

ADVANCE CARE PLANNING - HOW DOES IT WORK IN PRACTICE?

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Abstract: Talking to patients about dying is never easy, so anything that can improve this communication has to be a significant benefit. Recent national developments in the UK have highlighted the importance of choice for patients in both the place they die, and the interventions they would want to have. Such developments are aimed at improving quality of care and empowering patients and include the national NHS End of Life Care Programme (2009) and The Mental Capacity Act (2005). This article examines the evidence behind using Advance Care Planning (ACP) as well as the practical issues of who might be best placed to undertake these discussions and what documentation tools to use. It concludes that care should be individualised and full use made of established professional relationships. Communication needs to be to the highest standard as the risks of causing distress are significant. Full use of the breadth of the multi-disciplinary team can enable full discussion of wishes around spiritual, social as well as medical care.

What is Advance Care Planning?

Advance Care Planning is the discussion of preferences for treatment and care at the end of life. It encompasses all aspects of planning for the future. Traditionally, ACP only included making an advance decision to refuse treatment (ADRT) (previously known as a Living Will or Advance Directive). More recently it has encompassed broader and more philosophical aspirations of care which are not legally binding, known as Advance Wishes. These requests can be extremely valuable to guide decision-making when a person is no longer able to make decisions for themselves. Advance planning can also include putting affairs in order, writing a Will and planning a funeral.

The Mental Capacity Act (2005) has been a key piece of legislation in the UK, legally defining and supporting Advance Decisions to Refuse Treatment and clarifying the process of making a decision in someone's best interest. It has also enabled the option of appointing a proxy decision-maker to make healthcare decisions on someone else's behalf - a Lasting Power of Attorney for health and welfare. Advance Care Planning supports patient autonomy by enabling them to express their wishes for future care. Should they lose the capacity, these wishes can then be respected when making decisions about their care. However this does involve them being able to anticipate situations and our responses to them, something that can be extremely hard to do.

Simon et al (2008) comment that the process is perhaps better described as "relational autonomy" whereby decisions and preferences are made in the social, cultural, political context of the individual and not in isolation. It is this engagement of the preferences with the reality of the situation around them which can make the choices deliverable, as a negotiation has already taken place. Unless this process of discussion and negotiation is entered into with family and healthcare professionals, then requests may well be difficult to provide.

Is there evidence and is it useful?

Advance care planning has been used in Australia, Canada and the United States for many years. In America it is a legal requirement that all publicly-funded health services inform patients about advance directives, honour the instructions in these directives, and have clear policies and procedures to support this, as well as training the staff and educating the public about advance directives.

Davison and Torgunrud (2007) have been involved in implementing advance care planning for patients with end stage renal failure. They comment "outcomes of such an ACP process will not be measured by increasing the number of completed advance directives, but by improving satisfaction with the entire end of life experience and having outcomes match patient preferences." Perhaps, therefore, we need to look in more detail as to what

preferences individuals do express and whether these are achievable. Simon and Murray (2008) sought to gain insights into the patients experience when engaging with Advance Care Planning. They conducted a qualitative study with interviews of patients with end stage renal failure. They found that patients associated Advance Care Planning with hope for future goals and therefore viewed this as a positive process rather than one which diminished hope.

A further small study into the use of advance care planning in palliative care units demonstrated that completion of the documentation led to significantly lower depression scores after one week and higher satisfaction with their level of involvement in their care, compared to those who did not complete the documentation (Pautex et al 2008).

Horne et al (2006) undertook a prospective qualitative study into the reactions of lung cancer patients to Advance Care Planning discussions with their lung cancer nurse. The key findings were that nurses' attributes aided the discussion about future care and treatment and that, on the whole, patients appreciated the information and explanation offered to them. Further, the response of carers was also varied in this study- with some grateful for the discussion being opened up, and others preferring to 'take one day at a time'

In a study in an acute hospital in Australia following the introduction of an Advance Care Planning programme, the nurses reported feeling more confident about decisions at the end of life, and their role as patient advocates was strengthened (Seal 2007). They also reported better job satisfaction from the knowledge that they had been able to uphold patient's wishes in practice. A further small Australian study looked at the used of advance care planning in a nursing homes where they were able to demonstrate a marked decrease in the use of emergency ambulances, hospital admissions and mortality (Caplan et al 2006).

Using Appropriate Tools

Davison (2006) comments "there is a strong argument for shifting the focus away from the traditional information-giving and document-completion model of advance directives and replacing it with a relational, patient-centred process that

focuses on the broader goals of care". Advance Care Planning should not just include the medical aspects of refusing treatments but should encompass the practical aspects of putting affairs in order, as well as the personal hopes and fears of patients facing their last days. This can be achieved through a multidisciplinary approach and using appropriate documentation. In the recent Advance Care Planning Guide published by the Royal College of Physicians and other collaborators (2009) a variety of Advance Care Planning documents (including Preferred Priorities for Care) are reviewed. They conclude that none of the forms are ideal and that a combination of several documents is likely to be required.

Our experience in Weston-super-Mare led us to having a single leaflet containing an advance wishes form as well as information on appointment of a proxy, funeral planning and putting affairs in order checklist and an ADRT (westonhospicecare 2008). This approach aims to cover a wide range of future choices that patient's may wish to make and encourages multi-professional involvement in Advance Care Planning. These are subjects can be difficult to broach, but having an inclusive leaflet has been very useful in our experience and encourages the broader multi-disciplinary team to be involved in the discussions. In our team we see the chaplain as a key part of advance care planning with her discussions with patients frequently leading to consideration of the future and the making of plans sometimes linked to a funeral service and sometimes the expression of more general aspirations. Further support for advance care planning can then be easily handed on to other team members.

Who should initiate and/or undertake these discussions?

Key to the success of advance care planning is a team approach to the discussions. A conversation may be initiated by the community palliative care nurse, but then picked up by the complementary therapist, chaplain, doctor, occupational therapist or other multi-professional team member. In the 'Respecting Choices' programme in Australia facilitators were trained from any discipline including doctors, nurses, allied health professionals, social work and spiritual care (Blackford et al 2007, respectingpatientchoice (2007)). In a study looking at

Advance Care Planning for patients with inoperable lung cancer, the lung cancer nurses were the ones who undertook the ACP discussion. From the interviews it emerged that patients felt able to discuss options and choices with the lung care nurse because they had a pre-existing relationship and trust of their specialist knowledge.

Consequently, in order for nurses to be able to perform this role they need to have excellent communication skills as well as sound knowledge of the legal basis of advance care planning and best interests decision-making on behalf of someone who has lost capacity. A qualitative research study by Barnes and colleagues (2006) indicated that it was generally helpful to initiate such discussions at the time of disease recurrence or deterioration and that Advance Care Planning should take place over a number of meetings.

In the study of patients with end stage renal disease (Davison et al 2006) patients reported a number of elements of the ACP process that made it effective. These included: more information, linking information about prognosis and treatment options to the effect they may have on lifestyle, values, personal relationships and empathetic listening. It therefore seems that a broad-ranging sympathetic discussion about the future is valuable.

Integrating advance care planning into our daily practice requires excellence in communication skills. In addition, as palliative care teams we need to become more anticipatory in our practice and to take on the attitude that to avoid discussing future wishes with patients is to deprive them of making important decisions. On the other hand we also need to remain sensitive to the fact that there will always be some patients who struggle to discuss future plans, and engagement in such discussions is always voluntary.

There is significant support for the role of nurses in promoting and facilitating advance care planning. This would seem to follow naturally from their role as patient advocates. Nurses would seem to be ideally placed to introduce advance care planning, facilitate discussions amongst family members and monitor patient's wishes (Jacobsen 2000). Nurses spend very significant amounts of time with patients and their families and are therefore likely to be trusted and be well placed to engage appropri-

ately in a discussion (Shanley 2004). However, our local experience is that a team approach gives the patient flexibility as to who the patient wishes to talk to, and enables appropriate response to the patient needs. This enables all team members to respond in an integrated way to the wide variety of questions patients may ask: such as "how can I plan my funeral?" or "can I donate my organs for medical research?"

Where and when should these conversations take place?

The ACP process is a continuum which may take place over a period of time and involve a number of professionals starting the discussions and then handing on to their colleagues (Barnes et al 2007). In line with The Gold Standard's Framework (2009) these conversations should follow the identification of patients considered to be in the last year of life. For some patient groups this is more of a challenge than for others.

It will sometimes be appropriate for some of these conversations to be started in hospital, where a diagnosis of advanced disease or recurrence may have been made. A study into the impact of these discussions taking place in hospital found that the information and discussions were generally well received. In the study by Barnes and colleagues (2007) where mainly oncology patients in remission were interviewed, the participants felt the most appropriate time to discuss Advance Care Planning would be after a recurrence or when a treatment has failed and the prognosis is poor (Blackford et al 2007).

An admission to hospital for dementia patients is now recognised as a poor prognostic factor which should trigger ACP discussions. Admission to a residential care facility should also be considered to be an important time to start Advance Care Planning.

Wider Communication of Advance Care Planning

An important part of Advance Care Planning is communicating any wishes patients have made. In the study by Horne (2006) she found that all the participants agreed to have a written record of their wishes and for this to be shared with other mem-

bers of the healthcare team. If information is to be shared then consent to do so is needed.

Patients are encouraged to share any plans with their family and ideally plans will already have been worked through together. Plans should be readily accessible by out of hours medical and nursing teams as well as ambulance staff if they are truly to have an effect on the care an individual patient receives. Using computer systems to do this is a challenge and for the moment paper copies are often relied on. Locally we are exploring the General Practice and ambulance out of hours information technology systems as a good way to share this information. In addition the multi-professional hospice team has computer-held records which display an alert to the fact that a patient has written an advance care plan.

Within our locality, we have been impressed by the use of Advance Care Planning (ACP) in daily practice; it seems to enable patients to share significant information at a profound level. This is illustrated in the two case histories.

Case Histories

Case 1

A gentleman with pancreatic cancer was able to participate fully in advance care planning with the specialist palliative care nurse and the chaplain. He had planned the details of his funeral with the chaplain. In response to the question "Is there anything you would ideally like to avoid happening to you?" he answered:

"Dying Alone. Having to endure excessive pain. Being told everything is going to be alright."

These gave the team looking after him valuable insights into how he wanted to be treated and what level of communication he needed. After his death his wife spoke about gaining great peace from knowing she had been able to fulfil all his wishes and that she knew exactly what he wanted.

Case 2

A young lady with Motor Neurone Disease spoke to both the hospice chaplain, hospice consultant and nurse about her need to plan for the future. She was able to make funeral plans as well as completing the advance wishes document and an Advance Decision to Refuse Treatment.

In response to any special requests or preferences she stated she would like

"A Garden room with sunny outlook. Open access to visitors .Music. "She clearly stated that she did not want to go into hospital. She also stated her wish to donate tissues for research and refused non-invasive ventilation or tracheostomy.

Her specialist nurse commented " Using the Advance Care Document provided a focus....it acted as a catalyst to prompt discussions ...to put in place the breathing space kit, plan for tissue donation and funeral arrangements. It did not make her death easier to bear, but provide reassurance that their wishes would and could be followed to the best of everyone's ability".

Conclusion

Advance Care Planning is a key part of the care for people with chronic, life-limiting diseases. If we are to be able to allow people to die in their place of choice, we need to identify these patients and have a discussion about their wishes for the future. These wishes then need to be available to the wider health community, so that the wishes can be respected and followed through, even in the emergency setting.

We need to do more work to understand the patient and carer experience at the end of life and into bereavement. Does expressing your wishes mean that these wishes are more likely to happen or is its main benefit in terms of reducing collusion and enabling recognition and acceptance of a short prognosis? Furthermore without increased home support services are we setting up unrealistic expectations that patients do in fact have a choice in where they die?

We have been impressed how good advance care planning with a single leaflet has improved our communication with patients. The whole multi-professional team can be engaged in the process, with an emphasis on gaining a holistic understanding of the patient's philosophy, attitude and priorities. Advance care planning should never be simply a paperwork exercise but should facilitate important discussions for patients and their families.

As one patient said, "It is done and I haven't got to worry about it so, I found that absolutely wonderful."

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