

The final gift - Helping parents articulate their end-of-life wishes

<https://lovelegacydignity.com/the-final-gift-helping-parents-articulate-their-end-of-life-wishes/>

As a loving adult child, how do you get yourself and your elderly parent ready for their inevitable departure into the afterlife?

Recently, my phone rang. It was the husband of an acquaintance. I was curious – what can be the reason for a call? I take it. I tell him that although I'm in a public place, I can listen.

He explains that his widowed mother has reached her eighties, is currently in good health, but that it is a fair supposition that hers will be the next death in the family. He and his siblings would like her to have as good a death as possible. She's just reviewed her will as part of putting her affairs in order, up to date.

His mother wants help with doing her Living Will (otherwise called an Advance Directive). "Can you help her?" he asks. "Do you have time?" I answered positively and suggested that he send me his mother's contact details.

It was not a difficult decision to say yes. During my recent desert retreat, I had decided that my "repurposed" life going forward would include seeking more opportunities for such family conversation work as part of LoveLegacyDignity's (LLD) offering – the NPO that Mapi and I founded six years ago.

I did a late morning home visit. A tray of tea and biscuits graced the table as a welcome to our conversation. Marissa (not her real name) was well-prepared, thoughtful, and articulate. She had done some homework. She'd come across a generic template, which she'd completed. The short document basically asked her children to respect her Do Not Attempt Resuscitation (DNAR) request and ensure she would die pain-free without too much medical interference.

This was a good start. I suggested that her adult children would benefit from an Advance Directive/Living Will that was more comprehensive and more specific. The less grey areas the better to create ease and pre-empt family disagreements on, "What would our mother have wanted?" in the situation of her not being able to speak for herself. I'd come with printed copies of the Advance Directive that LLD offers as a free download on its website. We used that to guide our discussion.

We started with heart attacks and the Do Not Attempt Resuscitation (DNAR) (heart disease and cancer cause most deaths amongst the elderly). I asked Maryssa that if she had a medical crisis how did she think her family would respond? She thought her family would immediately phone Hatzolah medical rescue – the Jewish ambulance service (available to all irrespective of religious orientation). That's what her family did when her sister-in-law fell ill – it's Marissa's extended family practice. In Jewish tradition, Jessica Nutik Zitter MD writes in her book *Extreme Measures*, saving lives is considered such honourable work that, "Even the laws of the Sabbath could be put aside in favour of life-saving activities."

I've heard disturbing accounts of zealous Hatzolah emergency care responders. There's the family who were told that if the medical worker could not apply Cardio Pulmonary Resuscitation (CPR) they would not take the person to hospital. There's the Johannesburg woman in her nineties with advanced dementia who had a DNAR which she had signed years ago in anticipation of her decline. When she had a heart attack, her family panicked. They called Hatzolah whose medical rescue workers successfully applied CPR and she lived on.

They're sobering stories. The first could be urban myth, but the second I heard directly from the daughter-in-law.

Maryssa and I went on to discuss seven more items which often arise in end-of-life decision making situations:

- Antibiotics
- Intravenous hydration
- Kidney dialysis
- Interventions to assist with breathing
- Assisted feeding
- Place (home, hospital, hospice, nursing home)
- Palliative treatments

We had a good hour and a half. We agreed I would return in a few days thus giving Maryssa the time she needs to have certain conversations. Maryssa thanked me noting that a GP would not have had the time for this important discussion. She asked me to bill her, acknowledging my time and expertise – that everyone needs to be making a living.

I left wishing that such discussions could be made available widely, that they would be part of medical aid packages. Research shows that people with Advance Directives live a little longer, and yet they spend less on medical treatments in the last year of their life.

I also decided to call Hatzolah and ask for their input. I reached a very helpful paramedic manager. He reassured me that if the family had the document to show the DNAR, that this would be respected. He observed that a less experienced junior could be confused by the request.

I also spoke with Willem Stassen, Associate Professor at UCT who has a doctorate in Emergency medicine. He noted (a) Advance directives do not (yet) have the same legal binding as say in the USA, and that (b) it can be the luck of the draw as to whether an emergency care worker respects a DNAR. He sent me an academic paper <https://link.springer.com/content/pdf/10.1186/s12904-020-00663-5.pdf> which provide an overview on the need for a mindset shift in paramedics delivering pre-hospital care.

It is noted that there is a mindset issue at stake. Emergency care responders are generally proud to save a life at all costs. It will be challenging for people to stop, take a breath and make a calm judgement to respect that what the person has asked for is a palliative response, to die as good a death as possible.

I'm left with three takeaways:

- We need legally binding Advance Directives
- We need emergency care workers trained to handle more complexity to include a palliative response.
- We need to create more possibilities for resources to support family conversations on Advance Directives.