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Advance and future care planning: strategic approaches in Wales

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ABSTRACT

Background In Wales, the term advance care planning now falls under the wider umbrella term ‘Future Care Planning’, which also includes patients with diminished mental capacity and their significant others, to engage in deciding and planning future care. Over the last 5 years, work has been undertaken to create education formats, resources and national documents, and this has been informed by a national Advance and Future Care Planning steering group and national conference, which included patient and carer representatives. This helped collate relevant data.

Aim We outline key strategic approaches in Wales with regard to future care planning.

Results With data from our national conference and through feedback from stakeholders, a national repository of distinct resources, forms and education formats has been created. The approach seeks to cater for the disparate need of the Welsh population; there is not merely one format for multiple scenarios, but a choice of approaches, communication strategies and documents to suit bespoke needs.

Conclusion Advance and future care planning is an approach with many different facets. In Wales, we have found that some patients prefer a clearly set out, legally binding ‘Advance Decision to Refuse Treatment’ to guide their care, while others prefer a softer, guiding approach captured through an Advance Statement. All these formats are available to patients, carers and healthcare professionals, together with explanatory guidance notes, through a central Welsh website. Next steps involve getting a central electronic repository for these forms, which is accessible to healthcare providers and to patients.

Key messages

What was already known?

- ⇒ In recent years, an international definition for advance care planning has been agreed, which encompasses patients with decisional capacity who can engage in discussions.

What are the new findings?

- ⇒ In Wales, a national conference aggregated data from participants, including patient/carer representatives. A national steering group has agreed on ‘Future Care Planning’ as an umbrella definition, which includes patients with diminished capacity.

What is their significance?

- ⇒ Clinical: patients in Wales now have access to information resources and forms that can suit different needs. Patients who wish to fill in their own documents can do so via a centrally hosted site, which has guidance notes and documents.
- ⇒ Research: the approach in Wales offers several policies, information resources and forms, all catering for different needs. Research to compare different regional and approaches will be helpful.

INTRODUCTION

In palliative care situations, sensitive discussions about the future wishes and preferences of a patient and those close to them are encouraged. This can help give clarity on what should and should not be initiated when that person loses the ability to communicate. Primary care clinicians who have developed rapport with patients over many years have the advantage of being able to address their views on advance care planning (ACP). This includes a shared understanding on whether the patient wishes to be readmitted for certain investigations and interventions, future resuscitation attempts and preferred place of care and death towards the end of life.[1 2]

NICE (National Institute for Health and Care Excellence) Quality Standards on End of Life Care for Adults states that people approaching the end of life should feel satisfied that they have been able to discuss, record and review their needs and preferences if desired.[3] In addition, NICE guidelines on care of dying adults in the last days of life[4] state that healthcare providers should record individualised care plan discussions and decisions in a person's record of care and share the care plan with the person, those important to them and all members of the multiprofessional care team.

In Wales, the National Health Service (NHS) Wales Collaborative oversees the work of the Advance & Future Care Planning Strategy Group, which leads on areas such as Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) policy updates, advance decisions to refuse treatments (ADRTs) and disseminating information and education to patients and healthcare professionals. In this article, we outline some of the key work streams and future directions of travel.

DEFINITION

In 2017,[5] the European Association for Palliative Care (EAPC) published the agreed international definition of ACP: 'Advance care planning enables individuals who have decisional capacity to identify their values, to reflect upon the meanings and consequences of serious illness scenarios, to define goals and preferences for future medical treatment and care, and to discuss these with family and health-care providers. ACP addresses individuals' concerns across the physical, psychological, social, and spiritual domains. It encourages individuals to identify a personal representative and to record and regularly review any preferences, so that their preferences can be taken into account should they, at some point, be unable to make their own decisions'.

This EAPC definition sets out that ACP requires decisional mental capacity at the outset. In Wales, a strategic taskforce was set up in 2018 to define and plan a national approach towards ACP and best interests decision making in palliative care situations. It was informed by a national Welsh conference in 2019, which included patient and carer groups from a very broad spectrum of conditions.[6] An agreement was reached by the Welsh End of Life Care Board and national advance care planning representatives, to introduce the term *future care planning* as an umbrella term to capture both ACP, as well as *best interest decisions* for individuals who *lack* decisional capacity at the outset. The term 'future care planning' had been suggested by a patient representative who felt it described its premise more clearly than the more ambiguous term 'advance'. It was further noted that frequently, the word 'advance' was mistyped or misunderstood as 'advanced'. This definition involving the word 'future' was endorsed by Welsh Government and operationalised into national work streams.[7–9] See box 1 for definitions.

GOOD COMMUNICATION STRATEGIES

Sensitive and clear communication is one of the most important aspects of future care planning: it involves the challenging task of conveying a subject area that even skilled communicators sometimes find onerous.[10]

Box 1 Future care planning and some of its key components in Wales

Future care planning is a vast umbrella term and encompasses the following key areas. In Wales, several national forms and guidelines have been agreed and made available, in order to comply with the UK Mental Capacity Act, and to provide choice to patients, carers and healthcare professionals.

Advance decisions, also known as advance decisions to refuse treatment (ADRT for short), or living wills

An advance decision allows patients to write down any treatments that they do not to want to receive in the future and becomes relevant when they become unable to communicate decisions for themselves. The legal name is an *advance decision to refuse treatment*. The form and process is sometimes referred to as a 'living will' or an 'advance directive'. ADRTs are legally binding in England and Wales. This means that if a healthcare professional knows a patient has made an advance decision, they must adhere to it. Legal action may be taken if an ADRT is overlooked. Clinicians can challenge or query the validity of an ADRT, usually via the UK Court of Protection. There is an All Wales ADRT form and process, and this comes with bilingual (English and Welsh) guidance notes. See also: www.wales.nhs.uk/afcp

Advance statements

An advance statement of wishes and preferences allows patients to record anything that is important to them in relation to health and well-being. An advance statement helps to ensure that, if a person lacks capacity to make and communicate a decision, their prior wishes are known and can be followed by those involved in their care. Advance statements are advisory but are not legally binding. The central repository for future care planning in Wales has two options for filling in an advance statement: one that can work for patients who want clarity on future medical interventions and one that also incorporates wishes and preferences that go beyond medical questions, including religious or spiritual wishes and preferences. See also: www.wales.nhs.uk/afcp

Lasting power of attorney for health and welfare

A lasting power of attorney (LPA) allows individuals the choice of giving someone they trust the legal power to make decisions on their behalf if they later become unable to make decisions for themselves.

The person who makes the LPA is known as the 'donor' and the person given the power to make decisions is known as the 'attorney'. There are two different types of LPA: (1) LPA for property and financial affairs covers decisions about money and property; (2) LPA for health and welfare covers decisions about health and personal welfare. The latter is relevant to advance and future care planning.

With regards to health and personal welfare, an attorney can make decisions about medical treatment, place of care and activities of daily living. If an attorney refuses certain treatments on a patient's behalf, then this is legally binding and can only be challenged by making an appeal to the court of protection. An attorney cannot enforce certain treatments to be given. Patients in Wales can access this information site for further information and explanatory videos, which have been created by the

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Box 1 Continued

Advance & Future Care Planning Strategy Group and partners: http://www.advancecareplan.org.uk/lasting-power-attorney-lpa/

The Welsh Branch of the Court of Protection is located in Cardiff as part of the Civil and Family Justice Centre, and information on how to contact them can be found via their website. See: https://www.find-court-tribunal.service.gov.uk/courts/cardiff-civil-and-family-justice-centre

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions and forms

A 'Do Not Attempt Cardiopulmonary Resuscitation' form is a document that advises healthcare providers not to attempt cardiopulmonary resuscitation (CPR). The form is designed to be easily recognised and verifiable, allowing healthcare professionals to make quick treatment decisions in both community and hospital settings.

While it is not a legally binding document, it aids communication between patients, relatives and healthcare professionals to inform all involved that CPR should not be attempted. Without a DNACPR form in place, it is likely that CPR may be attempted by default. The General Medical Council (GMC)and Nursing and Midwifery Council (NMC) have clearly stated that clinicians can make a clinical decision not to administer CPR, even if no form is in place and that this is an individualised decision.

In Wales, since 2015, there has been an All Wales DNACPR policy, which comes with definitions and education resources. Version 4 was published during 2020 and can be accessed via a national website hosted by the NHS Wales Collaborative. See:www.wales.nhs.uk/dnacpr

Education resources are listed within the policy and include modules that doctors, nurses and allied healthcare practitioners, who hold ceilings of treatment discussions and fill in these forms, can readily access. It also includes short videos for patients, carers and healthcare professionals to understand CPR, and why this procedure often does not work. www.talkcpr.wales

Record of best interests decision form

In Wales, there is a national Record of Best Interests Decision making form and guidance pack (see: www.wales.nhs.uk/afcp). It helps with noting down the conversations and views of an individual ideally with the help of those close to that individual, when they lack decisional capacity at the time of assessment. This form, while not legally binding, records conversations and views obtained with regard to future care scenarios and can be useful when an individual lacks decisional capacity. All efforts should be made to obtain as much information from the individual, and mental capacity can significantly fluctuate even from day to day, so the individual must be at the centre and repeat attempts should be made and documented. Where this is challenging or not possible, despite best efforts, including providing hearing aids or translators, for instance, then those close to the patient should be consulted to help elicit what the person may have wanted in given situations. An independent mental capacity advocate should be appointed/consulted in situations where next of kin and proxy cannot be found. See also: www.wales.nhs/afcp

Hospital treatment escalation plan (TEP) forms

Continued

Box 1 Continued

TEPs in NHS Wales are limited to each episode of hospital care, and the document should be used as a 'living' and changeable document, where even during one episode of care, decisions within the TEP should be reviewed if the person deteriorates or improves. At present, TEPs are for short-term use only in the hospital setting but can follow the patient through their hospital journey. Once the patient is discharged to a community setting (own home, care home and prison), the NHS Wales hospital TEP is deemed to be no longer valid. The main reason for this is that TEPs are written at a specific window in time, when an individual may be frail due to multiple reasons, including reversible ones like sepsis or COVID-19 pneumonitis, for instance. A national TEP, provided by Aneurin Bevan University Health Board and endorsed by the deputy Chief Medical Officer for Wales, is available to all Health Boards and Trusts, and it has been through extensive quality improvement processes. Health boards in Wales who adopt it are required to have a person overseeing the TEP process, and audit data should be sent back to the central team in Aneurin Bevan University Health Board to ensure continuous feedback and evaluation. See: www.wales.nhs/afcp

This topic can seem confrontational if brought up too abruptly in healthcare conversations. Even though starting ACP conversations can be challenging, it is imperative to have these conversations early, when patients are still able to communicate their wishes. This allows healthcare professionals to facilitate these wishes when approaching end of life.

Patients have fed back that while such discussions can come as a shock when initiated by the clinician, they are necessary and are ultimately empowering.[8] They are a way to express their informed views on certain potential future scenarios, for instance, CPR.

The Serious Illness Conversations Cymru project has provided guidance for professionals regarding future care planning for these reasons.[11] Wales benefits from having an All Wales National DNACPR policy, which is overseen by a dedicated group, and the policy and DNACPR forms are available to the general public (www.wales.nhs.uk/DNACPR) Since the inception of this policy, it has been updated several times, and it includes training resources for staff. The Compassionate Cymru group in Wales, formerly Byw Nawr, has contributed to shared understanding resources that can help improve patient and carer knowledge.

The NHS Wales TalkCPR[12] video resources have helped introduce this topic widely to the general public and encouraged them to approach their healthcare team directly about it. It is important that such communications involve those close to the patient and are conducted in quiet spaces. The patient needs to be willing to continue with the conversation, and clinicians should incorporate frequent checking questions. Using key phrases throughout the consultation, such as 'Are you ok for me to go on talking about this, or

Box 2 Informed assent

Survival to discharge after cardiopulmonary resuscitation (CPR) is highly unlikely in certain conditions, such as sepsis or metastatic cancer. CPR is not indicated, nor can it be successful when irreversible dying is imminent.[15 16] Healthcare practitioners who feel that future CPR attempts are likely to cause harm should talk to their patients including those close to them about these likelihoods.

Informed assent uses a best interests framework, whereby the healthcare professional explicitly and clearly advises against future CPR by explaining why it is not indicated and its futility. This is contextualised further by stating that other treatments can still be offered, and it is merely CPR that is being discussed. The healthcare professional then checks with the patient and those close to them whether their views differ significantly from those proposed and elicits a shared understanding of the topic of DNACPR. Asking questions such as 'Does your view on this topic differ significantly from what the medical team are thinking?' can give the patient and their family some room to come in with their own opinions on future escalation measures.

is it all a bit much right now?', or 'Let me know at any point if you want me to stop', can give a sense of control back to the patient.

PRACTICAL GUIDANCE

Clinicians sometimes focus on completing tasks, including the need to document major decisions about future care planning on the designated forms.[13] Many such forms exist, but those who have authored them consistently state that it is the quality of the communication within the conversation that matters most.[14] In Wales, there are now many different types of documentation in place that have been agreed to suit different needs and clinical scenarios (see box 1).

With discussions surrounding DNACPR, the value of a discussion can be significant and may be held over several consultations. The concept of informed assent can be used to reduce the pressure on a patient or relative who might wrongly feel they have sole responsibility in decision making (see box 2).

In Wales, the strategy with regard to implementing good future care planning involves providing several types of forms, communication guides and resources to suit the needs of a diverse population. Some patients may wish to take control and fill in and cosign their own advance decision form, while others may prefer their clinician to help them set this up. Clinicians who are part of DNACPR decision making are required to have read the national policy.

CONCLUSION

Advance and future care planning is a complex topic area for healthcare professionals, patients, carers and policymakers alike. It is not likely that a 'one-size fits all' approach will ever meet the different needs of the population, and so different forms and approaches are offered in Wales. In fact, many people may still decide not to engage with advance care planning conversations, as they may find the mere thought of preparing for the end of life too troubling. However, the approach and vision in NHS Wales is to offer (and never force) different approaches and formats to individuals and invest in ongoing education and awareness, with open-access policies, guidelines and strategy approaches that are open to scrutiny and reviewed regularly. This approach is backed up by the extensive patient and carer feedback and data that have been collected over several years, including as part of a national conference. It includes guidance on how to future care plan with individuals who have diminished decisional capacity and where best interests approaches are required. Importantly, it encourages explanation and shared understanding of procedures such as CPR and why a DNACPR discussion and document may be important. It seeks involvement with patients and their significant others on these decisions, not shying away from areas that traditionally may have been considered as taboo or too difficult. Next steps involve getting a central electronic repository for these forms, which is readily accessible to all relevant care providers, but also has an option for patients to contribute a bespoke care plan into their health record.

FURTHER READING

- Ethical implications towards the end of life (General Medical Council (GMC) document): The GMC has published a document offering ethical advice with regard to end of life care decision making. See: https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life/cardiopulmonary-resuscitation-cpr
- The Six Point Communication toolkit for serious illness discussions has practical pointers on how to best prepare for such discussions. (*see: Pease N Chapter 49: communication to promote life near the end of life'. In: Kissane D, Blutz B, Butow PN, et al, eds. Oxford textbook of communication in oncology and palliative care. second edn. Oxford University press, 2017.*)
- NHS Wales Collaborative - Advance & Future Care Planning resources. See: www.wales.nhs.uk/AFCP
- Advance Care Planning Wales: Resources and news updates for Healthcare professionals: http://advancecareplan.org.uk/for-professionals/
- The TalkCPR website: Videos and resources for patients, carers and healthcare professionals on the topics of CPR and DNACPR: www.talkcpr.wales or: www.talkcpr.com or: www.talkcpr.cymru (for Welsh language resources).

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