

Helping Families Have End-of-Life Conversations

Arabella Tresilian

Elder Mediation World Summit 2018

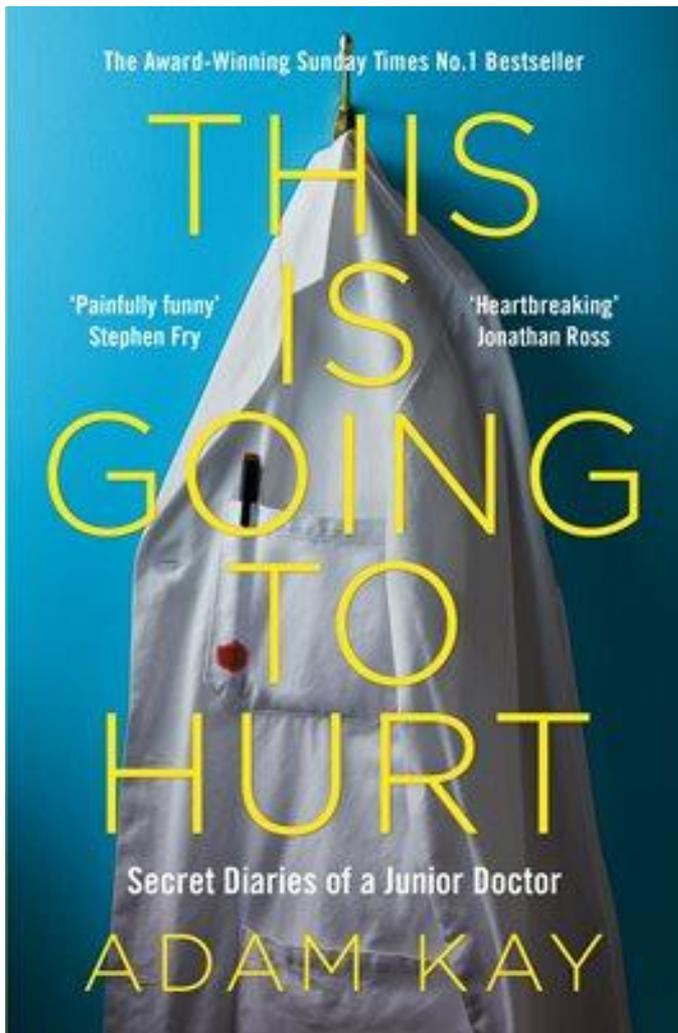
Bristol, 15 May 2018



The Idea:

It's time to shake it up





‘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?’”



Arabella **Tresilian**

The Conversation Project is dedicated to helping people talk about their wishes for end-of-life care.



Start your conversation today.

From EMIN...
...to Eminem





silian

The Story:

My beloved Mum's wishes





Arabella **Tresilian**



Fay Tresilian

Photographer

1943 - 2009



Arabella **Tresilian**

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

90%

of people say that talking with their loved ones about end-of-life care is important.

but

27%

have actually done so.

82%

of people say it's important to put their wishes
in writing

but

23%

have actually done it



living
dying Well

Why, do we prepare so well for birth, yet give so little attention to preparing for death?



Arabella **Tresilian**

living
dying Well



ADVANCE PLANNING FOR END OF LIFE



Arabella **Tresilian**

ADVANCE PLAN

WHAT DO YOU WANT?

Advance Statement

Statement of Wishes and Preferences

WHAT DON'T YOU WANT?

Advance Decision to Refuse Treatment (ADRT)

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR)

WHO WILL SPEAK FOR YOU?

Proxy Spokesperson

Lasting Power of Attorney

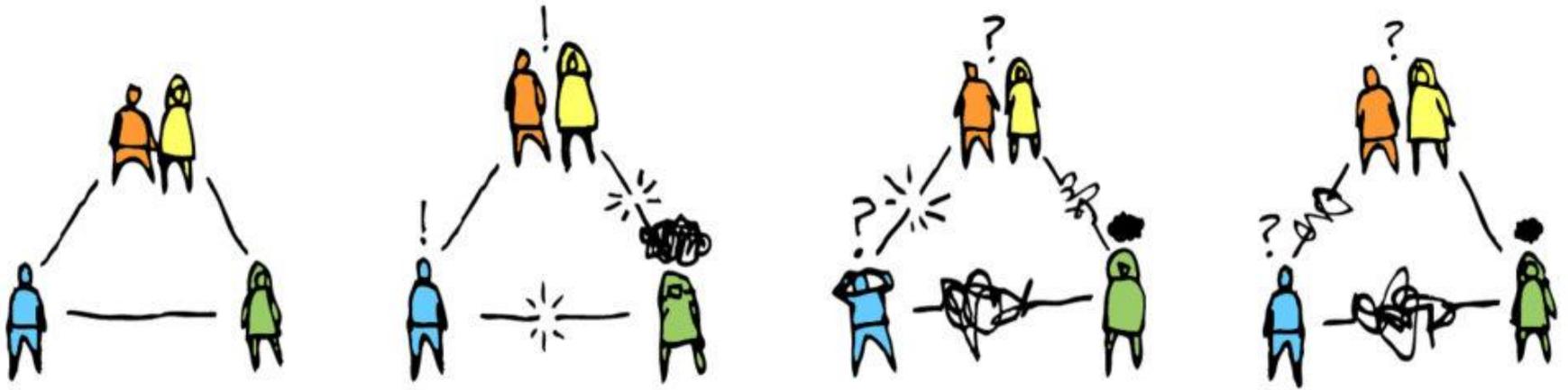
WHAT DO YOU WANT TO HAPPEN AFTER YOUR DEATH?



The Question: What can we learn?



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



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

- 'Each family dynamic is different.'
- 'Knowing the *family* dynamics before the conversation begins helps you know how to guide *individuals*.'
- 'Helping the dying person decide whether their *own* preferences are strong enough to go against the family member's wishes.'



2. Be flexible about ways to have these conversations



2. Be flexible about ways to have these conversations

- ‘..several members of the family there, so that they can hear the person, in their own words’
- *‘Invite family members to join!’*
- *‘a round-the-table conversation over a curry’*
- ‘the individual takes the plan away to discuss with those who are close to them.’



3. Help the person 'get going' on talking about plans



3. Help the person 'get going' on talking

- '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.'
- 'Use open questions such as 'What would be important to you at end of your life?'
- 'Because I am comfortable with the topic of death and dying, I find it quite easy to bring up the subject.'



4. Understand the potential benefits for loved ones



4. Understand the potential benefits for loved ones

- '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.'



4. Understand the potential benefits for loved ones

- '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.'



5. Understand the potential benefits for the person

Five Wishes: How comfortable I want to be

- ☞ I do not want to be in pain. I want my doctor to give me enough medicine to relieve my pain, even if that means I will be drowsy or sleep more than I would otherwise.
- ☞ If I show signs of depression, nausea, shortness of breath, or hallucinations, I want my caregivers to do whatever they can to help me.
- ☞ I wish to have a cool moist cloth put on my head if I have a fever.
- ☞ I want my mouth and lips kept moist to stop dryness.
- ☞ I wish to have my favorite music played when possible until my time of death.
- ☞ I wish to have religious and well-loved poems read aloud when I am near death.

5. Understand the potential benefits for the person

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.’***

Bandura, Albert (2001), [‘SOCIAL COGNITIVE THEORY: An Agentic Perspective’](#)



Arabella Tresilian

5. Understand the potential benefits for the person

- ‘Trust is soothing. The dying person is deeply satisfied’
- ‘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).’
- ‘a sense of peace, completion, involvement, resolution.’
- ‘they feel that they matter (unless relationships have broken down). [They can get] a sense of control and putting things in order.’



The potential benefits:

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.

(Abi)



Arabella **Tresilian**

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



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.)



6. ... to a person-centred approach

1. Discover the individual's values, beliefs, concerns, emotions, 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.



7. Our role is to create a new space



Thank you

**Arabella Tresilian
Mediator & Trainer
Bath, UK**

**arabella@arabellatresilian.com
+44 7769774671
@hemispherehouse**



Arabella Tresilian

End Note:

You can access the paper that accompanies this presentation here:

<https://docs.google.com/document/d/1pP-vnDhKObK0j7GSw1r12nCaYmDYLI1lapPNJGJ64Zs/edit?usp=sharing>

Please note that while freely available for you to access, this is copyrighted material. If you share any of the content, you must cite the source clearly as:

Arabella Tresilian (arabellatresilian.com) 2018

Thank you



Arabella **Tresilian**