Advance Care Planning

Exploring the barriers to a universal approach to End of Life Care.

Contents

Introduction

Engaging Communities Staffordshire (ECS) is an independent, community interest company that delivers Healthwatch Staffordshire, Wolverhampton, Walsall and Solihull.

ECS is primarily concerned with engagement with local communities surrounding the provision of healthcare in Staffordshire, the wider West Midlands region and beyond. The company provides a subscription service for partner organisations to conduct regular research and insight gathering that can help them improve their service design and delivery. We develop practical recommendations to improve services, replicate good practice, and improve service user experience, based on robust evidence collected from the voice and experience of service users and staff.

Our reports are designed to be transparent, clear, and easily accessible that create sustainable improvements in the delivery of services.

Engaging Communities deliver the contracts for Healthwatch in Staffordshire, Wolverhampton, Walsall and Solihull. This work is part of our Healthwatch Staffordshire contract delivery following a public consultation in 2015.

Background

After a public consultation with residents of Staffordshire, it emerged that End of Life Care (EoLC) was a priority area identified by the public, for Healthwatch to focus their work in 2016/17. Our local intelligence around EoLC suggested there were discrepancies in the way care was delivered across different parts of the County and the wider Midlands Region and also between Hospices, Hospitals and in the home. We are also aware that the Director of Public Health in Staffordshire has focused on End of Life (EOL) for his annual report for 2017 As a result, an EOL Advisory Group was developed with a sample of local service providers from St Giles Hospice Care, Beth Johnson Foundation, Douglas Macmillan Hospice, Alzheimer's Society Staffordshire and Shropshire, Donna Louise Trust, and University Hospitals of North Midlands (UHNM), led by Engaging Communities (ECS) and Healthwatch Staffordshire.

This project set out to explore the barriers to a consistent, holistic approach to EoLC through multi-disciplinary collaboration in Staffordshire, Walsall and Wolverhampton. This included looking into the experiences and opinions of EoLC professionals, staff, and service users. Three workstreams were devised which the group considered to be primary issues that needed consideration. These included Advanced Care Planning, Workforce Development and Pre/Post Bereavement Support.

As part of the objectives of the Advance Care Planning workstream, a Task & Finish group was set up to identify the barriers to a consistent, holistic approach to EoLC within Staffordshire, Wolverhampton, and Walsall. Research about Advance Care Planning (ACP) specifically in these three areas is limited, but research in other parts of England highlight some key areas that have caused barriers to effective Advance Care Planning.

As a direct initiative leading from the Mental Capacity Act, ACP can support patients to achieve their wishes and preferences at the EoL. An Advance Care Plan involves the discussion and recording of wishes and preferences as well as communicating them to family, friends and health professionals (NHS, 2009). Despite evidence that ACP can improve the quality of the lives of patients with life-limiting conditions, ACP is often still not undertaken within the health and social care system (Kononovas & McGee, 2017). The rest of this report will explore what ACP is, what the trigger points are for having an advance care plan in place, what is local and national best practice, what barriers there are to achieving this in Staffordshire, Walsall and Wolverhampton, as well as making recommendations to mitigate these barriers.

Plan & Methodology

This report is underpinned by the following research questions. The report will be structured to reflect the findings against these areas of enquiry. A discussion of the methodology justification and quality assurance for research design is also provided.

Research Questions

1. What is Advance Care Planning and what are the trigger point for ACP to begin?
2. What is the national and local best practice?
3. What are the barriers to achieving the national best practice in Staffordshire, Walsall and Wolverhampton?

Methodology

This report was compiled using relevant research and discussion from a clinical reference group, composed of professionals who have knowledge and experience of ACP. This research was led and completed by Healthwatch Staffordshire with input and support from Healthwatch Wolverhampton, Healthwatch Walsall, St Giles Hospice, Douglas Macmillan Hospice and University Hospitals of North Midlands (UHNM), Donna Louise Hospice as well as the Alzheimer's Society.

It also includes an overview of extensive background research using current, unpublished research specific to organizations as well as published academic reports.

Quality plan

We have a responsibility to ensure that the research we undertake and create is of high quality and aligned to best practice across the industry. Research ultimately provides the evidence on which sound decisions should be made, which is why it is important to state up front how quality was ensured during this project. The Research and Insight team underpins its research activities by applying the Market Research Society Codes of Conduct (MRS, 2014). ECS are a company partner of the Market Research Society.

During this project ECS adhered to a strict data protection policy that ensured that:

- Everyone handling and managing personal information internally understood they were responsible for good data protection practices;
- There was someone with specific responsibility for data protection in the organisation;
- Staff who handled personal information were appropriately supervised and trained;

- Queries about handling of personal information would have been promptly and courteously dealt with had they been received;
- The methods of handling personal information are regularly assessed and evaluated;
- Necessary steps were taken to ensure that personal data was kept secure at all times against unlawful loss or disclosure.

ECS have firm guidelines for data storage, data retrieval, data security and data destruction. There is also a strict process in place should a data breach occur (which includes containment and recovery, assessment of ongoing risk, notification of breach, evaluation and response). To further ensure the quality of the final report, an internal peer review process was initiated to ensure that the report is fit for purpose before submission. Where data is not robust it was suppressed to prevent disclosure.

Findings

What is ACP?

Advanced Care Planning (ACP) is a term we have frequently heard in the media recently, especially in regards to EoLC. So, what is ACP?

While there is a general understanding of ACP, there are varying definitions for what ACP is in reality. For the sake of this report, we have chosen this definition, "Advance care planning is 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" (ACP booklet, 2011).

ACP is a process whereby people can make a record of their wishes and preferences about their health and care for the future (The Dying Matters Coalition, 2015). It allows the individual to make advanced decisions about their health and social care, in case there is a time when they cannot make them for themselves. This could be because they may have lost capacity, their health has deteriorated rapidly or they struggle to communicate. This process is voluntary, and it is completely up to the individual whether or not they want to take part in it.

An advanced care plan allows the individual to put in writing that they want to refuse certain treatments (e.g. CPR), or their preferences about other care choices. Other examples would include aspects such as putting their finances in order and making a will, or updating a will they have already made (Alzheimer's Society, 2016). Other inclusions into the ACP are where and how they are cared for as well as where they would prefer to die. All ACP has to be aligned to the Mental Capacity Act.

The Mental Capacity Act

In 2005, the Mental Capacity Act (MCA) was established to protect people who have lost capacity to make independent decisions about their care and treatment by giving guidance on how decisions should be made regarding their health and care (NHS Choices, 2015). The MCA provides a legal framework for all health and social care professionals to follow when they are dealing with health and social care decisions for these individuals, and professionals have a statutory duty to comply with the framework (HM Government, 2005). The MCA applies to those who are 16 and over. The Act has a myriad of principles, one of which is that every individual is offered a chance to undertake care planning that is directed by the individual and not the professional. Other principles include, "The decision of an individual with capacity must be given priority over all other current documents, plans or opinions" (Northern England Strategic Clinical Networks, 2015, p. 4). According to the National Council for Palliative Care, as part of the Mental Capacity Act, "formalised outcomes of ACP might include one or more of the following: i) advance statements to inform subsequent best interests decisions; ii) advance decisions to refuse treatment which are legally binding if valid and applicable to the circumstances at hand; iii) appointment of Lasting Powers of Attorney for health and welfare and/or property and affairs" (NHS National End of Life Care Programme, 2011, p.10). Although advance statements are not legally binding, professionals are required under the Mental Capacity Act to take them into account when considering the individual's best interests. There is no set format for advance statements, although some local and national examples exist such as Preferred Priorities of Care.

Benefits of ACP

Overall, ACP has been associated with end-of-life care that has been reported to be satisfactory to patients. It is also said to have improved the patient experience (Durall, Zurakowski, & Wolfe, 2012). Although it may feel difficult at the time to think about the future while completing an ACP, it can also be reassuring to know that wishes and preferences have been made clear. Planning also avoids leaving unresolved problems for others to manage and can provide a clear direction, which is helpful if there are complex family relationships (Alzheimer's Society, 2012). Delaying discussions about a patient's preferences and wishes until they are imminently dying also makes it much less likely that

their wishes for end-of-life care will be met (Sleeman, 2013; Stewart, Goddard, Schiff, & Hall, 2011). Families with a completed ACP prior to the death of their relative have also reported experiencing less anxiety and stress after the death (Detering et al., 2010) and feel better prepared to make decisions around legal and financial arrangements (Royal London, 2016).

Additionally, ACP also encourages the shift of focus from curative to palliative (although this has been debated over by palliative professionals), ensuring that symptoms are managed well that can improve the quality of the patient's life (Brinkman-Stoppelenburg et al, 2014). An ACP can help individuals die in their place of choice (Khan et al., 2014) and therefore, could reduce the length and number of hospital admissions (Houben et al, 2014). For instance, a larger number of people would prefer to die at home (Kononovas & McGee, 2017), and having an ACP in place can allow health professionals and carers to make arrangements at home in advance, rather than for care in the hospital (Khan et al, 2014; Abel et al, 2013).

What are the trigger points for ACP being put in place?

ACP is normally initiated when a patient is approaching EoL (Joseph, 2010) or has been given a palliative diagnosis. The majority of formal ACP is supported by palliative care professionals, probably due to increased awareness, training and confidence in doing this. Generally speaking, ACP is triggered when:

- there has been a major change/deterioration in patient's condition
- a patient has expressed wish or preference about their care
- patients are at key trigger points such as diagnosis of serious illness, illness becomes incurable, deterioration in condition
- when patient has a condition that is likely to mean loss of capacity to make decisions in the future e.g. dementia
- when there is a significant shift in treatment focus
- where options for treatment require review
- following multiple hospital admissions
- at the time of an assessment of the individual's needs

However, professionals who work in EoL care state that this perhaps is not the ideal time for an ACP to be triggered. ACP can be undertaken at any point and a palliative diagnosis is not a prerequisite. It can and perhaps should be undertaken at any time in one's life, and can be done without someone else starting the conversation (Compassion in Dying).

Ideal time for ACP?

In April 2017, an article published in the Lancaster County in the US reports a similar opinion. It was reported that the theme for this year's National Health Care Decisions Day is, "It always seems too early, until it's too late" (Bhatia, 2017). The article goes on to mention that patients wait too long until the end-of-life to have decisions made, and suggests that such decisions do not need to wait till old age or a life-limiting prognosis for one to start the conversation.

Here in the UK, palliative healthcare professionals seem to hold a similar opinion. In a focus group conducted by St Giles Hospice regarding ACP, nurses pointed out that an advanced care plan does not have to be constrained to EoL and can be undertaken by anyone who would like their preferences to be communicated for their future health. Results of the focus group reported that most of the professionals regarded ACP as the responsibility of anyone and everyone to undertake, though this may not be the case for patients. Quotes from the focus group can be seen below:

Whose responsibility do you think it should be to initiate an advance care planning discussion?

> **Because there's no limitations. I've got one, I hope I'm not dying imminently, but there's no limitations as to when to make it, and I think that's the focus that we need to all consider is actually, we don't know what's going to happen to each of us in the future, so therefore on the proviso that you have these open and honest conversations, that you never leave those behind thinking, have I got it right, did I get it right, is that what she/he wanted?**

> **But not always about end of…not strictly end of life, sort of, a bit…sometimes a bit more global. A bit bigger than just what's going to happen right at the end, but what would you want to happen before you get to the end? How do you see things playing out?**

Aside from the opinions of healthcare professionals, the research into the benefits of having an ACP completed well before any palliative prognosis echoes this sentiment as well. Research conducted by Marie Curie also highlighted the importance of getting an ACP done well before hospitalisation (Royal College of Physicians, 2016). Having an ACP done early can not only provide preparation and comfort to the patient, but it also establishes the ownership of the ACP as being the patient's. The patient's choice is vital in the ACP process (NHS, 2009), and it is the expectation that the patient will be placed at the centre of all the choices made. Having an ACP done well in advance will also mean that the patient can establish the feeling of ownership well before any medical interventions are

needed. The care plan can be initiated by the individual at any time of their choosing and therefore, there is no necessity for the individual to have to wait for the offer to come through from a professional.

Without an ACP, in the event that the individual has lost capacity, decisions are made by an appointed 'decision maker'. The 'decision-maker' is usually the health or social care professional responsible for the individual's care at the time, however who the appropriate decision maker is based on the decision being made (Mental Capacity Act 2005, chapter 5) about who will act in the best interests of the individual. This process is not always the preferred option for patients, perhaps due to complex family relationships or in the interest of maintaining their autonomy. An ACP done in advance of palliative care, is one way of combating this.

Therefore, more awareness needs to be raised to move ACP out of palliative care so that members of the public are more likely to engage with it as a preparatory document.
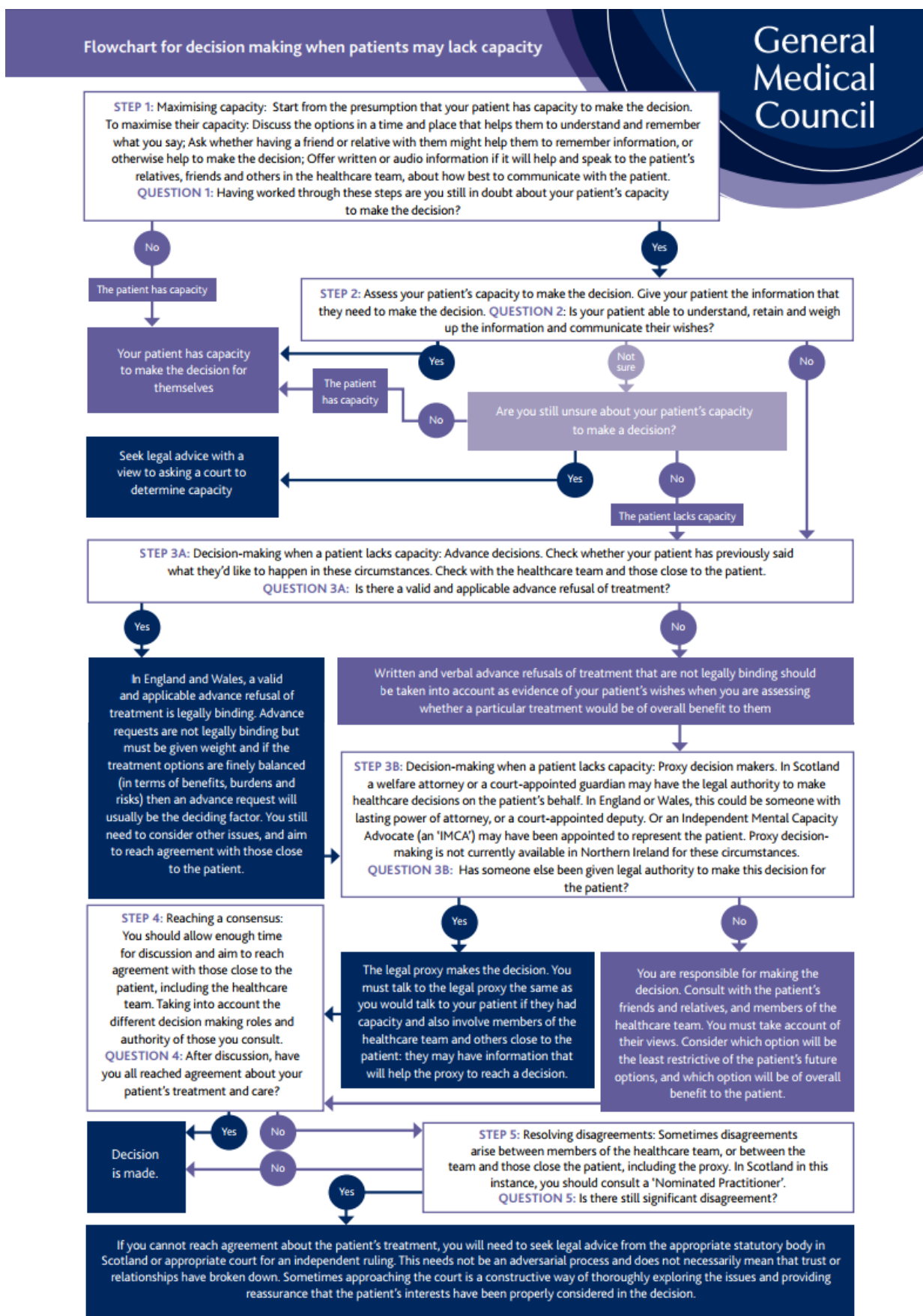
What is the national and local best practice?

National picture & background

To provide a comprehensive framework for EoLC, the first national EoLC Strategy (Department of Health, 2008) was published to endorse quality care for all adults at, or approaching EoL, across England. The strategy, which included the development of the NICE Quality Standard for EoLC (2011), provides guidelines on what quality EoLC should be like. In a report published in 2016 by the Department of Health, the government declared six commitments to the public to end differences in EoLC across the NHS by 2020. Of these six commitments, two of these were: "dying people making informed choices about their care" and "the discussion of personalised care plans with care professionals" (Department of Health, 2016).

National good practice models

ACP has always been a large part of the NHS EoLC Programme; however examples of national best practice models are not well-published. One such good practice example to advance care planning is known as Deciding Right, a regional initiative in the North East and Cumbria. The initiative was authorised through the Mental Capacity Act and the national guidelines for health and social care professionals. Individuals can choose to make their wishes known in advance through a number of methods and have their rights protected by the Mental Capacity Act, should they lose capacity.

In terms of identifying how to go about identifying lack of capacity, the General Medical Council came up with a useful flow chart for clinicians and nurses to use to identify if any patient under their care has capacity. It also has useful guidance about when to seek legal support. A copy of the flow chart can be seen below:

Flowchart for decision making when patients may lack capacity

General Medical Council

STEP 1: Maximising capacity: Start from the presumption that your patient has capacity to make the decision. To maximise their capacity: Discuss the options in a time and place that helps them to understand and remember what you say; Ask whether having a friend or relative with them might help them to remember information, or otherwise help to make the decision; Offer written or audio information if it will help and speak to the patient's relatives, friends and others in the healthcare team, about how best to communicate with the patient.
QUESTION 1: Having worked through these steps are you still in doubt about your patient's capacity to make the decision?

No → The patient has capacity

Yes →

STEP 2: Assess your patient's capacity to make the decision. Give your patient the information that they need to make the decision. **QUESTION 2:** Is your patient able to understand, retain and weigh up the information and communicate their wishes?

Your patient has capacity to make the decision for themselves

Yes → The patient has capacity

Not sure → Are you still unsure about your patient's capacity to make a decision?

No

No →

Seek legal advice with a view to asking a court to determine capacity

Yes ← | **No** → The patient lacks capacity

STEP 3A: Decision-making when a patient lacks capacity: Advance decisions. Check whether your patient has previously said what they'd like to happen in these circumstances. Check with the healthcare team and those close to the patient.
QUESTION 3A: Is there a valid and applicable advance refusal of treatment?

Yes

No

In England and Wales, a valid and applicable advance refusal of treatment is legally binding. Advance requests are not legally binding but must be given weight and if the treatment options are finely balanced (in terms of benefits, burdens and risks) then an advance request will usually be the deciding factor. You still need to consider other issues, and aim to reach agreement with those close to the patient.

Written and verbal advance refusals of treatment that are not legally binding should be taken into account as evidence of your patient's wishes when you are assessing whether a particular treatment would be of overall benefit to them

STEP 3B: Decision-making when a patient lacks capacity: Proxy decision makers. In Scotland a welfare attorney or a court-appointed guardian may have the legal authority to make healthcare decisions on the patient's behalf. In England or Wales, this could be someone with lasting power of attorney, or a court-appointed deputy. Or an Independent Mental Capacity Advocate (an 'IMCA') may have been appointed to represent the patient. Proxy decision-making is not currently available in Northern Ireland for these circumstances.
QUESTION 3B: Has someone else been given legal authority to make this decision for the patient?

STEP 4: Reaching a consensus: You should allow enough time for discussion and aim to reach agreement with those close to the patient, including the healthcare team. Taking into account the different decision making roles and authority of those you consult.
QUESTION 4: After discussion, have you all reached agreement about your patient's treatment and care?

Yes →

The legal proxy makes the decision. You must talk to the legal proxy the same as you would talk to your patient if they had capacity and also involve members of the healthcare team and others close to the patient: they may have information that will help the proxy to reach a decision.

No →

You are responsible for making the decision. Consult with the patient's friends and relatives, and members of the healthcare team. You must take account of their views. Consider which option will be the least restrictive of the patient's future options, and which option will be of overall benefit to the patient.

Yes | **No** →

No →

Decision is made.

STEP 5: Resolving disagreements: Sometimes disagreements arise between members of the healthcare team, or between the team and those close the patient, including the proxy. In Scotland in this instance, you should consult a 'Nominated Practitioner'.
QUESTION 5: Is there still significant disagreement?

Yes →

If you cannot reach agreement about the patient's treatment, you will need to seek legal advice from the appropriate statutory body in Scotland or appropriate court for an independent ruling. This needs not be an adversarial process and does not necessarily mean that trust or relationships have broken down. Sometimes approaching the court is a constructive way of thoroughly exploring the issues and providing reassurance that the patient's interests have been properly considered in the decision.

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While there are several examples of good ACP practice, including the Gold Standard Framework and Preferred Priorities of Care document (Dying Matters, 2011), there is not a single best practice model for adults that is currently used nationally by all services. In reality, services have used these as a basis but have developed their own methods and plans to suit their own requirements. Unlike adult services, the children and young people's services have a nationally agreed standard through the NHS's Child and Young Person's Advance Care Plan Collaborative.

Even though there is a uniformed approach to ACP for children and young people, this is not the case for adults. So why is the nationally agreed model for children and young people not transferable to adult care? EoLC professionals interviewed stated that the Mental Capacity Act is largely the reason. In the case of children and young people, decisions are made in the best interests of the child by someone with parental responsibility (Children & Young Persons ACP Collaboration, 2015). However, in the case of adults, the decisions are made solely by the individual it refers to, unless the individual lacks capacity to do so. Therefore, according to the professionals interviewed, it is unlikely that a nationally agreed standard can be attained with adults when there are complexities with mental capacities.

An evidence overview conducted by the Alzheimer' Society (Rahman, 2014) identified that there is no one profession that has been identified as being best placed to facilitate ACP and no 'best tool', also that there is a scarcity of research on tools that enable a values-based approach to ACP for EoLC.

Local Practices

Whilst the principles of ACP are broadly the same throughout the region, how it is implemented varies significantly, with many different documents in use. Some organisations have a specific team who undertake ACP as their main role and others will train larger numbers of their staff to do this. General discussions about patient preferences take place frequently and outside of a formal process. Most formal ACP is supported by palliative care professionals. There is limited awareness of ACP and the documents in use among generalist staff.

Staffordshire

As part of the NHS Five Year Forward vision, a new Sustainability and Transformation Programme (STP) was developed across the country to improve health and social care in the next five years (Staffordshire and Stoke-on-Trent Sustainability and Transformation Plan, 2016). For Staffordshire and Stoke-on-Trent, the plan (known as 'Together we are Better') focuses on a number of different areas of the health and social care issues, one of them being cancer and EoL (Healthwatch Staffordshire,

2016). The focus on EoL could perhaps push Staffordshire towards high quality EoLC, which would include quality completion of advanced care plans.

In Staffordshire, it has been recognised that experiences of EoLC could be better, that people coming to the end of their lives are not necessarily identified and, as such, are not placed on the palliative care register. This means that they are not always offered a choice about their preferences or given the opportunity to complete an advance care plan. In response to this, Katharine House Hospice are hosting training for care home staff, provided by National Council for Palliative Care on advance care planning. UHNM are hosting a conference on EoL, and through conducting research into the training needs of their staff, have identified Advance Care Plan awareness training as a need. The Douglas Macmillan Hospice provides an advance care planning service that helps people explore options to plan ahead and includes helping them to write Advance Statements, Advance Decisions to Refuse Treatments and to register Lasting Powers of Attorney.

Wolverhampton

In 2016, Wolverhampton CCG developed its Integrated EoLC Strategy 2016-2020 which includes "an integrated ACP developed across all partners including patients and carers".   This has been piloted since December 2016 and was assessed in June 2017 for its usefulness and then will be adopted across Wolverhampton. Part of this initiative involves the implementation of advance care planning to ensure wishes and needs of patients are met (Wolverhampton CCG, 2016).

Walsall

For the Black Country, which includes Walsall and Wolverhampton, the STP (known in this region as the 'Better Health and Care Plan') does not directly focus on EoLC (Sandwell and West Birmingham CCG, 2016). However, Walsall CCG and Walsall Healthcare NHS Trust have combined to provide an integrated approach to EoL in Care Homes to reduce the number of hospital admissions, utilising Advance Care Planning as a part of this approach. However, there is very little additional information on ACP within the region nor an overriding strategy to ensure implementation going forward with exception to the work carried out by the independent hospices in the area such as St Giles Hospice (the results of which we have used in this research).

What are the barriers to achieving good practice in Staffordshire, Walsall and Wolverhampton?

Research into ACP within these three locality areas is extremely limited. If such research is present, they were not publicly available for access. This is perhaps the largest barrier to a clear understanding of how ACP is delivered across the three areas.

Recently, St Giles Hospice ran a pilot study to identify attitudes, knowledge, facilitators and barriers of ACP practice in a Hospice. St Giles Hospice, whose catchment area covers both Staffordshire and Walsall, expressed some of the struggles with ACP; results of this research can be found interspersed as quotes in the following sections below. The barriers to ACP have been identified through a myriad of research done across England. While this research is not specific to the 3 local authority areas, similar themes arose through the research conducted with St Giles Hospice. These barriers have been divided into 3 sectors: commissioning barriers (i.e. barriers due to commissioner decisions and expectations), staff/provider barriers (i.e. barriers to ACP due to staff activities, organisational expectations and inputs), and public barriers.

Commissioning barriers

Lack of joined up systems

Systems used to record and gather ACP data have been suggested to be part of the barrier to effective ACP. According to the National Council for Palliative Care, systems need to be in place to allow for communication between health and social care professionals who are involved in the care of the patient. However, the findings from the research suggest that these systems are not connected to each other. Since ACP conversations may be undertaken by any professional involved in the patient's care, the lack of integration of IT systems could mean this information may not be communicated to other professionals, potentially leading to duplication of work:

> *I think that's very difficult when you're looking at different systems, and systems don't connect with each other, …it's about multi-professional, anybody can have those conversations, but because the cleaner wouldn't go and record it somewhere…*
> - *Quote about joined up systems from focus group participant*

Bureaucracy of ACP

Health professionals also reported that making ACP a compulsory task can lead to it becoming a tick box exercise and reduce the quality of the ACP (Robinson, et al., 2013; Seymour, Almack, & Kennedy, 2010). Under the pressure of having to meet targets set by commissioners, ACP becomes less about supporting preferences of patients (Robinson, et al., 2013) and rather about a tick-box exercise (Pollock et al). More importantly, this could go against the goals of ACP, patient-centred care and communication that is guided by a health care professional with expertise (Seymour, Almack, & Kennedy, 2010):

> **I think it feels like it's a requirement to go back to meet targets, rather than the patient's need or wishes.**

> **[There is an] expectation for us to actually have those conversations, and if we don't have those conversations, then we've almost failed.**

Staff/Provider barriers

Documentation problems

> **I heard the advanced care plan mentioned by two or three patients who said it looked very much like a travel brochure, and they felt it was quite the opposite in the sense they didn't like it because it was too clinical. So, for them they'd have liked to seem a little bit more, I suppose, personal. It's probably just the actual document and how it's presented maybe**

Documentation with ACP can also be problematic, due to the range of different documents in use. There are some national ACP documents, initiatives such as the 'Gold Standards Framework' (GSF) and 'Preferred Priorities of Care' (PPC) (Dying Matters, 2011) which provide an approach that encompasses the end-of-life system as a whole and some services have adopted these. However, the large array of documents can be confusing and cause problems with access and sharing of this information (Heyland et al, 2013), especially when there are different professionals of different specialities involved in a patient's care (Kononovas K, McGee A, 2017). The lack of consistency and standardisation of documents can be problematic for clarity and updating of information (Kononovas K, McGee A, 2017).

> **It gets split up, doesn't it? There's some conversations in the notes. There's some conversations go in the booklet. Some information ends up on the discharge letter, some on the discharge summary letter [but] I like the booklet. I think it's a good booklet. It's quite clear, it's quite easy and there's loads of space to change your mind.**

However, documentation itself has flaws as well, as it could make staff over reliant on them, thereby making the process a dogmatic, tick-box exercise that does not have any value (Van Den Block et al., 2015).

Therefore, the ACP process needs to find the balance between providing a structure to work within while providing the flexibility to cater to the patient and their preferred method of communication and expression.

> **I find with the actual documentation, it's a separate issue, but the documentation itself doesn't lend itself to those discussions that we've got at the moment.**

Follow up of ACP

Staff also commented on the fact that ACP is not always followed up, and therefore, any changes in preferences or updates are not followed through the chain so that every healthcare professional working with the patient is aware of their preferences and wishes:

> **Yeah, so we need to find a better system of making sure we follow up with an ACP.**

> **So if part of the discussion was some wishes that expressed by the patient to happen or not to happen where would you document that? Where would you put that? Because what you said is very clear, but if other elements of advanced care planning are sort of happening or happened while you were left with the patient or have a talk with the patient where would you document that?**

The need for a follow-up is also necessary in providing a review of any existing ACP already done. Research into multiple ACP meetings and reviews also report that they may be more effective than written documents alone (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Regular reviews were recommended for people with life-limiting conditions, as circumstances change. Also, it is possible that the ACP may have been done years before it was used and therefore, it needs to be updated if required.

Lack of confidence

It is expected that palliative nurses and staff are very confident and able to handle EOL discussions. However, because of their sensitive, difficult nature, staff can lack the confidence needed to be able to conduct ACP discussions with patients (Contro et al, 2004). Healthcare professionals regularly struggle to have these conversations, despite it being part of their job (Granek, Krzyzanowska, Tozer, & Mazzotta, 2013).

> **There'll always be a bit of dread when you take out the advance care plan, that even though you know you've had the conversations to build up to that event of, right, let's complete, so to speak, because that's what we're supposed to be doing, supposedly, I'll always have that dread, so therefore I will never feel completely competent.**

> **I feel competent from a very practical point of view, as in having had some teaching and understanding what the documents are locally, although they're different everywhere, and practically what I might do, but the patient, or the person and their family or friends or other healthcare professionals or whoever else you get when you start that conversation is a completely different ballgame then, isn't it?**

Research conducted by Northumbria University (2013) suggested that watching, observing or shadowing senior staff members who have conducted an ACP proved to be extremely beneficial for staff members' confidence levels. Taking part in formal education (i.e. training/theoretical updating), and having mentors that staff could go to, who are able to guide them through the practicalities and difficulties, were also highlighted as useful mechanisms that helped to improve staff confidence levels with palliative discussions (Stevens, White, Marples, & Atkinson, 2013).

Practicalities of preferences

In theory, the ACP is supposed to be able to help healthcare professionals make sure that the EOL wishes of a patient are followed through with. However, in reality, not all preferences are practically or clinically possible (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). Staff sometimes struggle with having ACP discussions as they know that they may not be able to provide what the patient wants due to a lack of services in their area, impracticality of request, expense of request etc. (Sleeman, 2013). While not all family members are comfortable in having ACP discussions with staff members and would prefer for it to be a private affair, not having a professional present could result in impractical preferences. Equally, it may be difficult for families to do an ACP without the relevant specialist knowledge, medical or otherwise, that the professionals may bring (Stewart, Goddard, Schiff, & Hall, 2011).

> **It's a tick box exercise that very much is, you know, we need to record this for government figures, but actually the reality is, we're never actually going to achieve most of that, so…and it is a case of, well, what's option one, what's option two, but still we need option three as well, because that's not been happening.**

> **People don't trust you anymore if you've let them down and you haven't fulfilled what they've put in the care plan.**

> **[My patient], he changed his mind weekly sometimes, he wanted the zoo and everything …We couldn't achieve it all. We were going to have animals come in here you know.**

Lack of experience

Sometimes, the lack of practical experience of not having done many ACP processes, especially for newer staff members, is a barrier. Research into EOL training also highlights this discrepancy that while there are advances made to EOL training that provides a clear theoretical understanding of palliative care, too little has been done to actually help staff apply this knowledge practically (Contro, 2004). It has also been reported that when staff feel less competent in the delivery of EoLC, they are more disposed to 'burnout' (Goldbery, Guadagnoli, LaFarge, 1987; Graham et al., 1996), endangering an already dwindling workforce.

> **I don't think I ever completed one. I think I've put little bits down on paper, but I don't think I've ever completed one, being honest, completely from start to finish."**

Time pressures

It has also been highlighted that ACP takes time and can be difficult to achieve with short, tight targets or immediacy:

> **I think sometimes it's about giving them the information and not expecting an answer straight away as well. Letting that develop in their mind, because they might not have even thought about it sometimes, and let them bring it back to you when they've thought about it. It's not about getting the answer in that one discussion. It can take a while to get the right answers.**

> **I think because it can be quite time consuming… [it is a] barrier to actually doing it and encouraging it to work.**

However, the Respecting Choices programme in the United States suggests a framework that can help to mitigate this. Created and used mainly in the United States, the programme involves a coordinated approach to ACP where non-medical trained facilitators work with palliative healthcare professionals to explore and document choices about a patient's future health (Brinkman-Stoppelenburg, Rietjens, & van der Heide, 2014). The program prides itself on using non-medical professionals, due to the lack of time physicians have to undertake these conversations, but emphasise that the facilitators will collaborate with healthcare professionals for their expertise, highlighting the importance of teamwork for a quality ACP (Respecting Choices, 2017). The use of non-medical professionals could therefore, free up the time taken with ACP (while retaining the expertise of the healthcare professionals) (Karen,

et al., 2010) and increase community engagement with ACP (Respecting Choices, 2017). Looking at volunteer or paid non-medical facilitators who are trained to undertake ACP can enable the NHS to provide good quality ACP discussions for patients, without compromising too much medical staff time (Karen et al., 2010). Furthermore, the involvement of the public into the medical sector can also help to bridge the gap of public and community engagement with ACP.

Public barriers

Lack of awareness

The research by St Giles Hospice also revealed that the largest part of the struggle is the lack of public awareness. Without the awareness and regular discussion about what ACP can do, the taboo of talking about death and dying remains, making it harder when the situation presents itself.

> I never had any personal experience before being in the present role until I was taught by the said teacher as to what it was, so I had no influence of it beforehand, and I think as well, perhaps there's another question, it's a shame that it isn't more out there, and it's up to us to actually provoke that conversation, and it should be anybody provoking that conversation.

In a research conducted on behalf of the General Medical Council and Age UK (Britain Thinks, 2015) participants were uncomfortable discussing ACP and were also more unwilling to consider a point in their lives where they may lose capacity.

Additionally, patients and families may sometimes not understand the reasons for ACP and may feel it is unnecessary and distressing that they have to make decisions over refusal or acceptance of treatments. Some life-extending treatments reduce the quality of a patient's life and knowing this information, and making these decisions to refuse certain treatments, can help to maintain one's quality of life at the end. Additionally, for a lot of people, if faced with a short amount of time to live, will pick quality of life over extending the amount of time they have left (Higginson, Gomes, Calanzani, 2013). Therefore, some patients and families who do not understand how complicated, invasive or limited the treatments to sustain someone at the EoL can be (McMaster University, 2015), may not see the benefits of an ACP. It can easily be viewed as an authoritarian initiative led by the staff (Almack et al, 2012), when it is in fact, patient-led.

This therefore provides a unique challenge, which requires a significant cultural shift to discussions around death and dying. Some suggestions from the research included broader conversations about dying and death that will engage the public as well as a development of a national campaign that may be able to help the public reflect, confront, and challenge ideas about these issues.

Fear of talking about death

The stigma around death and dying inevitably makes ACP a really difficult process for both health professionals and families (Granek, Krzyzanowska, Tozer, & Mazzotta, 2013). Death and dying are not always openly talked about in societies and families, and bringing up the subject can be seen as being 'morbid'. Barriers to talking about ACP are many, but the most commonly listed reasons are unrealistic expectations about preferences, differences between clinician and patient understanding of prognosis, and lack of patient/family readiness to have the discussion (Durall, Zurakowski, & Wolfe, 2012). Sometimes family members and/or the patient find it very difficult to accept a life-limiting condition, and therefore do not feel comfortable having any discussion about planning for it (McMaster University, 2015).

> **I tend to…to think of the sense of what's going that way, I also tend to sort of make it far more open as something that we all should be engaged in anyway, and then invite them as regards their wishes, and so it's a society's view, really, to change, isn't it, rather than making it this, well you're dying, so therefore here's your death plan, and so getting them to engage early as well, to plan for any future eventuality.**

> **50 years ago you would have a nuclear family where death was very common, the person would be at home, die at home, the wake would be at home, they would go to the funeral from home; it was very open. We hide it now. And that's the problem.**

Lack of interest

Some members do not want to engage in an ACP process as it can be stressful (Voogt et al., 2005) although some researchers argue that there is no significant research that proves that there is a difference in stress levels between patient and families who did or did not engage in ACP (Brinkman-Stoppelenburg, et al, (2014). In research conducted by Andreassen et al (2015), the impact of having an ACP done was varied. While some patients and relatives felt relieved and secure, others reported ACP as an 'irrelevant' process and that EOL decisions cannot be considered realistically until one is at EoL.

However, it becomes just as important to remember that ACP is a voluntary process. Any push from healthcare professionals can not only be problematic in achieving the patient-led objective, it can also damage the relationship between the patient and healthcare professional.

> **I think it's not for everyone, and I think it's important that we don't sort of try and push it on people, because there's people that just don't want to … I don't think it's us that should be pushing that on people. We can sort of start to open that discussion, but if they don't want to discuss it, then I don't think we should…I find that I'm okay with that.**

> **It can also cause arguments. I've left an ACP in a house at the request of the patient, and the family have come in and gone, no, no, that is not happening, don't want it to, because they have not…**

Discussions with palliative care professionals also revealed that putting pressure on people to do more ACP could lead to sloppy or bad practice. There needs to be support available to allow for ACP to happen rather than to add to the already heavy workloads of healthcare professionals, particularly nurses and GPs. They expressed that instead of adding it to the workload, realistic thinking needs to take place to identify exactly how the staff will be able to achieve it. To ignore such things will only compromise on the quality of the ACP activity, which should be a lot more than just a tick box exercise.

Conclusions

ACP as a process can be very helpful in assisting individuals to feel more secure and confident about decisions made about their future health, especially when issues with mental capacity at EOL are concerned. While the benefits of having an ACP in place has been documented widely, the point at which ACP is currently triggered is reported as being too late by EoL professionals. At the moment, ACP's position in the EoL pathway is not the ideal, and pulling it out of EoL and into the 'every day' public domain can only benefit more people while helping EoL professionals meet their needs more effectively in the future.

However, this will take significant social and cultural shifts that will be difficult to overcome due to the lack of awareness amongst members of the public. This tied in with the fear of talking about death and the lack of interest in ACP, which only creates barriers for quality ACP practice.

ACP also has no nationally agreed model for adults, making it difficult to have consistency across the various sectors. Commissioning barriers such as the lack of joined up systems that allow for effective information flow through the chain and the bureaucracy of how ACP is expected to be conducted, makes it difficult for services to provide quality care. Equally, documentation issues, lack of follow-up of ACP as well as staff's lack of confidence and experience about engaging with ACP discussions cause problems within services.

ACP as a concept can be incredibly effective for EoLC within Staffordshire, Walsall and Wolverhampton. However, steps need to be taken to mitigate the various barriers associated with ACP in order for the process to have the desired impact that meets the needs of EoL health issues.

Recommendations

Recommendations have been divided into those aimed at commissioners, service providers, and the general public.

Commissioners

Successful advance care planning requires system changes in order to ensure that the care a person receives, reflects their wishes. Health services also need to develop policy around Advance Care Planning and EoLC.

- Utilising shared online systems to develop a patient portal which can be accessed by all professionals involved in the patient's care. These shared online systems should be able to

work across healthcare services, providing relevant information to all the services the patient uses (eg. NHS, hospices, Third sector support services). Password protection and encryption can be embedded to ensure that only the relevant information in shared across services and that confidential information can remain private and within the individual servers. This should be looked at as part of the STP work both on digital and the Clinical Design Authority.

- Development of locally agreed ACP framework that puts the patient at the centre of the process. In the absence of a nationally agreed ACP framework it would be good if we could achieve a local one, which will allow for further benchmarking of Walsall, Wolverhampton and Staffordshire. Consistent documents within the different sectors, common, agreed understanding of what is actually needed in an ACP would be some of the things to look into.

Service Providers/Staff

The success of advance care plans rests on the communication between patient and health professionals, a co-ordinated approach that is part of the usual care a patient receives.

- Provider organisations should include the provision of ACP as part of their EOL strategy
- Ensure Advance Care Plans are available to patients (online or in hard copy form).
- Provider organisations should support staff training in ACP and ensure that this is resourced and staff are released for training. Training programmes need to not only focus on the theoretical grounding of ACP approaches but also provide staff with on-the-job training such as provision of mentors that staff can turn to as well as shadowing senior staff during ACP processes.
- Use of volunteer or paid non-medical facilitators who are trained to undertake ACP discussions with patients and their families. These facilitators should be able to liaise with relevant medical and social care professionals involved in the patient's care but are able to work independently, so as to protect the limited time that medical staff are able to provide.

Public

The public needs to be made aware of the importance of making provision for what their choices and wishes would be should they become ill. This needs a cultural shift in the attitude towards conversations

around illness, death and dying. There is an attitude that these types of conversations are morbid, and there is a reluctance to discuss it.

- Raise awareness of ACP outside of EoLC and to the general public, to promote discussion of personal preferences with family members. We have car insurances for the possibility of an accident, why wouldn't we be prepared for our future health preferences? More awareness needs to be raised, there is no need to wait until a terminal diagnosis to have an ACP (Advance Directive, Living Will or Advance Statement) put in place. This process could be incorporated into various life milestones such as buying a house, getting married or having children.

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