

BCUHB ACP

Facilitators Guide

This guide supports those who have been trained to help patients complete our Advance Care Plan.

The ACP is made up of individual sections, which are selected to complement each other, and fit together to provide a more comprehensive document.

However it is important to remember that **it is not essential to complete the whole ACP**. Patients should only complete the parts that they feel comfortable with.

Time scales for completion

If completing one section only, it may be entirely reasonable to discuss the section, and then complete it in one sitting, although some patients may want a break to consider things further before committing their wishes to paper.

If completing more than one section this should ideally be done over a number of sittings. This allows patients to consider issues in bite-size pieces, and allows them to discuss their thoughts with family and friends before reaching decisions they wish to write down.

Advance Care Planning is a process which is **patient-owned**.

Your patient decides which sections to complete, what to document and **what not to**, and who to involve within their decision-making process.

Your role is to gently guide them through this process, and to provide explanation and clarification of things they are unclear about or examples of things to consider.

Projection: It is important that you do not overly influence your patient to express an opinion based upon what you would do if it was your decision! Remember the process is all about what values your patient considers are important to them. There is more information on this later in this guide.

Capacity

It is important that your patient has **capacity** to express their wishes.

If you think your patient may not have sufficient capacity but are unsure about how to assess this further then you should seek the opinion of somebody who is competent at assessing capacity before continuing.

Patients are presumed to have capacity unless there is evidence present to question this. The following points should be kept in mind:

1. Capacity is not all or nothing – patients with limited capacity may have capacity to make some decisions, whilst not others.
2. Do not assume a patient does not have capacity if they have dementia. Many patients with early dementia have sufficient capacity to complete a full advance care plan, and the use of ACP in these circumstances may be especially valuable for their future care.
3. The comments recorded in the ACP **must** be the patients first-hand comments. Even if family or friends are confident they know what the patient wishes would have been before losing capacity this is not the correct place to record them.

Recent bad news or change in circumstances

Recent bad news, or a change of circumstances, may act as a perfectly appropriate trigger to encourage a patient to complete or review an advance care plan. Generally this should be supported.

However be aware that in these situations patients will occasionally express 'rebound' opinions which after further reflection they may no longer hold.

If you are concerned that this may be the case then there are two possible courses of action:

1. Encourage the patient not to commit anything to paper until a period of reflection has elapsed.
2. Encourage the patient to review their expressed wishes after a period of reflection to confirm they are still accurate.

Discussion first

It is generally best to discuss the options which arise within a section of the ACP before deciding what to commit to paper. Therefore we would recommend that you read through the section fully, discuss the issues which arise, and then start completing the section only when the patient is happy they know what wishes they want to record.

What is the purpose of this Advance Care Plan

There are two main purposes of an Advance Care Plan :

1. To help care staff, including medical staff, to make decisions which respect a patient's general wishes when they are unable to express their wishes for themselves. Such circumstances may be because a patient has lost capacity, either permanently or temporarily, or because their medical condition prevents them from expressing themselves.
2. To help patients consider the challenges they may face in the future in a less stressful way than would occur if they were to have to make difficult decisions in an emergency situation. Being able to think about these situations in advance gives many patients the opportunity of making decisions which are more considered than decisions they might make when 'swept away' when unwell.

This second reason is at least as important as the first, but is often overlooked.

Reviewing and Updating an Advance Care Plan

Encourage patients to review their ACP at appropriate intervals. The definition of appropriate will vary from patient to patient and depending upon their general health.

Encourage patients to implement a system which will ensure they are reminded to review their ACP and don't forget.

Ensure that you are familiar with the guidance within the 'Introduction' section of the ACP which explains how to update the ACP. If you have any concerns about the clarity of an ACP section after updating then you can access a replacement document from the BCUHB web-site or Macmillan information pods in the three acute hospitals: Wrexham Bodelwyddan and Bangor.

Sharing of information

In keeping with the concept that the Advance Care Plan is patient-owned, sharing of the contents **can only be done with the express permission of the patient.**

If the ACP is to have the greatest impact, elements of it need to be shared. The ACP has been designed to ensure that the minimum amount required will be shared and only with the necessary services, but even still **patient consent is required first.**

If patients are reluctant to share information then you should explain the reasons for why it is desirable to inform health care services about parts of the ACP. More information is shown in the ACP section named 'How to use this ACP'

Helping patients make impartial decisions

Making decisions about medical treatment can be extremely challenging at times and one of the roles of ACP Facilitators is to make sure that patients are allowed to make clear and impartial choices.

Training can be provided which will demonstrate some of the many ways in which patients can be influenced to agree to treatments and interventions they might not otherwise have wanted.

-Beliefs – patients (and healthcare professionals) may sometimes hold unrealistic beliefs about what a treatment can do for them.

-Omission – sometimes healthcare professionals do not share all options in the same way when discussing them with patients. This is often because the professional would not choose that option if it were their decision, and they have assumed (often without realising) that their patient wouldn't choose the option either.

-Past experience – patients past experiences, both good and bad, can lead them to make biased decisions. Past bad experiences can lead patients to refuse to consider treatments which may still be valuable. Past positive experiences of a treatment working might encourage patients to believe they will work again, even if other circumstances have changed considerably.

-Paternalism – sometimes professionals, carers or family will try to make a decision on a patients behalf because they are concerned the patient will be distressed if they have to make the decision themselves

ACP Section – ‘About Me’ (Green Section)

Much of this section will be self-explanatory. However, areas of confusion, or requests for clarification may arise with the following:

Key Worker – this is the professional who seems to be most involved in the delivery of care, or who has been the main point of contact in the past. It does not necessarily have to be a doctor or nurse.

Professionals viewing the advance care plan may wish to contact this named person to get further information about the care plan in place, or to give them an update of any changes they have made.

My wishes regarding my home life if I become unwell – when completing this section users should be aware that professionals **cannot** be relied upon to contact the people identified – instead the user should identify a person who will undertake their contact wishes if requested to do so. To do this, the nominated person must be aware of how to access this part of the advance care plan, and must have agreed to undertake this task.

My Pets –, professionals cannot be relied upon to undertake the wishes expressed regarding pets and so the user should identify a person who will do this when requested.

ACP Section – ‘My Health’ (Yellow Section)

Although information about the users health may be available from other sources, such as hospital and GP records, this section is more about **the user’s perspective** of their health.

Patients should be encouraged to be honest and reassured that they will ‘not be in trouble’ if their interpretation of their health, or how they use their medication, differs from their medical records. The value of the section is in encouraging users to realise that their perspective of their health is the **most important one** and to empower them to be in control of their health.

My priorities for future care – this section encourages users to write about what is important to them in their future care. No priority, however trivial it may seem, is inappropriate to write down!

This section is **not** an advance decision to refuse treatment (ADRT). Health care professionals should endeavour to follow any priorities recorded here but users should be aware that sometimes professionals may not, particularly when urgent or emergency situations arise.

ACP Section – ‘My Health’ (Yellow Section), continued

Users who feel strongly about making sure their priorities are respected should think about completing an advance decision to refuse treatment (ADRT). ADRTs are dealt with in the ACP Section ‘If I cannot make decisions for myself’ (orange/red).

Discussions with healthcare professionals

Writing down significant decisions with healthcare professionals is encouraged, because it will be a useful record for users to refer back to in the future. It will also help other health and care professionals to know what other professionals have said in the past.

Additional Pages which may be of interest

For users with certain conditions there may be other priorities they wish help to consider in planning for their future care which don’t necessarily apply as much to users without those conditions. An example may be the thinking about the pro’s and con’s of chemotherapy for users with cancer, or thinking about how to deal with swallowing difficulties in patients with motor neurone disease.

**ACP Section – ‘If I cannot make decisions for myself’
(Orange/red Section)**

This section is the most challenging, since it ‘signposts’ a number of legal situations.

Do Not Attempt Cardiopulmonary Resuscitation orders

Advance Decisions to Refuse Treatment (ADRT)

Power of Attorney

Do Not Attempt Cardiopulmonary Resuscitation Order: it is expected that in almost all circumstances a senior doctor (senior hospital doctor or patients GP) will be involved, in order to sign the form.

Facilitators should discuss DNA-CPR with users who express an interest, and help them clarify their thoughts. Users should then obtain agreement from one of the senior doctors identified above, who will sign the form.

ACP Section – ‘If I cannot make decisions for myself’ (Orange /red Section), continued

Advance Decision to Refuse Treatment (ADRT)

If the patient does wish to complete an ADRT then we strongly recommend that the ADRT On the ‘Compassion in Dying ‘ site is used. Just as the public are, health and care professionals can sometimes be bewildered by ADRTs. The risk of confusion is reduced by the use of the same format, which is why we recommend using a familiar ADRT.

If a user wishes to use a different ADRT then they should not be prevented from doing so, but the user should discuss their proposed document with a senior doctor to ensure that it can be followed by professionals if the need arises.

Lasting Power of Attorney – a lasting power of attorney is a legal document which must be filed with the Office of the Public Guardian to be valid.

Patients interested in completing a Lasting Power of Attorney should be given the Power of Attorney leaflet, and then directed to a solicitor of their choice or the Lasting Power of Attorney web-site.

If, after discussing the ADRT, you feel the patient is still unclear then you should encourage them to seek the help of a senior doctor. Likewise, if you are unclear that the user has capacity to sign an ADRT you should direct them to seek the help of a senior doctor.

If a user is clear about their wishes and clearly has capacity, then they should arrange to sign it in the presence of an independent witness. Health Board employed facilitators should **not** witness ADRTs, and facilitators employed by other organisations should confirm with their employers that they are allowed to. In addition, any witness should not be related to the patient, or have any conflict of interest in the care of the user. If doubt exists, refer the patient to their doctor, or a solicitor.

ACP Section – ‘Arrangements for after my death’ (Blue)

This section will be relatively self-explanatory.

Many more people than you think are willing to think about, and plan arrangements for after their death, so do not shy away from this section as it can be a source of great relief to relatives afterwards.

However, not all users will be comfortable with this section, so the same rule applies to this section as to all the others within the ACP –

1. Tactfully enquire whether the user wants to go through this section
2. If yes, then proceed accordingly.
3. If no, then if appropriate, tactfully enquire if there are reasons or worries for this that you or others are able to address. If not then let the user know they can look at this section at a later date.

Finally feedback

We are continually trying to improve this Advance Care Plan.

Feedback from users is positively encouraged. We don't just want to hear from users who have suggestions for improvements. We'd also like to hear from users who have found the ACP useful, and would like to share this with others.

Feedback should be sent to Rosalynde.johnstone@wales.nhs.uk