Advance care planning

This article will provide an overview of Advance care planning (ACP), discuss why advance care planning is important, highlight the barriers to having conversations and discuss the role of the nurse in supporting patients with ACP.

Introduction

Around half a million people die each year, approximately three quarters of which are expected (NHS England, 2014), therefore, there is the potential to improve how their care is managed in the final year, months or days of life. The End of Life Care Strategy (Department of Health (DH), 2008) highlighted that whilst individuals may have a differing opinion of what constitutes a good death, for many this would involve being treated as an individual, with respect and dignity, being free of pain and other distressing symptom, being in familiar surroundings and having close friends and family close by. However, the report goes on to suggest that whilst some people do achieve a good death, the reality is different for many. There have been reports such as the Independent Review of the Liverpool Care Pathway (Neuberger, 2013), and Leadership Alliance for the Care of Dying People (LACDP) (2014), which highlight that despite evidence that there are examples of good end of life care, there remain inconsistencies, with patients dying in pain, distress and not in a place of their own choosing.

The Parliamentary and Health Service Ombudsman (PHSO) (2015) state that one of the main sources of complaints around end of life care is around communication, in particular health care professionals not always having open and clear communication with patients, and allowing them to make their choices and wishes known in a timely manner. One of the key recommendations from the EOLC Strategy is that patients should have the opportunity to have their needs continuously assessed, and their wishes and preferences documented in a care plan.
and available to all (family and health care practitioners) who come into contact with the patient (DH 2008). One of the key ways in ensuring that the patient receives individualised patient centred care, which takes into considerations their wishes and preferences is to have an advance care plan.

**What is an Advance Care Plan?**

Advance Care Planning is a process that supports patients at any stage of health, and is a means of extending autonomy, by planning for future care in the event if someone becomes unable to make their decisions or wishes known (Izumi, (2017), Brinkman – Stoppelenburg, Rietjens and Heide (2014). In essence, it is a process of discussions about treatment and no treatment options, and recording the preferences of care of patients who may lose capacity or the ability to communicate in the future (Fig 1).

**Fig 1**

<table>
<thead>
<tr>
<th>Definition of Advance Care Planning</th>
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<tbody>
<tr>
<td>“A voluntary process of discussion and review to help an individual who has capacity to anticipate how their condition may affect them in the future and, if they wish, set on record: choices about their care and treatment and/or an advance decision to refuse a treatment in specific circumstances, so that these can be referred to by those responsible for their care or treatment (whether professional staff or family carers) in the event that they lose capacity to decide once their illness progresses”.</td>
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NHS England (2014)

Whilst ACP is a continuous process, involving many conversations with the patient and those important to them, key documentation that support an ACP are an Advance Decision to Refuse
Treatment (ADRT) formerly referred to as a Living Will, an Advance Statement and a Lasting Power of Attorney (Fig 2).

**Fig 2**

<table>
<thead>
<tr>
<th>Supporting documents</th>
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<tbody>
<tr>
<td>- Advance Decision to Refuse Treatment (ADRT). This is when an individual can specify what treatment they would not want to receive in a specific situation. For example, Do Not Attempt Resuscitation (DNAR)</td>
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<tr>
<td>- Advance Statements – A record of the patient’s wishes and preferences (not legally binding). For example, an individual may document their preferred place of care</td>
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<tr>
<td>- Lasting Power of Attorney (LPA)- Giving one or more-person legal authority to make decisions about Health &amp; Welfare/Property &amp; / or Finance</td>
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All these documents only become legally binding when the patient loses capacity.

(Hebb, (2018); National Institute for Health & Care Excellence (NICE), 2018)

**Why is an Advance Care Plan important**

There are a number of reasons why advance care planning is important. These include:

- Empowers patient and family
- Reduces burden on the patient, family carers and health care professionals to make decisions on behalf of the patient.
- Reduces uncertainty
- Determines future goals.
- Prevents unwanted treatments
- Prevents unnecessary hospital admissions.
- Identifies preferred place of care/death

**Barriers to ACP Conversations**

<table>
<thead>
<tr>
<th>Patient</th>
<th>Not wanting to have a conversation</th>
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<tbody>
<tr>
<td></td>
<td>Physical deterioration/ Phase of illness</td>
</tr>
<tr>
<td></td>
<td>Emotional unpreparedness</td>
</tr>
<tr>
<td>------------------------------</td>
<td>-----------------------------------------------------------------------------------------</td>
</tr>
<tr>
<td>Capacity</td>
<td>Does the patient have capacity to make decisions?</td>
</tr>
<tr>
<td>Environment</td>
<td>Not conducive to sensitive conversations</td>
</tr>
<tr>
<td>Time</td>
<td>Not enough time (rushing a conversation), the wrong time (left too late)</td>
</tr>
<tr>
<td>Health Care Professionals</td>
<td>Lack of training, knowledge (lack of knowledge to recognise an appropriate opportunity to commence an ACP conversation), skills, and confidence.</td>
</tr>
<tr>
<td>Family</td>
<td>Unaware of need to have conversation</td>
</tr>
<tr>
<td>Public awareness</td>
<td></td>
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(Thomas and Lobo (2011); Deciding Right (2019))

The Role of the Nurse

Conversations about health and future care, sit with all health care professionals but particularly nurses due to the close nature of their role alongside patients. Nurses should adopt a proactive approach in terms of ACP- similar to midwives supporting pregnant women to develop birth plans, knowing that during labour they may not be able to effectively express their preferences and wishes (Lyons, 2018; Mannix, 2017, Royal College of Physicians, 2018). The development of ACP is underpinned by the first theme of the Nursing and Midwifery Code (NMC) (2015) which states that in order to prioritise people, they should be treated as individuals, with dignity and their preferences and concerns should be listened and responded to. This requires nurses to have the necessary skills and qualities to engage and facilitate these conversations. Nurses must therefore have a good understanding of the Mental Capacity Act (2005) and how a lack of capacity, whether permanent or fluctuant can impact on patient care and decision making. (NICE, 2018).

Key components of facilitating ACP considerations are:
Conclusion

This article has highlighted the importance of open and honest conversations with patients regarding their future care wishes and preferences. Although there are barriers to facilitating these conversations, the nurse is a pivotal role within the healthcare team in ensuring the conversations happen in a timely manner and are delivered by compassionate, confident and skilled individuals.
References


(Accessed June 2019)
Available at https://www.NICE.org.uk (Accessed: 12\textsuperscript{th} July 2019)


NHS England (2014) *Capacity, care planning and advance care planning in life limiting Illness* 


