouraged to make funeral-home choices that may not be consistent with the family's values, such as the most expensive coffin available.

The alternative to this is what is now being called a 'home funeral'⁴ — which allows families to make the most meaningful choices (based on *their* values) for post-death care, visitations, funeral/memorial services, etc., in *their own way* and in *their own time*.

The moment that the funeral home arrives to take the body away can be a particularly difficult one for the primary caregiver. They have usually been giving 24/7 care for many months, if not years — building their world around their loved one's needs. Then, suddenly, that role disappears — often with no real sense of closure to it. In all likelihood, the caregiver's reaction includes a sense of relief (although we are often uncomfortable acknowledging that) — but that sense may be overwhelmed by both the grief of losing their loved one, and the confusion at the loss of one's current role.

There are many advantages in doing post-death care at home, as a form of extended caregiving. There are two particularly significant advantages. First of all, the primary caregiver has the opportunity to gift their cherished family member or friend with one final act of caregiving⁵ by washing and dressing their loved one's body. Secondly, the following period of several days allows them to gently transition out of the caregiver role, while their loved one 'lies in honour' in the family home before burial or cremation.

Post-death care at home also allows the rest of the family and friends to take part in the caregiving — perhaps more directly than they were able to in the past. The final washing and dressing of the body — which requires at least two people — is a wonderful way for those closest to the Death Journeyer to show their care one last time, in a very tangible way. It helps them face the reality of the death and draws out the depth of their grief — and to do so collectively, which then makes it much easier to share grieving in the future.

The continued care of the body during the 'home funeral' (primarily keeping the body at regulation temperature via dry ice or Techni-Ice) allows the close family to organize visitation and final farewells with other family members, friends, and any community group that the Death Journeyer was involved with — and to do so in their own time and way, instead of paying for each scheduled hour at a funeral home.

Children are often extremely creative in finding their own way to process the reality of death and say their 'final farewells', if given the time and opportunity to do so — which a home funeral facilitates. Adults who are uncomfortable participating in post-death care, or simply don't feel that they are the appropriate person to do it, can be helping to build or hand-paint a coffin — which is also a wonderful way for children to be directly involved.

Being able to say one's 'final farewell' in the privacy and comfort of the family home (the older meaning of a 'wake') encourages friends, neighbours, and community members to identify tangible ways that they can be supportive. This could include offering to take on the more practical parts of a home funeral (assisting the family in filling out and filing formal paperwork, arranging further visitation times, helping with funeral arrangements, etc.) or the more common offerings to a bereaved family, such as food and flowers. This helps them to address the reality of the death in their own way, and begin to share their grief — while offering their own 'last gifts' to the Death Journeyer and their family.

And this kind of direct support by the Death Journeyer's whole community can help the primary caregiver release their role gently and gradually, as well as recognize the grief/grieving that can be shared in the future. Primary caregivers often feel desperately alone in their caregiving before the death — even if receiving some practical and emotional support. Extending caregiving into post-death care at home (especially with the support of the Death Journeyer's wider community) can give the caregiver, for perhaps the first time, the opportunity to truly feel 'not alone' in the last days of their caregiving — and may even heal some of the hurt/resentment, or simply loneliness, from the past months or years.

Written by Pashta MaryMoon and Mia Shinbrot — co-directors of CINDEA

Additional information

CINDEA (Canadian Integrative Network for Death Education and Alternatives), website www.cindea.ca — also see the 'Resources Post-death' page <http://www.cindea.ca/resources-post.html> for Death Midwifery and Home Funeral Guide practitioners in your province/territory

National Home Funeral Alliance (U.S. but includes Canadian resources) <http://homefuneralalliance.org/>

¹ Donna Wilson is a professor of nursing at the University of Alberta and a researcher into dying in Canada, quoted in "Choosing where to die: Allowing for choices: dying at home, in a hospice or in palliative care" by Bethany Cairns and Mariam Ahmad, special to CBC news. Posted: May 17, 2011, <http://www.cbc.ca/news/health/story/2011/05/04/f-milestogo-choosing-where-to-die.html>

² Funeral Consumers Alliance, "Dead Bodies and Disease: The 'Danger' That Doesn't Exist" — <http://www.funerals.org/frequently-asked-questions/142-embalming-myths-facts>

³ 'pan-death' care refers to a continuum of care before, during and after death. The person moving through the pan-death continuum may be called the Death Journeyer.

⁴ Further information about home funerals, and post-death care, can be found at the CINDEA (Canadian Integrative Network for Death Education and Alternatives) website www.cindea.ca

⁵ In ancient and many non-Western cultures, post-death care was/is considered the right and responsibility of the family — their final 'gift' of love and respect.