



Advance Care Planning

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Learning objectives

By the end of this session you will:

01

Have a better understanding of why ACP is so important, whilst acknowledging that it can feel difficult starting these conversations

02

Understand the discussions and decisions important within ACP

03

To understand the medico-legal aspects relevant to ACP



What is ACP?

- ***‘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)



Why is it important?

Advance Care planning is a key means of:

- improving care for people nearing the end of life
- enabling better planning and provision of care to help them live well and die well in the place and the manner of their choosing
- It enables people to discuss and record their future health and care wishes
- to appoint someone as an advocate or surrogate, thus making the likelihood of these wishes being known and respected at the end of life.
- The main goal is to clarify peoples' wishes, needs and preferences and deliver care to meet these needs

<https://www.goldstandardsframework.org.uk/advance-care-planning>



What are the benefits of ACP?

For you:

- you are able to identify the treatments you would or would not wish to receive
- peace of mind comes with knowing that others know what you would want

For others:

- helps to avoid conflict between family / friends if they know what you want
- minimises the need to make difficult decisions under stressful situations

Advance Care Planning (ACP)

1. Think

2. Talk

3. Record

4. Discuss

5. Share

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

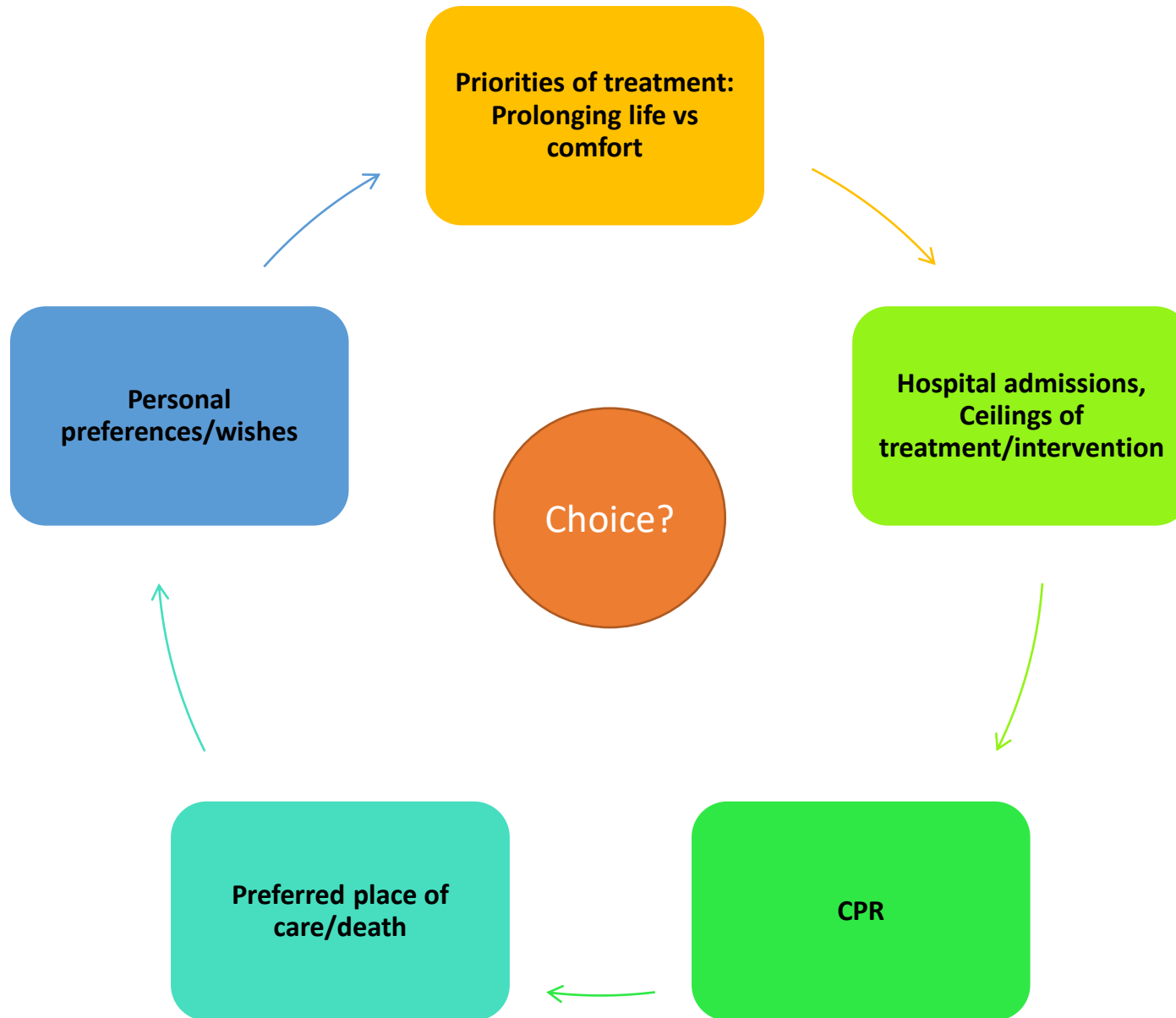
2. **Talk**- with family and friends, and ask someone to be your proxy spokesperson or Lasting Power of Attorney (LPOA) if you could no longer speak for yourself

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.





DNACPR discussions

- How confident do you feel in initiating DNACPR conversations?
- Go to www.menti.com and use the code
- 7654 4964



DO NOT ATTEMPT CARDIOPULMONARY RESUSCITATION
Adults aged 16 years and over DNACPRaduit.1(2015)

Name _____
Address _____
Date of birth _____
NHS number _____

Date of DNACPR decision:
/ /

DO NOT PHOTOCOPY

In the event of cardiac or respiratory arrest no attempts at cardiopulmonary resuscitation (CPR) are intended. All other appropriate treatment and care will be provided.

1 Does the patient have capacity to make and communicate decisions about GPR? YES / NO
If "YES" go to box 2
If "NO", are you aware of a valid advance decision refusing CPR which is relevant to the current condition? YES / NO
If "NO", has the patient appointed a Welfare Attorney to make decisions on their behalf? YES / NO
If "YES" they must be consulted.
All other decisions must be made in the patient's best interests and comply with current law.
Go to box 2

2 Summary of the main clinical problems and reasons why CPR would be inappropriate, unsuccessful or not in the patient's best interests:

3 Summary of communication with patient (or Welfare Attorney). If this decision has not been discussed with the patient or Welfare Attorney state the reason why:

4 Summary of communication with patient's relatives or friends:

5 Names of members of multidisciplinary team contributing to this decision:

6 Healthcare professional recording this DNACPR decision:
Name _____ Position _____
Signature _____ Date _____ Time _____

To go where no man has gone before.....



When is it appropriate to start discussions around DNACPR?

- If there is an identifiable risk of cardiac or respiratory arrest, either because of an underlying incurable condition (such as cancer or advanced heart failure), because of the person's medical history (such as myocardial infarction or stroke), or current clinical condition (such as overwhelming sepsis).
- If there is such a risk of cardiac or respiratory arrest, it is important to make decisions about CPR in advance whenever possible. There should be a full clinical assessment of the chances of a successful outcome, and also of whether any timely intervention (such as escalation of care to a higher level) may reduce the likelihood of cardiac or respiratory arrest, and increase any chance of recovery.



Medico legal aspects - Tracey

Following the court ruling in the **Tracey judgment in 2014**, when making this decision clinicians must:

- Communicate with clear and honest conversation with the patient (or those close to the person if they lack capacity to make a decision about CPR).
- A decision to delay or avoid communicating a DNACPR decision can only be made if it is likely to cause the person physical or psychological harm. **A discussion should not be withheld because it is difficult or uncomfortable for the clinician or their team.**
- Explain the value of coming to a shared understanding about the person's care but be clear that consent for the decision is not required, and indeed can often be the cause of great stress for patients/those important to them.
- Every decision about CPR must be made on the basis of a careful assessment of each individual's situation. These decisions should never be dictated by 'blanket' policies. Any decision about CPR should be communicated clearly to the patient and all those involved in their care.
- MCA



Why does it matter?

- Failure to make timely and appropriate decisions about CPR will leave people at risk of receiving inappropriate or unwanted attempts at CPR as they die. The resulting indignity, with no prospect of benefit, is unacceptable, especially when many would not have wanted CPR had their needs and wishes been explored.
- In most hospitals the average survival to discharge is in the range of 15-20%. Where cardiac arrest occurs out of hospital, the average survival rate is lower, usually 5-10%. The probability of success in any individual is influenced by other factors and in many people with advanced chronic disease or metastatic cancer, the likelihood of CPR being successful is lower.



What if the patient or those close to them demand CPR or don't agree with a DNACPR

Most people do not understand how DNACPR decisions work

- Polling by Compassion in Dying revealed that most people did not understand why a DNACPR decision is made; what their rights in the decision-making process are; or what treatment and care will be given if a doctor decides they are 'not for CPR'.

But people want to know

- The polling also found that, if a healthcare professional were to raise the topic of a DNACPR decision with them, more than three-quarters (77%) of people would either welcome the conversation, or be willing to explore the topic even if it worried them. Just 6% said they would not want to talk about it.
- <https://compassionindying.org.uk/wp-content/uploads/2021/03/Better-Understanding-Better-Outcomes-DNACPR-decisions-before-and-during-the-pandemic.pdf>
- It is ultimately a clinical decision and the person and/or those close to them do not have a legal right to demand treatment that is deemed to be clinically inappropriate.
- Healthcare professionals also have no obligation to offer such treatment.
- Offer a second opinion if the person or those close to them disagrees with the DNACPR decision.



What if the patient or those close to them don't want to talk about DNACPR?

- They don't have to talk about CPR if they don't want to. However its important to explain why we wish to talk about it and try and reach a shared decision. Document the reason clearly on the EPR why they declined the discussion and inform the GP.
- You may wish to encourage them to talk about CPR with their family, close friends or carers and arrange a follow up to revisit the conversation.
- You may be able to facilitate them discussing CPR with another healthcare team they know well (GP, oncology etc).
- Provide links to literature (NHS website, CMC etc).

How to commence DNACPR conversations

- www.youtube.com/watch?v=Y52YwLcVQQs&list=PLzViUx1Kacvxj3XthM2S3VJLWbjr8uCRZ
- You tube video of “let's talk about when the heart stops beating”. Kath Mannix speaks between 3.41 and 24.20 minutes. <https://www.youtube.com/watch?v=6Jf4RLRzzOw>



CQC recommendations: Our review of 'do not attempt cardiopulmonary resuscitation' decisions during the coronavirus (COVID-19) pandemic.

- DNACPR decisions need to be recognised as part of wider conversations about advance care planning and end of life care, and these decisions need to be made in a safe way that protects people's human rights.

Information, training and support

- People must always be at the centre of their care, including advance care planning and DNACPR decisions.
- Everyone needs to have access to equal and non-discriminatory personalised support around DNACPR decisions, that supports their human rights.
- Clinicians, professionals and workers must have the knowledge, skills and confidence to speak with people about, and support them in, making DNACPR decisions.

A consistent national approach to advance care planning

- People, their families and representatives need to be supported, as partners in personalised care, to understand what good practice looks like for DNACPR decisions.
- People, their families and/or representatives, clinicians, professionals and workers need to be supported so that they all share the same understanding and expectations for DNACPR decisions.
- People need to have more positive and seamless experiences of care, including DNACPR decisions, when moving around the health and care system.

Improved oversight and assurance

- There must be comprehensive records of conversations with, and decisions agreed with, people, their families and representatives that support them to move around the system well.
- Integrated care systems need to be able to monitor and assure themselves of the quality and safety of DNACPR decisions.
- Health and social care providers must ensure that all workers understand how to speak up, feel confident to speak up and are supported and listened to when they speak up.
- CQC must continue to seek assurance that people are at the centre of personalised, high-quality and safe experiences of DNACPR decisions, in a way that protects their human rights.

What is the difference between an DNACPR and an Advance Decision to Refuse Treatment (ADRT)

- A DNACPR decision is made and recorded to guide the decisions and actions of those present should the person suffer cardiac arrest, but is not a legally binding document.
- An Advance Decision to Refuse Treatment (ADRT) is (as defined in the Mental Capacity Act 2005 – England & Wales) a legally binding document that the person has drawn up (when they had the capacity to make decisions) and in which they have stipulated certain treatments that they would not wish to receive, and the circumstances in which those decisions would apply. Where a properly drawn-up ADRT refuses CPR (despite acknowledging that their life would be at risk) a healthcare professional who attempts CPR on that person in full knowledge of the valid ADRT would be at risk of a charge of battery.



- In England and Wales: An ADRT can be verbal or written
- If an ADRT refers to refusing life-sustaining treatment, it must be written.
- Written ADRTs are legal only when:
- Signed by the person or someone else with them at the time of being written
- Signed in the presence of a witness
- Signed by the witness
- They are dated
- They state the exact treatment to be refused in which situation
- They contain a statement 'I refuse this treatment even if my life is at risk as a result' if applicable



Important note to the person making this advance decision:

If you wish to refuse a treatment that is (or may be) life-sustaining you must state in the boxes

"I am refusing this treatment even if my life is at risk as a result."

Any advance decision that states that you are refusing life-sustaining treatment **must be signed and witnessed on page 3.**

My name	
----------------	--

My advance decision to refuse treatment

I wish to refuse the following specific treatments:	In these circumstances:

My signature (or nominated person)	Date of signature
---	-------------------

To go to hospital or not to go – that is the question....

- Does the patient have a reversible medical problem that would benefit from hospital admission/treatment?
- Does the patient have an acute clinical presentation that requires urgent investigation in hospital e.g Xray/CT/MRI – if found to have this condition are they well enough/or would they wish to undergo treatment?
- Other things we would consider in patients admitted to the hospice: Does the patient, and those important to them, understand that treatment options may be limited and that they may deteriorate in hospital and potentially die there...how does this sit if their preferred place of death is home or hospice.



1. This plan belongs to:

Preferred name: _____
 Date completed: _____

Full name: _____
 Date of birth: _____
 Address: _____
 NHS/CHI/Health and care number: _____

The ReSPECT process starts with conversations between a person and a healthcare professional. The ReSPECT form is a clinical record of agreed recommendations. It is not a legally binding document.

2. Shared understanding of my health and current condition

Summary of relevant information for this plan including diagnoses and relevant personal circumstances: _____
 Details of other relevant care planning documents and where to find them (e.g. Advance or Anticipatory Care Plan; Advance Decision to Refuse Treatment or Advance Directive; Emergency plan for the carer): _____

I have a legal welfare proxy in place (e.g. registered welfare attorney, person with parental responsibility) - if yes provide details in Section B Yes No

3. What matters to me in decisions about my treatment and care in an emergency

Living as long as possible matters most to me Quality of life and comfort matters most to me
 What I most value: _____ What I most fear / wish to avoid: _____

4. Clinical recommendations for emergency care and treatment

Prioritise extending life Balance extending life with comfort and valued outcomes Prioritise comfort
clinician signature or clinician signature or clinician signature
 Now provide clinical guidance on specific realistic interventions that may or may not be wanted or clinically appropriate (including being taken or admitted to hospital +/- receiving life support) and your reasoning for this guidance: _____

SPECIMEN COPY - NOT FOR USE

CPR attempts recommended For modified CPR CPR attempts **NOT** recommended
Adult or child Child only, as detailed above Adult or child
clinician signature clinician signature clinician signature

ReSPECT 3.0 © Resuscitation Council UK

Does the person have capacity to participate in making recommendations on this plan? Yes No
 Document the full capacity assessment in the clinical record.
 If no, in what way does this person lack capacity? _____
 If the person lacks capacity a ReSPECT conversation must take place with the family and/or legal welfare proxy.

6. Involvement in making this plan

The clinician(s) signing this plan is/are confirming that (select A, B or C, OR complete section D below):

A This person has the mental capacity to participate in making these recommendations. They have been fully involved in this plan.
 B This person does not have the mental capacity, even with support, to participate in making these recommendations. Their past and present views, where ascertainable, have been taken into account. The plan has been made, where applicable, in consultation with their legal proxy, or where no proxy, with relevant family members/friends.
 C This person is less than 16 years old (16 in Scotland) and (please select 1 or 2, and also 3 as applicable or explain in section D below):
 1 They have sufficient maturity and understanding to participate in making this plan
 2 They do not have sufficient maturity and understanding to participate in this plan. Their views, when known, have been taken into account.
 3 Those holding parental responsibility have been fully involved in discussing and making this plan.
D If no other option has been selected, valid reasons must be stated here: (Document full explanation in the clinical record.)

7. Clinicians' signatures

Grade/speciality	Clinician name	GMC/NMC/HCPC no.	Signature	Date & time
Senior responsible clinician:				

8. Emergency contacts and those involved in discussing this plan

Name (tick if involved in planning)	Role and relationship	Emergency contact no.	Signature
Primary emergency contact: <input type="checkbox"/>			optional
<input type="checkbox"/>			optional
<input type="checkbox"/>			optional
<input type="checkbox"/>			optional
<input type="checkbox"/>			optional

9. Form reviewed (e.g. for change of care setting) and remains relevant

Review date	Grade/speciality	Clinician name	GMC/NMC/HCPC No.	Signature

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How Coordinate My Care works

Coordinate My Care is an NHS service that coordinates urgent care for patients. It starts with the patients filling in an online questionnaire called MyCMC. MyCMC then goes to a doctor or nurse who knows the patient who completes the Coordinate My Care (CMC) plan by adding the patients diagnosis, medical details, resuscitation status, medications and recommendations for the urgent care services to follow in an emergency. Once completed the plan is approved and is immediately visible to all the urgent care services including 111, out of hours GPs, the ambulance (in their vehicles) and the emergency departments. This way everyone is in the loop with the patient in the middle.



CMC at a glance

143,044

care plans in total

1,670

new care plans added in
September 2021

8,655

views of CMC care plans by
urgent care in September
2021

Lasting Power of Attorney

A lasting power of attorney (LPA) is a legal document that lets you (the 'donor') appoint one or more people (known as 'attorneys') to help you make decisions or to make decisions on your behalf.

This gives you more control over what happens to you if you have an accident or an illness and cannot make your own decisions (you 'lack mental capacity'). You must be 18 or over and have mental capacity (the ability to make your own decisions) when you make your LPA.

There are 2 types of LPA:

- health and welfare
- property and financial affairs

You can choose to make one type or both.



How to make a lasting power of attorney

- 1 [Choose your attorney](#) (you can have more than one).
- 2 Fill in the forms to [appoint them as an attorney](#).
- 3 [Register your LPA](#) with the Office of the Public Guardian (this can take up to 20 weeks).

It costs £82 to register an LPA unless you get a [reduction or exemption](#).

You can [cancel your LPA](#) if you no longer need it or want to make a new one.

Health and welfare lasting power of attorney

Use this LPA to give an attorney the power to make decisions about things like:

- your daily routine, for example washing, dressing, eating
- medical care
- moving into a care home
- life-sustaining treatment

It can only be used when you're unable to make your own decisions.

Property and financial affairs lasting power of attorney

Use this LPA to give an attorney the power to make decisions about money and property for you, for example:

- managing a bank or building society account
- paying bills
- collecting benefits or a pension
- selling your home

It can be used as soon as it's registered, with your permission.

ICD deactivation

- When a patient is nearing the end of their life, it is usually recommended that any implanted device is deactivated.
- The British Heart Foundation guidelines (2009, p. 8) recommends:
 - “Health professionals working with dying patients should be made aware of the increasing numbers of patients who have an ICD implanted, particularly for the treatment of heart failure.”
 - “Health professionals have responsibility to ensure that the function of the ICD is optimised in the best interests of the patients, particularly for those close to the point of death.”
- Deactivation should be discussed as part of Advance Care Planning. Deactivation is most relevant as patients approach NYHA stage IV or if patient has significant co morbidities eg diagnosis of cancer or dementia.- see Appendix 2



What is an ICD/CRT-D?

- An ICD and CRT-D are implanted devices used to treat ventricular tachycardia and ventricular fibrillation, which are life threatening heart rhythms, by:
- Monitoring the heart rhythm and delivering an electrical pacing impulse or shock when it senses an abnormal fast life-threatening rhythm thus returning it to normal and preventing sudden cardiac death
- Preventing the patient's rhythm from going too fast through its pacemaker function. This is known as fast pacing or anti-tachycardia pacing (ATP)
- Some models provide pacing support in the event of the heart going too slowly (Bradycardia). This part of the device is not switched off during deactivation.
- Cardiac Resynchronisation Therapy defibrillators (CRT-D) devices are implanted in heart failure patients to resynchronise the 2 pumping chambers of the heart (ventricles) for the management of heart failure. It helps to reduce breathlessness and tiredness. It may also help reduce fluid overload. This part of the pacemaker/ICD is not switched off during deactivation.
- Cardiac Resynchronisation Therapy Pacemakers (CRT-P) devices are also implanted in heart failure patients but they **DO NOT** have a defibrillator function.
- A newer type of ICD (subcutaneous ICD) has a lead that is placed underneath the skin rather than within the heart.



FAQs

- **Q. Does the device need to be removed?**

- A. No, it is similar to the procedure that you have when you get your regular ICD/CRTD device checked.

- **Q. Will it hurt?**

- A. It is the same as a pacing check procedure. The physiologists may need to do some tests at the same time which may make you feel dizzy but it won't be painful.

- **Q. Will my heart stop pumping?**

- A. No your heart will continue to pump as the ICD does not make your heart pump. In a CRTD device the resynchronisation therapy will still continue to work.

- **Q. Will I die when it is switched off?**

- A. No, it only works when your heart rate is beating too fast in an irregular rhythm. You will not notice any difference when it is switched off. You won't collapse or faint (consider reviewing the patient's understanding of deactivation if this question is asked).

- **Q. What if my heart goes too slow?**

- A. The ICD/CRT will still work to prevent your heart going too slow. Switching it off will only stop the electric shock when your heartbeat is in an abnormal rhythm.

- **Q. Will the anti-tachycardia pacing still work?**

- A. No, as this only works when the defibrillator delivers a shock. You cannot switch one off without the other.

- **Q. Can my device be reactivated?**

- A. Yes it can be.





Patient Information leaflets

- ACP
- DNACPR decisions
- Just in case medication
- What to expect in the last days of life
- What to do when someone dies at home

MND Case study

- Mary is a 50 year old who has recently been diagnosed with MND. Her neurology team have noted a deterioration in recent weeks. She has bulbar involvement and has noticed that she can feel out of breath at times and talking and eating are a bit slower than normal. She has approached you asking to discuss ACP.
- What areas do you think might be important to discuss with her?



Some areas you may wish to cover

- Options and preferences around communication –letter boards, text to speech devices.
- Options and preferences around feeding – role of PEG feeding
- Options and preferences to support breathing – role of NIV
- And if NIV is an option, preferences around when to withdraw NIV
- LPAs, ADRT
- Future Hospital admissions
- DNACPR
- Preferred Place of care
- Preferred Place of death
- Resources available: MND association <https://www.mndassociation.org>



Summary

We hope you...

- have a better understanding of why ACP is important and the benefits to patients and families
- Understand the discussions and decisions important within ACP
- Understand that DNACPR discussions should not be had in isolation but as a part of wider ACP discussions
- Understand the medico-legal aspects relevant to ACP



Any
Questions

