Challenging dominant perspectives that assume older people are given more choice and control by putting plans in place for issues that can arise with ageing and end of life.

(Francis Duffy, University of Sydney, ANZSWWER 2018 – PhD research 2018)

• Ideas about planning ahead for ageing are gaining more traction as our population ages

• Advance Care Planning principles based on optimising choice, control, protection. This aligns with s/w values, e.g. self-determination, human rights, human dignity, prioritise client’s interests etc.

• In 2010 AASW submission to Health Ministers’ Advisory Council, on developing National Framework on ACD, supporting the benefits of promoting ACD & Sub Decision Makers.

• Examples of support for ACP as empowering older people:
  • Australian Government, Department of Health, 2017;
  • Australian Government Productivity Commission, 2011;
  • Dementia Australia, 2018
  • AASW
  • NSW Gov. Planning Ahead Tool’s website;
• NSW Gov. Planning Ahead Tool’s website for Legal Resources and Health Professionals (2017):
  • ‘When you have planning ahead documents in place – a Will, Power of Attorney and Enduring Guardianship – you can rest assured that your rights and wishes can be respected because they are properly documented’.

  • ‘If you do not have planning ahead documents prepared when they are required, a court or tribunal may need to appoint someone to make decisions for you. The opportunity to choose who you would like to act on your behalf will be lost. It is definitely better to plan ahead’.

• Underpinnings of Planning Ahead Frameworks:
  • A certain faith in predictability and how one will respond in a particular situation
  • Those bestowed with power will use it appropriately
  • An acceptance that interpretation and adherence to documented plans will be done with integrity
  • E.g. faith in health professional’s interpretation (that instrument is safety proof)
  • Rationalist, Modernist, ability to Reason

• Social Work Educators: How are we to teach students about how to think about Advance Care Planning for older people?
  • This presentation asserts that planning ahead for ageing and end of life issues, is a problematic undertaking and social workers need to take a considered, cautious and critical social work approach.
Advance Care Planning/Directives

Pros
- Empowering client - clear instructions about what clients want
- It gives client a voice, esp. if they lose cognitive function or in crisis
- It relieves carers/family of having to make difficult or traumatic decisions
- Can prevent family conflict – especially if different views among family/friends

Concerns
- Pressure for efficiency: In hospital 2016–17, 42% separations & 48% Length of Stay are for people > 65 (AIHW 2018)
- Ageism is most prevalent in the health system & employment (Minichiello et al 2012 etc.)
- Many caring professions see ageing as time of decline and can taint their attitude towards older people, e.g. their ‘capacity for recovery’. This is also evident in language used in health: e.g. ‘bed blockers’ ‘frequent fliers’ ‘failed discharges’ (O’Loughlin & Kendig, 2017; Duffy, 2016)
- Could ageism, budgets and bed pressure in hospitals impact interpretation of advance care directives (ACD)?
- Research (Michael et al 2017) - If more older people living in nursing homes, had specific advance care directives - it could prevent unnecessary admissions to hospital. (This warrants unpacking)
A student experience on placement

- Older woman has ACD and is NFR if she has cardiac arrest
- Has cardiac arrest in hospital and nurses carry out CPR
- Son is a doctor, seen to be controlling and is angry ACD is not followed.
- Older woman is so relieved that she was resuscitated as she said she was not ready and did not want to die.
- Woman’s husband states that if this happens again his wife is not to be resuscitated.
- Woman is very upset about husband’s remarks
- Student is left concerned and is not sure about her own stance on ACD
- N.B. if the woman had been left to die, it would likely be accepted that was a good outcome as her wishes on her ACD were followed, and her present views would never be known!
Participants’ mixed views on ACP (Duffy, PhD research)

• “It’s such a tough question. You and I can talk about it for hours and hours and hours, but until you’re in that situation, you don’t know how you’re going to act”. (Ronan, 30s)

• “Both Don and Greta, my parents, had been very clear with each other that they didn’t want to be debilitated and didn’t want to be a burden and all of that sort of thing; all the stuff that Jean says. My father got bladder cancer and he actually died of it in the end. Now in the last few months of his life, he got a bad infection and was in hospital. He was in hospital, he had to go to intensive care. I think he had to have some sort of surgery, or some fluid taken of something. At that time, I wasn’t there but the doctor said to him “now Mr Homer, what if something happens to you while you’re in intensive care or what if you have a heart attack or a stroke or something like that because there are risks to it” and so even though he and my mother had been very clear with each other that they didn’t want to be resuscitated or anything, he just turned around and said and sort of looked as if “what on earth are you talking about” and he said “give it a go”. So all the plans just flew out the door in the face of the reality of the situation”. (Rosie)
Participants’ mixed views

• “I mean how do you know what you are going to need, you’re going to have to write down 47 different alternatives, and then something different might happen anyway, so umm, some things you got to play as you go along...I haven’t done any of those things and I can’t see myself doing it, but umm, because as I say, how many possibilities are there, a whole lot... anyway it’s not always helpful, although in some situations it probably is and it takes a lot of anguish out of peoples decisions, but I’m not sensible enough to make [laughs] a plan, that is not flexible”. (Betty, retired R.N.)

• “Well it depends who you give the power of attorney to... Harrison has been talking to me about doing a power of attorney... But then he doesn’t always want me to do what I want to do... sometimes someone grabs a power of attorney because they are after their money, umm... I’m not sure. I know the power of attorney gives a lot of power”. (Grant, 80s)
Participants’ mixed views

“Can I tell you Francis. Working in the community all of my adult life, we’ve seen people with financial control under their children who would not – with a lot of money, who would not buy them a pair of pyjamas, would not buy them a cake of soap, would not do any of that. Now that may have interfered with my thinking a little... even wills are taken to the cleaners, so you could have a will and writing down – and there’s a lot of trouble at the moment going on with directives (advance care directives) I can tell you. Some of them have been taken to Court of late”.... (Venice)

“It depends on how many people are involved, if you had a big close knit family, then you’d probably would, would be better to have something written, I would think, so there’s no mistakes, so everyone knows exactly what is there, but then that does reduce your flexibility, ’cause then someone tries to make it enforceable, or think that they are beyond help, therefore off they go, versus someone who doesn’t think that, you know, you have a document that can be used, that’s what I’m always worried about”. (Paddy)
Participant Mixed views

• “Yeah, we did that, do not resuscitate...Well that covers it for me, you know if I get to the stage where I have a stroke and I can’t look after myself, I don’t want to be resuscitated, it’s just, my wife is of the same opinion”. (Kane, 80s)

• “If I’d had a stroke I’d like to be gone...Which one you’d be in? Yes. I can see what you mean”. (Margaret, 90s)

• “But the problem is if you appoint a power of attorney, being one of the boys or mum, it’s going to be very difficult because of course there’s going to be accusations very quickly about taking the riches but apart from the land that this house is sitting on, there’s nothing” (Flano, grandson).
To have legal instruments or not? and should we be advising older people about making them?

• For most participants who had not made formal or even informal plans, they believed they were acting responsibly in protecting themselves and exerting choice in conscious acts of resistance to the pressure exerted on them to have formal plans in place (Duffy, 2018).

• The President of the Australian Law Reform Commission, Professor Croucher (2017), reporting on inquiry into elder abuse initiated by the Fed. Gov. in 2016, cautions on the potential for misuse of legal instruments to take advantage of older people, whilst also acknowledging the potential benefits of having legal instruments.

• Miskovski (2014) ‘inheritance impatience’, describes a situation when the beneficiaries of someone’s estate wishes to hasten access to their inheritance by misusing an authority instrument given to them (e.g. power of attorney).
Conclusion: Advance Care Planning/Directives

- You cannot accurately predict what is going to happen, the specific detail, there are many possibilities, nuances,

- It is only hypothetical to predict how you will think, feel, act – in a situation you have not yet experienced? You might you adjust/adapt to disability/health decline. You might not be ready!

- Concerns advance care directive (ACD) once put in writing be misinterpreted or misused.

- Instruments can protect, e.g. EPOA, however they also give power away

- Could ageism, budget rationing influence interpretations of ACD.

- Knowledge about reversibility of serious health problems is essential

- What level of health literacy and critical thinking does client have

- Could internalised ageism influence plans (don’t want to be a burden)

- Planning can stir up family conflict, grief, whilst also preventing it.

- NFR discussions can be experienced as offensive/ageist to some people,
References

• AASW, 2010, Submission by the AASW to the Clinical, Technical and Ethical Principal Committee of the Australian Health Minister’s Advisory Council regarding A National Framework for Advanced Care Directives, Consultation Draft, https://www.aasw.asn.au/document/item/2254


• Dementia Australia, 2018, https://www.dementia.org.au/about-dementia/i-have-dementia/advance-care-planning


