Advance care planning (ACP) has been shown to improve quality of life for people with life-limiting diseases and their families, but it is still not widely used. In 2012, only 5% of people responding to the British Social Attitudes survey reported having a living will or advance care plan in place (Shucksmith et al, 2012).

About half a million people die in the UK every year (Office for National Statistics, 2016), but not everyone has the opportunity to make choices about their end-of-life care or treatment ahead of their death. As a result, some people may not receive the best possible care and may experience additional problems towards the end of life. Through structured discussions between patients, their families and/or carers and the health professionals looking after them, ACP (also known as anticipatory care planning in Scotland) helps to ensure that patients’ wishes and preferences for their future care are known to all, particularly in the event that they become unable to make decisions due to their medical condition (Mullick et al, 2013).

ACP is often used by people who have a life-limiting illness and know that, towards the end of their lives, they may become unconscious or lose the mental capacity to make decisions; this can happen, for example, in progressive and degenerative illnesses such as advanced cancer, dementia or heart failure. ACP allows them to share their wishes with their informal and professional carers, who then know what they want and can plan care accordingly. It involves several steps, notably:

- **Opening the discussion**;
- **Exploring the person’s wishes and preferences**;
- **Identifying, recording and communicating the person’s wishes and preferences**.

A variety of documents can be used to record people’s end-of-life care wishes and preferences, such as a ‘preferred priorities for care’ document, an advance care plan or, in Scotland, an anticipatory care plan.

In England, Wales and Scotland, adults can create a power of attorney for their
health and welfare. This is a legal document through which they allow someone else to make decisions about their health and welfare on their behalf. It is also possible to create a power of attorney for property and financial affairs.

People can also write or complete an advance decision to refuse treatment (ADRT), which in Scotland is known as an advance directive. This is a written statement of their wish to refuse specific treatments in specific situations. It allows them to make sure everyone knows what treatment they do not want in case they become unable to express their wishes – for example, if they do not want to be given antibiotics for an infection and/or to be resuscitated if their heart stops and they only have a short time to live.

In its broader context, ACP can also prompt people to make a will, plan their funeral and/or consider organ and tissue donation.

Growing awareness

In recent years, a number of strategy documents that highlight the importance of ACP have been published in the UK including, in England, the End of Life Care Strategy (Department of Health, 2008) and What’s Important to Me – A Review of Choice in End of Life Care (DH, 2015). The latter supports the recommendation that, by 2020, everyone who is affected by a terminal illness is offered a choice about where and how they will be cared for. These and other country-specific documents have led to health professionals becoming more aware of ACP.

However, further improvements are needed before ACP is fully integrated into mainstream practice. Currently, a minority of people use it. According to the British Social Attitudes survey, in 2012, only 5% of people reported having a living will or ACP in place (Shucksmith et al, 2012). Another survey found that only 6% of people had written down their wishes and preferences for their future care, should they be unable to make decisions for themselves (ComRes, 2014). A mutual insurer has estimated that about 70% of bereaved spouses are not prepared for the death of their partner (Royal London, 2016). Exploring ACP in the literature gives us useful insights into what can be done to improve its integration into mainstream practice.

Benefits of ACP

Many papers included in our literature review highlight benefits of ACP for individuals, their families and carers, and health and social care professionals. ACP ensures care is individualised by putting patients’ wishes about what care and treatment they want to receive, as well as when and how, at the centre (Hickman et al, 2015). It allows professionals to have structured discussions with patients and service users about their wishes regarding treatment preferences, goals and preferred place of care, all of which need to be part of the conversation (Kite, 2010). It also increases the use of palliative care by shifting the goal of care from curative to palliative, thus allowing all those involved to focus on managing symptoms and improving quality of life (Brinkman-Stoppenenburg et al, 2014).

According to Khan et al (2014), ACP helps individuals with life-limiting illnesses to die in the place of their choice. Many people would prefer to die at home: ACP gives them the opportunity to say so, which increases the likelihood of it happening. For this reason, Houwen et al (2014) suggest that ACP reduces the number and/or length of hospital admissions, whether for life-sustaining treatment or for end-of-life care. It allows health professionals and carers to make arrangements so people nearing the end of life can spend more time at home, in a care home or in a hospice, rather than being in hospital (Khan et al, 2014; Abel et al, 2013).

ACP can improve end-of-life care for people with dementia or other neurodegenerative diseases: discussing care preferences early in the disease trajectory gives them the opportunity to plan their care before their cognitive function deteriorates and they lose capacity to express their wishes and make decisions (Ampe et al, 2015). It can also improve the bereavement experience of families: Detering et al (2010) have shown that families of people who had completed ACP before death experienced less stress, anxiety and depression after their relative’s death. Bereaved spouses will be better prepared if they can make appropriate legal and financial arrangements before their partner’s death (Royal London, 2016).

Barriers to ACP

The literature also makes it clear that there are still many barriers to ACP, making it less effective or preventing it from happening altogether. A major barrier is the difficulties around initiating discussions: health professionals may not want to take responsibility for starting the conversation because there is no agreement on who is supposed to do this (Lotz et al, 2014). Meanwhile, patients do not always understand what ACP is and how it can benefit them; they may view it as a ‘paternalistic’ process initiated and led by
healthcare staff (Almack et al, 2012). Patients who open discussions are more likely to do so if they are concerned about the burden caused by their illness and their families’ practical needs (Horne et al, 2012; Levi et al, 2010). As for families, they may create barriers simply by not sharing their relative’s end-of-life care preferences with the professionals involved (Noyes et al, 2013). Planning and thinking about death is considered morbid by some patients and makes them fearful of doing this; family or friends may not want to discuss dying to avoid upsetting a person who can no longer be cured (Horne et al, 2012).

Another barrier is poor timing. If the ACP process is launched too late in the disease trajectory, it is less likely to be effective, whereas starting it early helps people get the most out of it; for example, if ACP is not discussed until death is imminent, it is too late for the person to plan ahead and preserve their autonomy at the end of life (Pollock and Wilson, 2015). Patients who do not understand, or have not been told, their death is approaching are less likely to see why ACP is relevant for them and so less likely to engage in it (Guo et al, 2010).

ACP can be made more difficult by the confusing array of documents that can be used for recording a patient’s wishes and the range of processes for sharing and accessing that information (Heyland et al, 2013). As several professionals from different teams and specialties may be involved in a patient’s care, it is important to have consistent documents that can be understood, shared – and ideally also updated – by all.

Barriers can be specific to certain conditions or patient groups. For example, people with a cognitive impairment arising from a neurodegenerative condition will not be able to plan ahead if they have already lost mental capacity (Robinson et al, 2012). People with heart conditions often experience an unsteady decline in their health, and the unpredictability of their disease trajectory makes it harder to know when ACP discussions would be appropriate (Johnson and Booth, 2010).

How to improve ACP uptake

Patients commonly have positive views about ACP discussions and often trust nurses more than any other health professionals when making end-of-life care decisions. Nurses therefore have an important role to play in improving ACP uptake (Hinderer et al, 2015; Box 1) outlines strategies to achieve this. Patients are more likely to use ACP if they understand the negative consequences and implications of treatments or interventions that they will likely receive towards the end of life (Janssen et al, 2013). For example, patients who have a terminal condition and are at risk of having a cardiac arrest can specify that they do not want to receive cardiopulmonary resuscitation if their heart stops.

Box 1. Strategies to improve ACP uptake

- Use standardised processes, eg, when patients arrive at a healthcare facility with a specific condition (such as incurable cancer), health professionals will know they are eligible for an ACP discussion.
- Health professionals should gradually prepare patients and their families for the discussion; a number of approaches can be taken. For example, patients need to know about their condition and all the treatment options including the best supportive care available to them. Mentioning best/worse case scenarios with every treatment decision may also help patients understand the risks involved and encourage them to think about supportive care such as ACP (Laryionava et al, 2015).
- Health professionals should follow up ACP discussions in order to reiterate its suitability to patients, as this increases the likelihood that they will make plans for their future care (Jones et al, 2011). Follow-ups help in situations when patients are still unclear about their preferences and help those who are not exactly clear about their prognosis.
- Health professionals should help patients to use ACP documents to state their wishes, so that these are accurately recorded and can be shared and accessed by all (Aw et al, 2012).

How to enhance ACP quality

Better communication, appropriate skills and the use of systems facilitating ACP can all enhance its quality. Nurses as well as doctors need training so that they have the right skills to initiate and manage ACP conversations well (Seymour et al, 2010).

End-of-life care staff need information about patients’ conditions so that they are aware of patients’ needs and know when to start the ACP process (Handley et al, 2014). While cancer patients are often still able to discuss their preferences in the palliative stage, people with Parkinson’s disease, for example, may not be because of the deterioration in their cognition and physical condition; timing is therefore crucial (Richfield et al, 2013).

Discussing ACP with the right health professionals at the right time can improve both its quality and its effectiveness; for example, informing cancer patients of their prognosis and offering them ACP before first-line chemotherapy will help them understand how ACP can help and why it is useful to start it early (Tokito et al, 2015).

Discussion

This literature review has identified a number of reasons why ACP is useful for people approaching the end of life. It enables individuals to fulfil their end-of-life wishes by allowing them to receive the treatment and care they want in the place of their choice, leave instructions for carers and make practical arrangements. However, a number of barriers are preventing ACP from being used more widely and more adequately. Health professionals can overcome some of these barriers by:

- Taking steps to inform and empower patients;
- Putting better systems in place;
- Taking responsibility for initiating discussions;
- Ensuring they have the right skills.

People with life-limiting conditions are more likely to use ACP if they understand their prognosis and are well informed about ACP, its relevance and benefits. Making resources about ACP more widely available – for example, in outpatient clinics, libraries and GP surgeries – and offering them in different formats would help inform people and empower them to broach the subject, which would make ACP a less paternalistic process. Further research is needed to help us understand what else can be done to empower people to use ACP.

Ensuring reliable systems are in place to identify suitable patients would help increase the use of ACP and prevent missed opportunities, ensuring that the right patients are offered ACP at the right time.

Health professionals should take more responsibility for initiating ACP conversations. They need to be clear about who is the best person to start the conversation, and when it should be started. This will vary from person to person, so having an individualised
approach is important. Nurses are often best placed to initiate and follow through these discussions as they have a key role in the care of patients, particularly those with life-limiting illnesses.

Health professionals need to receive appropriate training – which can be a combination of formal training and online resources – so they feel confident having ACP conversations. Box 2 lists resources around planning care near the end of life.

**Conclusion**

Discussing ACP involves lifting the taboo around death and dying in order to help people live well until the end. In that sense it is part of a bigger societal shift, marked in recent years by several initiatives and movements (Box 3). More needs to be done for ACP to become part of mainstream practice, so people have the opportunity to plan ahead and receive better care at the end of life, even when they are no longer able to make decisions.

This literature review has identified a number of reasons why ACP is currently not being used more widely, but also a number of factors likely to increase and improve its use, and nurses have an important role to play in this. With more training and skills to initiate ACP discussions, nurses can make a real difference to people who may benefit from this specific type of care planning.

When ACP is implemented, it may also reduce pressure on hospitals by allowing some people to receive treatment and care at home when they would otherwise have been admitted to hospital. However, this also means there may be greater demand for community nurses to provide care at home if ACP uptake increases.

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**Box 2. Resources aiming to help plan end-of-life care**

- Advance Care Planning toolkit for healthcare generalists, Macmillan. Cancer Support
  Bit.ly/ACPToolkit
- Preferred priorities for care, Cancer Research UK
  Bit.ly/ACPPriorities
- Guide on advance decisions to refuse treatment, National Council for Palliative Care
  Bit.ly/RefuseTreatment
- **Advance Care Planning: A Guide for Health and Social Care Staff, NHS**
  End of Life Care Programme
  Bit.ly/ACPGuideHCP

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**Box 3. Resources aiming to lift taboo around death**

- compassionatecommunities.ie
- deathcafe.com
- dyingmatters.org
- endoflifehealthforall.com
- goodlifedeathgrief.org.uk
- phperti.info
- thinkaboutdeath.org

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**References**


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**For more on this topic go online...**

- Starting end-of-life conversations in hospital
  Bit.ly/NTEoLCConversations