

# Advance care planning re-imagined: a needed shift for COVID times and beyond

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## Introduction

While the use of advance care planning (ACP) is a widespread recommendation for those patients who have life limiting illnesses, the evidence base for taking this approach needs expanding. A systematic review in 2014 found some positive impact in the use of ACP.<sup>1</sup> A further systematic review in 2016<sup>2</sup> of randomised controlled trials suggested that the evidence was open to bias and that higher quality trials are needed to be able to demonstrate scientific evidence of effectiveness. Part of the problem lies in differing outcome measures and lack of differentiation between Do-Not-Resuscitate orders, Preferred Place of Care, Preferred Place of Death and Treatment Escalation Plans.

The evidence for its use is therefore not specific enough. This lack of clear answers may also not be either the only reason or the most important reason which hinders the widespread uptake of ACP. Many clinicians have a natural reluctance to initiate conversations about death and dying for fear of perpetuating, or precipitating, a loss of hope among patients and families. Just as importantly, many patients find this style of intervention counter-intuitive to their own personal experience and expectations. In this article, we argue that ACP should be focussed around what matters most to people, rather than the current emphasis on a narrow harm reduction of avoiding unwanted treatments, recommending a more socially inclusive approach to ACP.

The positive impact of social relationships on happiness, well-being and length of life is profound.<sup>3,4</sup> This is where we suggest ACPs should focus their joint discussions and plans. In the

context of end-of-life and palliative care, Horsfall and colleagues<sup>5</sup> provide evidence that

1. Home is central to caring network formation and function in end-of-life care.
2. A primary carer's ability to sustain caring can be supported when caring is at home.
3. Maintaining identity, a sense of belonging, and connections are central to well-being.
4. Place is crucial to maintaining identities and connections.
5. Nurturing carer well-being may best be achieved at home.

People choose to be cared for and die at home (and this might also include the care home) not just because it is a safe, familiar place, but also because meaning and value in life are found in the people we know and love as well as in the places we know and love. This is the social ecology of care: linking personal health and well-being to its local environmental determinants.<sup>6</sup> It is the positive impact of good relationships with people and place that matter most in life, and consequently at its end, and not solely for the patient alone but to their whole caring network. We argue that ACP should be focussed on this dimension of care in the first instance, rather than focussing only on where people die, what treatments they might refuse or whether they have a do-not-resuscitate order in place. The underlying rationale is drawn from the acknowledged linkages between identity, place and well-being and further described within a public health palliative care approach. These above fundamentals, once discussed with patients and their loved ones, can lead into and open up the other areas, including ceilings of treatment or places of preferred death. When conversations begin about values, other approaches to life, death, dying and community flow more easily.

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### The public health approach to palliative and end-of-life care

Kellehear<sup>7</sup> first described the public health approach to palliative and end-of-life care in his book *Health Promoting Palliative Care*. Subsequent texts provided further elucidation.<sup>8,9</sup> Drawing on the principles of health promotion and harm reduction, Kellehear<sup>10</sup> applied them in a practical way, pointing out that death, dying, loss and caregiving is everyone's civic responsibility, not just solely that of health and social care services. Death literacy, similar to health literacy, is a necessary part of the public health approach<sup>11</sup> and knowledge of ACP fits neatly into this model. Kellehear<sup>12</sup> describes how principles of community engagement and development are part of the broader approach in increasing the use of ACP. It is possible to extend the principles of health and well-being promotion and harm reduction further in order to get a clearer understanding of how ACP use can be further developed to be more relevant to professionals, patients and families.

According to the Ottawa Charter, 'Health Promotion' is a health strategy that aims to incorporate skills and community development, create supportive environments for health, endeavours to build healthy public policy and looks at re-orienting health services.<sup>13</sup> The Ottawa Charter for Health Promotion, formulated in 1986,<sup>14</sup> describes five key areas of action:

1. Building healthy public policy,
2. Creating supportive environments,
3. Strengthening community action,
4. Developing personal skills,
5. Re-orienting healthcare services towards prevention of illness and promotion of health.

In the context of ACP, health and well-being promotion focusses on building supportive environments, not just as a way of coping with care needs, but as a way of building positive relationships and goals for both patient and caring network. Abel and colleagues<sup>15</sup> describe how these networks function and how they can be used to enhance meaning and value within the caring network at the same time as coping with the demands placed upon it. Leonard and colleagues<sup>16</sup> confirmed the evidence behind this approach.

Harm reduction, an approach originally used to provide an alternative other than abstinence in drug and alcohol dependency<sup>17</sup> has been successfully extended into a variety of other fields,

including smoking, teenage pregnancy and sexually transmitted diseases such as HIV/AIDS. Therapeutic interventions in palliative and end-of-life care can be seen as a part of harm reduction, whether this be physical, social, psychological or spiritual. A process of disease exchange takes place for the administration of drugs. The benefits of taking them outweigh both the side effects of the drug and the symptoms arising from the physical and mood associated impacts of the disease. Likewise, addressing concerns and worries are a form of harm reduction. Of themselves, their relief does not automatically contribute to well-being, although relief of distress creates the necessary environment in which well-being can flourish. ACP in its current use is concentrated around harm reduction, avoiding interventions that are deemed to be potentially harmful. These include unnecessary or unwanted admission to hospital, inappropriate resuscitation and administration of treatments that may prolong life when this is not desired. While the metrics are accessible and measurable, the focus on them at the expense of health and well-being promotion has the consequence of not allowing the patient and caring network determine what matters most to them.

### Re-imagining ACP: beginning at the beginning and not at the end

Both primary care and hospital physicians can struggle to start ACP conversations.<sup>18,19</sup> There are a number of perceived barriers, including not having enough time, lack of coherence of the physician view of best treatment from that of the patient, and not knowing the right time to initiate the conversation in the context of chronic illness among others reasons. Furthermore, beginning a conversation on ACP can be seen as a death sentence by patients who may not feel they are close to death while there is still significant life to live. This discordance of experience and aspiration can be particularly harmful to the physician-patient relationship, as patients may feel that their physician is giving up on them.

'Completion rates' for ACP are dependent on diagnosis and local practice, with people with cancer diagnoses having higher completion rates than those with multiple chronic conditions.<sup>20</sup> These conversations are deemed to be difficult by the health professionals who conduct them. A perceived lack of communication skills of the attending physician is quoted as the main reason

for the lack of completion of ACP in different settings. However, it may also be true that clinicians are sensitive to the loss of hope that comes from having conversations about death and dying. Many people, particularly when they are not close to dying, are more concerned with how they can live their life to the full for the time they have remaining. The reluctance to have ACP conversations may be fully justified. Physicians recognise that patients may want to approach the subject through doing what matters most. This need to do 'what matters most' may not be best addressed through a narrow harm reduction strategy of plans to avoid treatments that many patients may not even have started to think about.

Changing the priorities of the conversation will help to make clinical discussions easier and more relevant with the added advantage of increasing the uptake of ACP. We suggest future ACP conversations focus on three main areas:

1. What matters most to you in life when you are well?
2. Which of these will become priorities when you become less well?
3. How can you gain access to support from your social network of support at a time when you become less well so that you can ensure the priorities you describe in #2?

The answers to the first question will vary considerably, depending on cultural and social differences and backgrounds as well as individual preferences and values. The answers to the second question may differ from addressing these broader concerns after breaking bad news. This is because there is a difference between what worries people in life when things are going well and what is most important to them in their life when their health becomes threatened or becomes an obvious limited resource. Question 2 naturally flows from question 1. An example might be,

It is great that you are feeling better after the recent events. It may seem a bit counter-intuitive for me to bring up this topic now that you are feeling better, but have you thought at all what might happen the next time you become very unwell? Is this something you feel ready to talk about now?

This acknowledges the positive improvement but builds in a discussion about future events and how they might be navigated.

There are barriers to enhancing supportive networks when discussing the third question. These include people feeling that they are managing fine at the moment, to invasion of privacy, to not wanting to bother or be a burden to family and friends and many others. It is important to have this conversation not just with the patient but with main family members present. An individual's personality and the degree to which they are embedded in their community will have a strong bearing. Success in respecting someone's wishes, particularly to be cared for and looked after at home as they become increasingly unwell, is difficult to achieve without the cooperation of the family and other close members of the caring network. Discussing what kind of help is useful at end of life clarifies the many different ways it is given. Help can be broadly divided into two categories. The first is practical support, not just to the patient but among the caring network itself. Tasks such as shopping, cooking, cleaning, tending the garden or walking the dog all add to the work that is needed to be able to look after someone.<sup>15,21</sup> Sharing these tasks among the caring network not only preserves health in the longer term, it also becomes a source of shared kindness and compassion among people. As the person with the illness becomes less well, practical tasks will include personal care and may involve manual handling. This may not be needed until the later stages of an illness and plenty of help can be shared among the caring network before this point is reached.

The second kind of help is that of love, laughter and friendship. Loss of identity can happen to both the person with the illness and those who shoulder the main responsibility of caring. Loss of identity can occur as a consequence of loss of job, regular social interaction, or the gradual social inequality forced on one through disabling illness, dependency or home care responsibilities. This can happen both to the person with the illness and a main carer who shoulders most of the responsibility. Nourishing people's sense of value through compassion, love, laughter and friendship can be transformative at a time where people may feel particularly downhearted about their own sense of self-worth.

In summary,

1. Current ACP discussions are mainly focussed on end-of-life care decisions. The term 'end-of-life care decisions' is commonly understood in purely clinical terms. That type of discussion refers firmly to

death and not to the longer part of dying, which may extend to weeks, months and sometimes years before the final days or hours of life. ACP too often confines itself to planning for crisis, final treatment choices and terminal outcomes, and not to *living with dying*. However, *living with dying* is actually how most patients experience 'dying'. It is frequently not the short and commonly institutional experience witnessed by clinicians in hospitals, hospices or nursing homes.

2. Because ACP places the emphasis on proximity to death and not on *living with dying*, the priorities inherent in this approach do shock. These priorities can so obviously clash with a patient's lived experience. ACP that integrates the insights from a public health palliative care approach, working with the linkages between identity, place and well-being, feeds but also *realigns clinical concerns* with the concerns of all dying people and their carers, that is, with concerns about health and well-being and the social supports that underpin those experiences and aspirations.
3. Finally, the social ecology of the dying experience and also its care experience logically necessitate a social model of care in ACP administration and decision-making. This will mean any ACP must be an *inclusive process* that recognises, encourages and embraces a patient's social network. That social network will be the most important ingredient to any assessment of quality of care at the end of life. In the context of a public health palliative care, the phrase 'end of life' here refers to the *lived experience* of dying and its care and not solely its clinical manifestations in an individual patient case.

In methodological terms then, a public health palliative care approach to ACP means that the emphasis must be on

1. the priorities and values of a person's lived experience,
2. the envisioning of patient's social networks,
3. the recognised centrality of experiences of health and well-being as the best guide to an individual's vision of harm reduction,
4. the value of shared decision-making for creating sustainable and desirable outcomes for all.

Logically emergent from these discussions will be secondary commitments and goals about treatment choices, places of eventual death, do not attempt cardiopulmonary resuscitation (DNACPR) discussions and forms, and a host of other civic and clinical desires in the final days as all of these emerge as part of a wider vision of *living with dying and caring*. Approached this way, ACP becomes a social model of health, part of a broader strategy of support while living with dying, and not a threat of hopelessness or an omen of death. The need to document harm reduction decisions of ACP such as DNACPR remains, requiring health professional input of these decisions on the health record. What matters most conversations do not necessarily need a professional to initiate them. However, it is vital that professionals know about them to be able to formulate goals of care that match with patient and family wishes.

Our recommendations about changing the nature of this discussion means that it is not limited to any particular stage of a chronic illness. A conversation about what matters most can be had as a part of routine clinical care. Moving to discussions about end of life flow much more easily if the what matters conversations are started at an earlier stage of illness. This can help to avoid what can be a shocking, forced discussion as a sense of urgency develops among health professionals about ensuring place of death is written down on paperwork.

### Measurement and research

Having clear qualitative and quantitative outcomes of medical interventions is a necessity to be able to demonstrate their effectiveness. The need for measurement of ACP outcomes remains. Good communication between health and social care organisations is part of high-quality care. What matters conversations help to give a joint focus on how and where care is delivered.

We hypothesise that broadening the approach to ACP to include health and well-being promotion will help to increase its uptake. In addition, we hope that these conversations will reduce the reluctance of professionals to initiate ACP conversations, resulting in higher completion rates. Anecdotal clinical experience of their use is that satisfaction is increased in both the patient and the caring network. These are outcomes that can be measured as part of a pragmatic prospective clinical trial. Proving this to be the case will help to change clinical practice of ACP discussions.



## COVID-19 and beyond

Our article has been written during the COVID-19 pandemic, during which there are enormous challenges to accessing medical care. Normal end-of-life services have been significantly restricted in the United Kingdom, with only the most severely unwell being admitted to hospital. Restriction of use of ventilation is a necessity and people who might have received ventilatory support prior to the pandemic may be denied access to it at the current time. People who are admitted to hospital for terminal care may not be permitted visits from relatives and the numbers attending funerals is limited. There is a pressing need for a different kind of ACP when, in the context of a fast moving infectious disease, there is little time for prolonged family or community discussion. The choice of place of care previously available may be denied, home or hospital, and neither may be one's preferred place.

Trying to have a sensitive conversation at this time is even more important. Understanding people's views on a host of treatments and what is important to them more generally is key, particularly when the option of going to hospital may not be included. On the contrary, the possibility that one may rapidly end up in hospital, separated from family while dying, requires even greater re-imagining of ACP. ACPs may need to plan for the ready assemblage and stowage of 'emergency kits' as they do in the United States for crisis preparedness<sup>22</sup> (<https://www.ready.gov/kit>) (in the United Kingdom, these are commonly referred to as grab-and-go or simply go-bags. See <https://www.bbc.co.uk/news/uk-49637873>). But instead of bags that contain torches, radios, water bottles and food, perhaps the advance care plans for COVID-19 end-of-life care circumstances will need other 'life-saving' but no less social items to have at the ready to go at a moment's notice. In Wales, paramedics have received Serious Illness Communication skills training, so that they can feed into the ACP approach.<sup>23</sup> If the paramedic guidelines alerted future patients and families to the importance of ACPs, especially ACPs in fast moving circumstances, then these patients and families who have not prepared their own go-bags can be made aware of their value, and then quickly prepare one, at the point of paramedic service.

A 'well-being' bag with important photographs, cell phones or iPads, precious personal items associated with loved ones that one can plan to hold as a reminder of physically absent

next-of-kin, could be transformational in some of these uncharted situations, especially when isolation measures are in place. These personal and social items may be among the most important basics for health and well-being at the end of life in the current circumstances. With people now spending more time at home because of stay-at-home orders, and with the wider associated awareness of the risk to life, the COVID-19 lockdown period provides an important civic opportunity for people to anticipate, reflect and prepare for personal risk. Even after the initial lockdown period, many people will spend greater periods working from home rethinking their usual personal assessment of life-threatening risk from remote (ageing) to proximate (infectious disease). This is an important public opportunity to re-imagine ACP expanding its execution from simple written plans to practical preparations in the home. Well-being bags are simply one example of this possible evolution for ACP.

Consistent with a public health approach more broadly, ACPs in the context of other life crisis planning and preparation, for bushfires, earthquakes, hurricanes and floods, has plenty of public health role models to use and modify for use at the end of life irrespective of its diverse epidemiological sources. Planning a well-being bag for fast moving and unexpected dying could have wider use in future epidemiological contexts of deadly infectious disease. This is the final way in which ACP has been limited: much ACP thinking has been focussed on chronic, long-term illness and not the faster moving contexts of intensive care and disaster management. This is one more reminder, if any further were needed, that ACP is in urgent need of re-imagining of its current priorities as an end-of-life care intervention.

## From a primary care perspective

It is starting the conversation that matters far more than reaching a defined conclusion. Good ACP is a process of reconciliation and refining views of what is most important, a shared understanding of values. Over several conversations with loved ones, we can share an understanding of priorities, balancing factors and the steps that might need to take place to support these priorities and enable them to be achieved. The 'what matters most' conversation extends beyond end-of-life care and is in keeping with the primary care approach used in Frome, becoming a routine aspect of patient care.<sup>24</sup>

We all deal with uncertainty, and a conversation on what matters most offers hope and a chance of a better course of an illness. A shared understanding enables a framework in which to make decisions as a situation changes. It supports those around the individual to process and come to terms with future loss. It can help to create an action plan of support. It should be an affirmation of what each person wants in the life that remains and how best the network around them is able to support this. Above all, this should be a process of positive choices: Out of these discussions, there may come decisions about ceilings of care. But the discussion is about what matters to the individual. That is what is important and that is where the focus should remain.

Intuitively, this conversation is the most pressing and relevant need. It provides acknowledgement of our human condition, suffering, joy and understanding. This is the conversation that supports a fellow human being on their journey through life. Harm reduction decisions may flow from this but only within the context of supporting the individual to achieve what matters most

#### From a hospital palliative care perspective

In a hospital support palliative care context, the newer approach described here may build on existing foundations. Hospital palliative care teams have felt a strong drive to encourage conversations around harm reduction, that is, talking about views on future interventions and their risk/benefit in the context of the individual, and much of their education, for generalist staff, has focussed on this. This has meant that ACP is synonymised with DNACPR, for instance, and that this area is a headline topic. Some ACP education meetings end up being focussed only on treatment escalation. But another way of doing this is to start from health and well-being, starting more broadly, and then narrowing the focus later on to the harm reduction aspects of care. If the main topic starts out with 'What do you most like doing at home?' and 'What stops you from doing that at present?' then that can be a gentler introduction to topics like someone's views on preferred places of death. And it helps get a firmer understanding of the person and their surroundings. What makes them tick?

When considering some of the themes that have come up in specialist palliative care during

COVID-19, then the uptake of more digital solutions has been at pace and remarkable. Systems that may have taken years to enter the mainstream NHS and charity IT systems are being fast-tracked in, and there is even a choice of providers. In hospital and hospice settings, tablet computers have been set up for video messaging and streaming, so that even very unwell patients in isolation can interact with their loved ones and communities. Articles and blogs to help those less accustomed to technology have been written in response to the crisis.<sup>23,25</sup>

This information, again with their consent, is shared on handover and referral forms, to enable community palliative care teams to have discussions. Some of these discussions will be challenging. We must acknowledge that digital video solutions will never have the same quality that face-to-face interactions have, and we must note down the pros and cons during this crisis, as it is likely to form our future approaches, even when COVID-19 has gone.

#### Building on a current strategy: an RCGP end-of-life care perspective

In 2019, a partnership between The Royal College of General Practitioners (RCGP) and Marie Curie launched the 'Daffodil Standards': the UK General Practice Standards for Advanced Serious Illness and End of Life Care. The Standards aim to take a public health, population-based approach to palliative and end-of-life care, providing high-quality care for those affected by life-limiting illness irrespective of diagnosis. The standards cover the traditional areas of harm reduction: early identification, good care planning and attention to symptom control but also include the compassionate community domain. This includes what matters most to both the patient and the caring network. The emphasis is not just on planning for deteriorating illness but also on making the most of life for all. ACP should therefore focus on how this can be achieved and move beyond the confines of planning around place of death. *The ongoing conversations include patients and families as the unit of care.* Making the most of life is a *joint venture* with this. Health care can help this process through a health and well-being approach to ACP. These public health principles are not limited in application to end-of-life care. Re-imagining ACP not only addresses who is offered discussions to support ACP but

also deepens connections between general practice, their registered population, and the local community network underpinning and supporting that population.

## Conclusion

Building supportive networks at end of life fits within the conceptual framework of the Ottawa Charter for Health Promotion, through creating supportive environments, strengthening community action and developing personal skills. The Shanghai Declaration on promoting health in the 2030 Agenda for Sustainable Development,<sup>26</sup> an updated reiteration of the Ottawa Charter for Health Promotion, recognises the importance of cities and communities being essential for health. This broader definition of health includes well-being and social ecology. Our recommendations in this article present a challenge of re-orienting health services, linking medical care with that of community action and activation. This requires the caring network to be seen as the primary consideration for intervention at end of life, rather than being limited to person-centred care.

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