

Intergenerational Dialogue Facilitation for Advance Planning: Helping Families Have End-of-Life Conversations

A paper presented by [Arabella Tresilian](#), Mediator & Trainer, at

[The Elder Mediation World Summit & Symposium 2018](#)

University of Bristol, 15th May 2018

Abstract:

Prevention of elder care disputes involving older people and their adult children is better than their eventual resolution, especially at end of life, when time is an unknowable factor and emotions run high. Trained Elder Mediators can help adults and their grown-up children converse about later life wishes in a way that can make the conversation uplifting, bonding and affirming. The charity, Living Well- Dying Well trains End of Life Doulas in helping their clients to write down their wishes and desires for their end of life care. This presentation explores how Living Well-Dying Well's End of Life Doulas assist their clients to undertake conversations about advance care planning with *(NIHR)*. *She is a co-author of Living Well Dying Well's internal training manual on their adult children.* We explore the difference between intergenerational conversations, and conversations between elders and their peers, or elders and their health professionals. We look at how sharing in advance care planning affects adult children's experience of their parent's end of life, and how older people feel knowing that their

adult children have contributed to the expression of their end of life wishes. In parallel, we explore the barriers to these intergenerational conversations and how Elder Mediators can ease them, taking into account perspectives on factors such as 'capacity', 'agency' and 'cognitive autonomy'.

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My thanks to the Elder Mediation International Network for the invitation to present at the Elder Mediation World Summit and Symposium 2018, and to the participants of my research survey for their invaluable contributions to our understanding of end-of-life conversations.

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Helping Families Have End-of-Life Conversations

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The Idea: 'From EMIN to Eminem'

Good afternoon fellow Elder Mediators, later life practitioners and friends. I come to you today to present one idea, to tell you one story, and to ask one question.

- **The one idea:** It's time to shake up intergenerational dialogue on death and dying, and we as Elder Mediators are beautifully situated to help with that good work.
- **The one story:** How my beloved Mum conveyed her end-of-life wishes to our family (brace, yourself - there's some irreverence... but I assure you, it's all hers.)
- **The one question:** End-of-Life Doulas are not mediators as such, but they have plenty of experience of brokering intergenerational dialogue on a person's wishes for their death (aka Advance Planning), so as both a health and social care specialist mediator and an End-of-Life Doula, I asked myself, and a handful of fellow doulas, 'What can we learn from End-of-Life Doulas about facilitating successful conversations between people, and younger generations, on communicating about what's important to them when it comes to their own death.'

[SLIDE: The Idea: It's time to shake it up]

[SLIDE - NEW: This is going to Hurt, by Adam Kay]

In his 2017 autobiographical book, *This is Going to Hurt*, former hospital doctor Adam Kay underscored how brutal healthcare practices can be when guided by the principle of extension of life at any cost: *'People don't realise quite how horrific resuscitation is - undignified, brutal, and with a fairly woeful success rate [of around 16% within a hospital setting]. When discussing Do Not Resuscitate orders, relatives often want 'everything to be done' without really knowing what that means. Really the form should say, 'If your mother's heart stops, would you like us to break all her ribs and electrocute her?'*

So how do we ensure that healthcare professionals are not pitted against either patients or families in finding themselves committed to delivering 'life-saving medical treatment' when a life is naturally drawing to a close? How do we work towards helping people approach death in *association* with their families and healthcare professionals?

[SLIDE: Conversation Project]

Non-medical initiatives like [The Conversation Project](#) and [Before I Go](#) encourage us to discuss end-of-life wishes' with our loved ones ahead of death, or loss of mental capacity. It is clear that such conversations help healthcare professionals too. Let me give you an example...

[SLIDE: FROM EMIN to EMINEM]

I am going to make the unlikely segue from EMIN to.... Eminem. How? By sharing with you a US medic's reworking of a song by Eminem & Rihanna.

Dr Zubin Damania said he felt “voiceless in the face of a gargantuan healthcare non-system built to do things to people, rather than for people” so he developed a blue-scrubbed rapping doctor alter ego, “ZDoggMD”, who could drop mad truth via YouTube in a way that “Dr. Damania” never could. He wanted to speak out for himself and fellow healthcare workers, who ‘told of “hating themselves” after being forced to administer such tortures as rib-shattering CPR and mechanical ventilation on elderly patients whose families refused to let go, not understanding the horrors that our “do everything” approach can inflict.’ ([Ref](#))

[SLIDE: ZDOGGMD video - add subtitles - pause at 3.33 - <https://youtu.be/NAInRHicgWs>]

[Read from final frame:] *“It always seems too soon, until it's too late. Talk about your end-of-life wishes now with those you love.”*

Medical professionals want to know they can do the right thing by the dying individual, who may not be able to express themselves... and who may want a different healthcare outcome to the one their loved ones want for them at the moment of crisis.

[SLIDE: The Story: My beloved Mum’s wishes]

Which brings me to my story, about my beloved Mum and her end of life wishes.

[SLIDE: THE PILLOW]

On the 4th Feb 2009, my mother waved me out of the kitchen where she was working intensively at her laptop, designing a website. In her early retirement from professional photography, at precisely 65 yrs, 4 months, & 15 days old, Mum was as busy as any of

her three adult children. My younger sister was about to move out of the parental home, and on to join our brother in London, the very next day. So I'd come over from work to say goodbye and wish her good luck. My father had gone to pick up my 9 year old daughter from school, to give us more time together before the big departure.

"Come and join us in the sitting room in a while?" I asked Mum.

"Sure," she replied smiling wryly from behind the screen as she wrestled with Wordpress, "I'm just working on this 'effing' website..."

Though I didn't know it at the time as I closed the kitchen door behind me, those, my friends, would be her glorious last words.

When my daughter Ana came running in from school half an hour later, I heard her go straight to the kitchen to see Granny. Soon after, the sitting room door clicked open and Ana came softly over to me and my sister, ashen-faced, to say that Granny was lying on the kitchen floor. "I think she is very tired," she whispered, "because her eyes are open but she doesn't want to get up." Our beloved Mum had experienced an almighty stroke. And she could have been lying there paralysed for up to thirty minutes. By the time the ambulance got Mum to hospital she was unconscious, a state which she slipped back out of on occasion over following days, rallying with heart-breakingly communicative, meaning-charged, silent eye gazes but she never regained the power of speech and slipped further towards coma as the brain damage advanced.

At some point in those ten precious days in hospital before Valentine's Day when Mum slipped away, my father, sister, brother and I were taken gently but deliberately into a side room by a doctor. To our horror and astonishment, we realised that we were being asked about resuscitation.

"Well, of course! Isn't the saving of life what we are all here for?!" was my instant internal response. Suddenly I was being torn from the hotly-held notion that my (*merely*

65 year old) Mum would make a recovery from catastrophic brain damage in a marvellous family fairytale of Mother Optimism conquering Mother Nature. Our stunned silence shifted when the doctor asked gently, “Maybe you have a sense of what *she* would want in this situation?”

Wide-eyed, we all instantly looked at each other, because we all had the exact same words ringing in our heads... Repeatedly, uninvitedly, to our discomfort and our mirth, Mum had instructed us in her inimitably blithe style, “**If I ever end up as a ‘vegetable’, please, put a pillow over my face!**” And in that moment, we all knew we had Mum’s explicit consent, blessing and *instruction* to invite the doctor to place a Do Not Resuscitate notice on her medical notes. Mum had let us know her wishes in advance, and had she not, perhaps we would have fought to hang on harder to her, and possibly have committed her, speechless and paralysed, to a helpless, protracted end-of-life she had never wanted.

[SLIDE: PIC of MUM]

Instead, we remember her as she was in this rare picture of her (photographers are always on the wrong side of the camera) taken by my sister in the kitchen, a few days before the stroke struck. [4m22]

We were of the lucky ones. Many families don’t have any conversation at all about end-of-life wishes, however much we say it’s important to us to do so.

[SLIDES: STATS from the Conversation Project]

- 60% of people say that making sure their family is not burdened by tough decisions is "extremely important" but 56% have not communicated their end of life wishes.

[SLIDES: STATS from the Conversation Project]

- 90% of people say that talking with their loved ones about end-of-life care is important but only 27% have actually done so.

[SLIDES: STATS from the Conversation Project]

- 82% of people say it's important to put their wishes in writing but 23% have actually done it.

[SLIDE: LWDW1]

Living Well Dying Well is a UK organisation which encourages people to reflect on how to live life fully, while planning and preparing for the end-of-life. It specialises in training people to become End-of-Life Doulas. Founder Hermione Elliot says, 'Traditionally, Doulas are present at the birth of a child. They work alongside the midwife to provide emotional, spiritual comfort and practical assistance to the mother and to gently lead the newborn into the world. Now, there is an emerging non-medical role: End-of-Life Doulas, individuals who help those who are dying, and their families, to feel safe and supported, as they make the transition from this life to what's next.'

[\(https://www.lwdwtraining.uk/doula-training/\)](https://www.lwdwtraining.uk/doula-training/)

[SLIDE: LWDW2]

Invited into the confidence and planning space of the person who is dying, End-of-Life Doulas are well placed to support people to undertake 'Advance Planning', so Living

Well Dying Well developed a toolkit to help Doulas support people to do this. I was lucky enough to help develop the toolkit, which looks at various elements of what it calls the Advance Planning ‘umbrella’, including writing down:

[SLIDE: ADVANCE PLAN UMBRELLA]

- WHAT YOU DO WANT via an **Advance Statement** also known as a **Values Statement or a Statement of Wishes**. It’s not legally binding and lays out the wishes, values and beliefs that underpin the Advance Decision. It provides healthcare professionals with a basis for understanding decisions made, which are important to the individual.
- WHAT YOU DON’T WANT: **Advance Decision to Refuse Treatment (ADRT)** is often shortened to **Advance Decision (AD)**. Valid and applicable ADRTs are legally binding. Elsewhere they are referred to as **Advance Directives** and the law is different.
- WHO WILL SPEAK FOR YOU: Your Healthcare Proxy, or persons named in your Lasting Power of Attorney
- WHAT WILL HAPPEN AFTER YOUR DEATH: for example, Funeral Plans, Organ Donation, Post Mortem and Autopsy, Wills, Executors.

[SLIDE: The Question: What can we learn?]

As individuals we may make Advance Plans, but how good are we at communicating those plans and wishes to those loved ones who may be present, involved and in good enough health to act upon, and advocate for, or even otherwise have blocked, our wishes, when the time of our death comes? What does it take for effective intergenerational dialogue to occur, whether between parents and children, aunts and nephews, cousin and cousin twice removed, older friend and younger friend?

Wonderful organisations like the wonderful Conversation Project and Before I Go are helping to turn the tide towards getting talking, but I wondered, as an end-of-life doula and an accredited mediator practising in the health and social care sector, what is the role of the *mediating person*, a neutral person who facilitates those conversations between generations, either when a person is dying, or way before when they are in good health; either when interpersonal disharmony has arisen or when relationships are good.

I undertook research with thirteen End-of-Life Doulas, some trained by Living Well Dying Well like me, and some not, to ask them to tell me what they had learnt about facilitating intergenerational dialogue on advance planning for end-of-life. This is what I learnt from the practitioners, from the UK, Canada, Nepal and the US.

[SLIDE: 1. Get the measure of the family's unique dynamic 1]

1: Get the measure of the family's unique dynamic

Start with the understanding that families are *dynamic* systems of often non-cohesive views, beliefs, values, hopes and fears about death and dying.

[SLIDE: 1. Get the measure of the family's unique dynamic 2]

So, hold back and observe for a while: '***Each family dynamic is different.***'

Understand that a family may need *time* for this conversation. Linda recommends '*allowing time, being honest and being non-emotional. Have the conversation as early as possible into diagnosis as it gets much harder when they are closer to death.*

Knowing the family dynamics before the conversation begins helps you know

how to guide individuals. *Don't be afraid to stop the conversation and re -start it another day. Always be flexible.'*

Emily explained, '*Usually helping people explore their options is the best preparation, but sometimes there is a family member with strong views, so it's a case of **helping the dying person decide whether their own preferences are strong enough to go against the family member's wishes.** Some people decide that they simply don't want to upset anyone, so will give up their own hopes and not try to persuade the relative whose beliefs clash with their own.'*

[SLIDE 2: Be flexible about ways to have these conversations 1]

2: Be flexible about ways to have these conversations

Keep in mind there is no set logistical **way** to have these conversations - practically speaking, there are many ways. And keep an open mind about **who** will be involved.

[SLIDE 2: Be flexible about ways to have these conversations 2]

Hilary recommends an 'in person' approach: '*I find it most powerful when there are **several members of the family there so that they can hear the person, in their own words, discuss their end-of-life options.***

You can make an event of it and make invitees feel special. Hilary highlights the value of 'invitations': '***Invite family members to join.***' She says. 'We don't use video [link] currently, but I do love that idea too.'

Abi describes a 'conversation over a curry': '*In one situation I worked with a woman to communicate her plan to her husband and son. Both were initially bemused as to why*

*she felt the need to have an End-of-Life Plan and it was almost as if they were humouring her in having a **round-the-table conversation over a curry** about the content of her plan. As events unfolded though they saw its purpose, for example communicating to the medics that there should be a DNACPR in place to support the Advance Decision; [and] to uphold her expressed wishes about a non traditional funeral when this was being challenged by more remote relatives like cousins.'*

Abi points out that we don't need to meet the family members at all: '*In the main I have supported **the individual who then takes the plan away to discuss with those who are close to them.***'

[SLIDE: 3. Help the person 'get going' on talking about plans 1]

Bear in mind, you must first be prepared to work around people's natural reticence to talk about their own end-of-life wishes, some time before they will be willing to discuss it with their families.

[SLIDE: 3. Help the person 'get going' on talking about plans 2]

Linda recommends '*not going in with forms to fill out, just gentle conversations. **You might see an antique in the house and question who is going to get that and lead on from there. If pets are involved I ask gently where they are off to. Asking the client who they trust most, and who would they wish to speak on their behalf, and then lead into how we can make it happen.***'

On the other hand, Karen is more direct. She advises: '*Just bring it up!! ... **Use open questions such as 'What would be important to you at end of your life?'**, or 'Have you thought about...? Or 'What do you think about...'*

It seems if we are unafraid of the topic of death and dying, and have no qualms about treating it as an everyday topic of conversation, we may have a more successful conversation. Karen goes on to say '***Because I am comfortable with the topic of death and dying, I find it quite easy to bring up the subject. In my husband's family.. they are all very good when it comes to talking about care packages, how to get the groceries, who will visit at a certain time, but they are not good at the 'dying' conversations. I have openly raised the subject with my mother in law and she was really pleased because for her it is very important to be in control of her life as far as possible.'***

[SLIDE: 4. Understand the potential benefits of plans... for loved ones]

4. Understand the potential benefits of plans... for the loved ones

My understanding is that if we are really clear about **how much and why** these conversations are beneficial, we are given courage to help people overcome their reticence to talk about death. So let's first become familiar with the benefits experienced by family members like children, when they *have* participated in an end-of-life wishes process.

[SLIDE: 4. Understand the potential benefits of plans... for loved ones]

The doulas say that:

- 'it brings peace of mind, relief and comfort'
- 'it makes all the difference in the world'
- 'to be able to come to a mutual understanding of wishes is essential to avoid PTSD and to help facilitate an easeful end-of-life situation as much as possible.'

- 'the younger generations can attain a sense of continuity. It can show them how to think about death - it makes death less fearful.'
- 'It shows death comes to us all, and that you can leave something behind.'
- 'It shows that families mattered and they were important to the dying person.'
- 'For some the [loved one's] death can be transformative, liberating - but also devastating if [there are] unresolved issues, or secrets.'
- 'the younger generation feel part of the journey, that they are trusted and respected.'
- 'It gives clarity, nobody is running in the dark, there is a path to follow.' 'Knowing that they have carried out the wishes of their relative/friend gives a little peace of mind to them after the event.'
- 'It brings comfort and eases them into grieving.'
- 'the [younger] carer feels a valuable sense of duty to be fulfilled, and relief when the lifting of the burden of decision is understood.'

[SLIDE: 5. Understand the potential benefits for the person 1]

5. Understand the potential benefits for the person

We are emboldened to support these intergenerational conversations when we really understand that they positively affect the **older** person's experience at end-of-life.

[SLIDE: 5. Understand the potential benefits for the person 2]

In defining human agency, Albert [Bandura](#) (2001) suggests that *'the capacity to exercise control over the nature and quality of one's life is the essence of humanness'*. In sharing their wishes for end-of-life, a person is using their own limited *'direct personal agency'* to assure for themselves a future *'proxy agency that relies on others to act on one's behest to secure desired outcomes, and collective agency exercised through socially coordinative and interdependent effort.'*

[SLIDE: 5. Understand the potential benefits for the person 3]

The result, Annie reflects, is trust and satisfaction: ***'Trust is soothing. The dying person is deeply satisfied'*** knowing they have discussed and expressed their end-of-life wishes.

Karen reflects on her experiences of writing Advance Directives with clients and family, and says process gives the person ***'PEACE ... They know they have some control over what happens to them, they know the paperwork is in place which is as good as it can be in the lead up. They also know that their family has to abide by it (in the main).'***

Juliet believes it gives ***'a sense of peace, completion, involvement, resolution. "[They] can leave knowing things are sorted. [It] opens up conversations, [and] they feel that they matter (unless relationships have broken down). [They can get] a sense of control and putting things in order.'***

[SLIDE: 5. Understand the potential benefits for the person 4]

Abi summarises the benefits of intergenerational dialogue on advance planning in her eyes:

1. *The person has spoken openly about their death and dying - what they want and don't want. It is no longer something that is perceived as difficult, should be left unsaid or is rather tasteless - it's no longer to be avoided.*
2. *It stops unhelpful speculation about the right thing to do at a time of crisis or grief*

3. *Conflict between family members can be headed off as there is the reference point which can be reverted to of respecting end-of-life wishes*
4. *It is an opportunity for the dying person to know how dying can be done peacefully*
5. *The bereaved can have the comfort of knowing that they did what the deceased wanted.*

[SLIDE: 6: Bring all of yourself to a person-centred approach]

6: Bring all of yourself to a person-centred approach

Our toolbox of resources mainly comes from our own life experiences. And we want to use that personal toolbox to help place the person we are working with at the very centre of their planning process.

[SLIDE: 6: Bring all of yourself...]

1. Bring all of yourself to the situation, underpinned with your life experience, knowledge and understanding.
2. Go with the flow and trust your instincts - they always work.
3. Go where the client takes you, but be assertive and directive when relating to a client's wishes being honoured.
4. 'It's sometimes difficult to refrain from giving advice. I counter this by writing the word 'facilitator' on my arm.'
5. Work towards building a warm, trusting, open and honest conversation with integrity, care, compassion and deep empathy - always a person centered approach. (It's usually over a cup of tea, nothing formal.)

[SLIDE: 6 ... to a person-centred approach]

1. Discover the individual's values, beliefs, concerns, emotions, wishes, preferences, what is important to them
2. Be led by the client through the natural course of conversation, picking up on themes, using your intuition
3. 'Draw on biographical information: imagery, drawing, photos are excellent, items in the home. [You can ask,] 'How old is this? Where did you get it? From whom? What were they like?'
4. Talk about what happened at end of life in the past, and how it compares to now in their eyes.

All of us are affected by death and it be can helpful to bring our own personal experience of loss to bear, especially if there is a reluctance to have the conversation:

Alexis explains 'My sister died from pancreatic cancer three years ago. I refer to my own experience and how much I have learnt about death and dying. I tend to stress the importance of talking about death and dying when we still have the capacity to make decisions and ensure we share our wishes and preferences with our loved ones.'

[SLIDE: 7. Our role is simply to create a new space]

7. Our role is simply to create a new space

The inevitability of death is a powerful force we will all contend with as part of being human, and yet an almost (but not quite) equal force is our drive for survival and the

denial of death's arrival. As doulas, as mediators, as family members and friends, we have the capacity to introduce a third force which **holds, honours and even reconciles** those paradoxical, counter-balancing forces. If we understand the profound impact it can have on the person who is dying, **and** on the generations bearing witness to their death, we may find ourselves emboldened, humbly, lovingly, quietly, to offer to help create that sacred space for our fellow friends on earth.

[SLIDE: Thank you]

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