



Sussex Community
NHS Foundation Trust

Advanced Care Planning

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Excellent care at the heart of the community



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In relation to this presentation I declare that I have no conflict of interest

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Excellent care at the heart of the community

Definition

- *‘Advance care planning is a process that supports adults at any age or stage of health in understanding and sharing their personal values, life goals, and preferences regarding future medical care. The goal of advance care planning is to help ensure that people receive medical care that is consistent with their values, goals and preferences during serious and chronic illness.’*

International Consensus Definition of Advance Care Planning (Sudore et al 2017)

Introduction

- Advance care planning (ACP) is an umbrella term for many different aspects such as DNR and PPC
- ACP offers patients the opportunity to plan their future care, including medical treatment, while they have the capacity to do so.
- ACP is also a way of improving care for patients nearing the end of life and enabling better planning to help them live well and die well in the place and in the way that they choose.
- It allows patients to discuss and record their future health and care wishes and also to appoint someone as an advocate.
- The main goal of ACP is to clarify a patients' wishes, needs and preferences and deliver care to meet these needs in line with the UK Mental Capacity Act 2005

Who can be involved in ACP

- You!
- Health and social care providers play a key role in introducing ACP discussions at important stages of patients' lives
- Many people will already have considered these things even if they have not written anything down
- Every appropriate person should be offered ACP discussions' by their usual/chosen healthcare provider which then becomes part of their care plan



ACP Process

Advance Care Planning (ACP)



1. **Think**- about the future - what is important to you, what you want to happen or not to happen if you became unwell

2. **Talk**- with family and friends, and ask someone to be your proxy spokesperson or Lasting Power of Attorney (LPOA) if you could no longer speak for yourself

3. **Record**- write down your thoughts as your own ACP, including your spokesperson and store this safely

4. **Discuss** your plans with your doctor, nurses or carers, and this might include a further discussion about resuscitation (DNAR or Respect) or refusing further treatment (ADRT)

5. **Share this** information with others who need to know about you, through your health records or other means, and review it regularly.

Things to consider prior to ACP discussion

- ACP is a structured discussion with patients and relevant others about their wishes for the future.
- ACP is an important yet simple conversation that can change practice and empower patients.
- Be sensitive – some patients may not want to talk about ACP.
- Remember that everyone is different – their wish for knowledge, autonomy and control will vary eg, prognosis.
- Remember that patients may make choices that seem unwise – this doesn't mean that they are unable to make decisions or their decisions are wrong.
- Check that your patient has got capacity
- Check your patient has a Lasting Power of Attorney

Case study 1-respecting patients choices

- 32 yr old-Mike
- Oesophageal cancer-palliative-few months prognosis
- Wife and 2 yr old son
- ACP discussion-did not want to die at home, hospital or hospice
- Decided to go to Spain, stop all medication, wanted to feel well enough to take his son swimming and enjoy holiday with wife
- MDT team very concerned about Mikes choices- however respected & documented in PPC documentation
- Went to Spain, came off all medication, took his son swimming
- Wife called from Spain to say he had died in his sleep in their hotel room



Mental Capacity

- The Mental Capacity Act supports ways for people to plan their care and support in advance.
- Advance statements. These are not legally binding but should be considered carefully when future decisions are being made (In MDTs for example). They can include any information the person considers important to their health and care.
- Lasting power of attorney. This involves giving one or more people legal authority to make decisions about health and finances.
- Advance decisions (AKA Living will). These are for decisions to refuse specific medical treatments and are legally binding such as Advance Decisions to Refuse Treatments (ADRT), plus decisions on resuscitation (DNACPR or RESPECT) or if they want to be allowed to die naturally (Allow Natural Death/ AND).

Loss of capacity and ACP

- It is important to anticipate a time when patients may not be able to make decisions in future.
- This relates to the Mental Capacity Act 2005 and development of advocacy or best interest decisions where patients are unable to make clear decisions at a crucial stage in their lives, not just due to dementia, but also due to changes in levels of consciousness and the incapacity of severe illness.
- The process of having ACP discussion is as important as the outcome. It provide a possibility of clarifying future choices so that the issues can be fully discussed, fears can be addressed, and a more realistic and pragmatic approach can be taken to living out the final stage of life in the way that is important to the patient.

Loss of capacity

- If a patient lacks capacity to decide about CPR or treatment first check to see if they have an Advance Decision to Refuse Treatment (ADRT) that says that they do not want CPR. Always check to see if a patient has a Lasting Power of Attorney (LPA) for health and care decisions.
- If a patient would like their LPA to make decisions about CPR, then they must complete and sign the section on life-sustaining treatment in the LPA document.
- LPA forms can be found on gov.uk website for both health decisions and financial decisions (see link below)
- <https://www.gov.uk/government/publications/make-a-lasting-power-of-attorney>

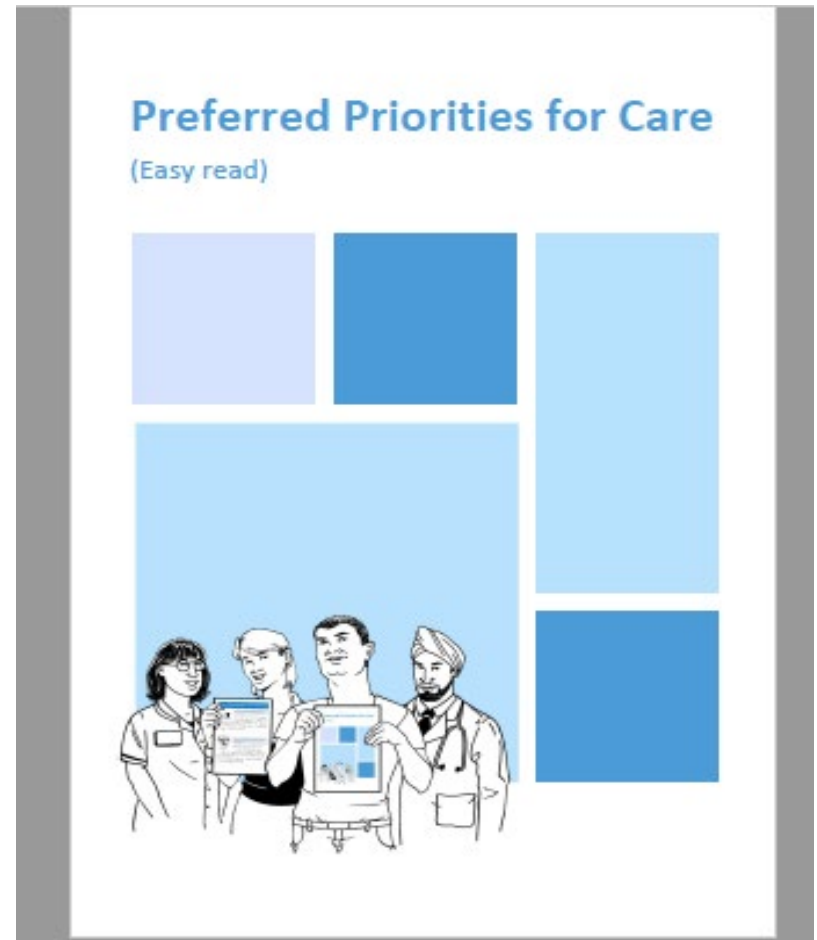
Case study 2-LPA

- 38 year old - Sarah
- Husband 2 children
- Brain tumour-palliative
- Potential loss of capacity
- ACP with Sarah and husband whilst she still had capacity- wanted to protect children from seeing her suffer and make things easier for her husband
- Appointed husband as LPA to enable him to make future decisions
- Deteriorated and partner was able to follow her wishes which was to die in a hospice and DNR in place



Preferred Priorities of Care (PPC)


- The PPC is a document for patients to write down what their wishes and preferences are during the last year or months of their life.
- This document is used by some hospitals in UK. Other hospitals have developed their own form for this purpose.



Alternative ACP documentation

PLANNING FUTURE CARE

Wishes & Preferences
for My Future Care



This Plan belongs to: _____


Planning Your Future Care

What is this Plan for?
This Care Plan is your opportunity to think ahead and write down what is important for you about your future care. This will enable those who care for you to take full consideration of your wishes and preferences, both now and when you approach the end of your life.

What can be included in the Plan?
You can use this plan in whatever way you like. You may like to include information about where and how you would like to be cared for at the end of life, the kinds of treatment you would like to have, and any other issues that are important to you. As it is entirely your plan, you can include or leave out anything you wish. This is not a legal document, and you do not have to include any legal information in it, if you don't wish to.

Do I have to make a Plan?
No. You do not need to do this unless you want to. You may wish to talk about your wishes with family and health professionals instead.

'Thinking Ahead' – GSF Advance Care Planning Discussion



We wish to be able to provide the best care possible for all patients and their families, but to do this we need to know more about what is important to them and what are their needs and preferences for the future.

The aim of any discussion about thinking ahead, often called an Advance Care Planning Discussion, is to develop a better understanding and recording of peoples' priorities, needs and preferences and those of their families and carers. This should support planning and provision of care, and enable better planning ahead to best meet these needs. This philosophy of 'hoping for the best but preparing for the worst' enables a more proactive approach, and ensures that it is more likely that the right thing happens at the right time.

This example of an Advance Statement should be used as a guide, to record what the patient DOES WISH to happen, to inform planning of care. In line with the Mental Capacity Act (2005), this is different from a legally binding refusal of specific treatments, or what a patient DOES NOT wish to happen, which is called an Advance Decision (to refuse treatment) (ADRT).

Ideally an Advance Care Plan should be discussed to inform future care at an early stage. Due to the sensitivity of some of these issues, some may not wish to answer them all, or may quite rightly wish to review and reconsider their decisions later. This is a dynamic planning document to be adopted and reviewed as needed and is in addition to Advanced Directives, Do Not Resuscitate plan, or other legal document.

Name:		Date completed:	
Address:		GP Details:	
DOB:	Hosp / NHS no:	Hospital contact:	
Family members involved in Advance Care Planning discussions:			
Name:		Contact tel:	
Name of healthcare professional involved in Advance Care Planning discussions:			
Role:		Contact tel:	

Patient signature	Date
NEXT of kin / carer signature (if present)	Date
Healthcare professional signature	Date
Review date:	

ACP July 2013 V21 w/8 2013 Used under license by the Gold Standard Framework Centre CIC

PPC Document

- The PPC aims to help patients and relevant others plan their care. This enables everyone involved in a patient's care to be aware of what they want and how they wish to be cared for. AKA an advanced care plan.
- This plan was originally developed for patients who had cancer and were living at home. It focused on where they wanted to be cared for when they were dying. It was then expanded to include other wishes and preferences that people might have when they are coming towards the end of their life.
- Planning ahead and deciding what a patient wants can help them stay in control at a difficult time. We have already discussed the need for control and how important it is.
- One of the biggest gifts we can give our patients is control.

Questions to ask our patients

- Most patients need help and support from their doctor or nurse in ACP. We can help a patient decide what is possible and realistic for them.
- What do they understand about their illness and what their outlook is.
- Ask what fears they may have, such as being in pain or being a burden to their loved ones.
- Ask them who they would like to care for them now and in the future.
- Ask where they would like to die, such as at home, in a hospice or hospital.

Questions to ask our patients

- Ask them what they do and don't want to be told, for example how long they have to live.
- Is there anything they'd like to do while there is still time, such as having a holiday
- Spiritual or religious beliefs they would like taken into account
- Name of the person they have appointed to make decisions on their behalf if they're unable to
- How they would like practical matters dealt with, such as the care of a pet
- What they would like to happen to their body after they die
- The PPC is not a legal document however if a patient reaches a point where they cannot make a decision about their care, what they have written in the document should be taken into account.

Case study 3-conversations help with clarity and bring perspective

- 28 year old patient-Ben
- Didn't want to take HIV medication as daily reminder
- Stopped all medication
- Openly spoke about wanting to die
- Very low CD4 count-clinically very unwell
- ACP and PPC documentation filled out with Ben both respecting his wishes but being realistic about wishes
- Liaised with GP and DNR was put in place



- Ben had romantic view of death
- The process of ACP was an open and honest and realistic discussion
- HIV community team maintained engagement and walked beside Ben on their journey
- Referred to palliative care for symptom control-example of robust MDT working with primary and secondary care
- Two years later Ben decided they no longer wanted to die and started medication again. ACP documentation updated and DNR no longer in place



Case study 4-pt refuse ACP

- 59 yr old-John
- Terminal cancer
- Visited regularly and discussed ACP
- John did not want to discuss ACP- was in denial and wife found this very difficult to cope with
- Wife called one day and said John was in bathroom with chest pain
- Wife had already called ambulance
- On arrival John visibly unwell and very frightened asking if he was about to die. Was not prepared for death
- Ambulance arrived and John had a cardiac arrest
- Paramedics carried out CPR for over an hour as no DNR in place.
- Very traumatic for wife and not the outcome hoped for in terms of preparing John for death



ReSPECT

- ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment.
- This is a summary of personalised recommendations for a patient's clinical care in a future emergency in which they do not have capacity to make choices.
- The agreed clinical recommendations include whether or not CPR should be attempted if the patient's heart and breathing stop.
- The plan is created through conversations between a patient and health professionals involved with their care.
- The plan should stay with the patient and be available immediately to health and care professionals faced with making immediate decisions in an emergency in which the patient has lost capacity to participate in making those decisions. Copy in patients notes

ReSPECT form

The diagram illustrates the layout of the ReSPECT form, divided into two main columns of sections. The left column contains sections for patient details, information about the person and their health, preferences for care, clinical recommendations for care, and a cardiopulmonary resuscitation (CPR) decision. The right column contains sections for decisions about mental capacity, emergency contact details and those involved in making the plan, clinician details, and review details. The form is designed with a purple border and various shades of purple and white for the background of the sections.

Labels for the left column:

- patient details
- about the person and their health
- preferences for care
- clinical recommendations for care
- cardiopulmonary resuscitation (CPR) decision

Labels for the right column:

- decisions about mental capacity
- emergency contact details and those involved in making the plan
- clinician details
- review details

<https://www.bsuh.nhs.uk/library/wp-content/uploads/sites/8/2019/02/ReSPECT-Form-v2-writable-3.pdf>

Do not attempt cardiopulmonary resuscitation (DNACPR) decisions

- A DNACPR decision is made by a patient, their doctor or healthcare team.
- DNACPR is a medical treatment decision that can be made by a doctor even if a patient does not agree.
- A DNACPR decision is usually recorded on a special form. Some examples are a DNACPR form, a treatment escalation plan, or a recommended summary plan for emergency care and treatment (ReSPECT) process.
- This form is kept in a patient's medical records. It may also be printed and kept with the patient if they are at home or in a care home.
- All those involved in a patient's care should know that a DNACPR form has been put in their medical records. The importance of robust MDT working

When is a DNACPR decision made

- Anyone who has capacity to do so can refuse CPR if they wish.
- This is a choice a patient can make at any time, for example when they are healthy or when you are approaching the end of your life.
- A patient can make it clear to their doctor or medical team that they do not want CPR if their heart or breathing stops.
- A patient can change their mind about their DNACPR decision at any time. If they do, they need to tell their doctors and nurses so that the DNACPR form is marked as no longer valid.

Recording and sharing advance care plans

- During the conversation with a patient, record the discussion and any decisions made and check that the patient agrees with your notes.
- Give them a written record of their advance care plan, which they can also take to show different services such as their GP or consultant.
- Advisable to scan or create an electronic record of the ACP that could be accessed by hospital staff or out-of-hours doctors.
- It's a good idea to review the patient's plan regularly to make sure it still reflects their needs and their wishes.

What are the benefits of ACP?

- Enables greater autonomy, choice and control - respects the patient's human rights, enabling a sense of retaining control, self-determination and empowerment.
- Improves the quality of end of life care provided for our patients
- There is greater concordance with wishes if they have been discussed, for example more people die in their preferred place
- Reduction of unwanted or futile invasive interventions, treatments or hospital admissions, guiding those involved in care to provide appropriate levels of treatment
- Economically cost-effective in reducing costs

What are the benefits of ACP?

- Enhanced proactive decision making reduces later burden on family, friends and relieves anxiety
- Enables better planning of care, including provision by care providers
- Greater satisfaction, reduced anxiety and depression in both patients and relevant others
- The process can itself be therapeutic and enable resolution of relationships
- Enables deeper discussions and consideration of spiritual issues, reflection on meaning and priorities and realistic hope.

Case study 5- ACP doesn't always go as planned

- 45 year old female patient with HIV-we will call her Jay
- Separated from husband-he was her appointed LPA
- Due to dementia she had fluctuating capacity
- Jay moved out of marital home in to sheltered accommodation
- Jay had been off ART for 5 years plus and when she had capacity she made it clear then she didn't want to be on treatment



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Case study 5- ACP doesn't always go as planned

- She was a strong Bhudist and talked about the fact she did not fear death
- Very low CD4 count, emaciated and end of life
- Referred to palliative care
- ACP documentation filled in with LAP
- District nurses involved
- DNR in place
- MDT meeting held with plan to move patient into hospice after the weekend at LPA's request



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Case study 5- ACP doesn't always go as planned

- All relevant staff notified of admission into hospice
- District nurses called out night before admission due to patient being in pain
- District nurse on duty panicked and called 999
- Ambulance took Jay to A&E where she received two units of blood and IV antibiotics
- Jay lived for a further four months on a hospital ward before moving to a nursing home where she died
- One decision changed the plans drastically and prolonged her life which is not what Jay had wanted.
- Communication between health care professionals is key for ACP to work effectively



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Conclusion

- **GSF Summary Statement on ACP**

'Every appropriate person should be offered ACP discussions' by their usual/chosen healthcare provider which then becomes an action plan against which quality of care is measured'

- ACP can make the difference between a future where a person makes their own decisions and a future where others do.
- ACP enables greater autonomy, choice and control - respects the patient's human rights, enabling a sense of retaining control, self-determination and empowerment.



Links and articles of interest:

- [Evidence that use of GSF helps improve Advance Care Planning Discussions in different settings](#) - K Thomas, J A Armstrong Wilson, Foulger, T Tanner, National GSF Centre (Published September 2016)
- [An introduction to advance care planning in practice](#) - A Mullick, J Martin and L Sallnow, BMJ 2013;347:f6064 doi: 10.1136/bmj.f6064 (Published 21 October 2013)
- [Thinking Ahead - Advance Care Planning \(ACP\)](#)
- NHS End of Life Care Programme - [Advance Care Planning Powerpoint presentation 2008](#) by Prof. Keri Thomas
- GMC have new guidance for doctors, [Treatment and care towards the end of life: good practice in decision making](#), came into effect on 1 July 2010
- GMC End of Life Care Guidance: Learning Materials - [Case Studies](#)
- GMC End of Life Care: [Advance Care Planning](#)
- The National Council for Palliative Care - 'Planning for your future care' - a simple guide to introducing advance care planning discussions to patients.

Further information

- [Decision-making and mental capacity](#) (NICE guideline, including implementation resource).
- [Mental Capacity Act Code of Practice](#) (available from Office of the Public Guardian).
- [Planning for your future care: a guide](#) (NCPC/University of Nottingham/National End of Life Care Programme. An information source for people considering advance care planning).
- [My future wishes: Advance care planning for people with dementia in all care settings](#) (NHS England).
- [Advance planning and decision-making](#) (SCIE).
- [Advance decisions to refuse treatment](#) (NCPQSW, Bournemouth University).