



ADVANCED CARE PLANNING

*A guide for
patients and carers*

Always there to care

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What is Advance Care Planning?

Advance Care Planning is a process whereby individuals plan ahead for a future deterioration in health, so that others can act in your best interests if you ever find you are unable to speak for yourself. This is a voluntary process. Advance care planning is advisable for anyone, but we would particularly recommend it for those with a progressive life-limiting medical condition. It is best to do this at a time when you are relatively well, so you can best consider the options and have relevant conversations with your loved ones regarding your wishes. Remember, simply thinking and talking about something doesn't make it happen! It is best to consider this process like an insurance policy – you may not need it, but if you do it can be very helpful.

What is Advance Care Planning?

We recognise that living with chronic and life limiting conditions can leave people feeling powerless as though the condition controls them. We also recognise that when an individual becomes unwell, sometimes decisions need to be made quickly and individuals may at that time feel overwhelmed or too poorly to express their preferences for care. This is why considering potential decisions ahead of time allows for you to express and document what you would want to happen to you in certain circumstances. From years of experience of looking after patients with your condition, we have seen the empowering effect advanced care planning can have on an individual. A process of giving back a degree of control about what does or doesn't happen to an individual if they become unwell.

What things should be considered

Considerations around your health care

- Where you would like to be cared for particularly if health professionals feel you may be dying?
- Cardiopulmonary resuscitation – a separate leaflet that covers this in more detail is available at your request.

Preferences around emergency care

For those who have very poor health or are frail, they may recognise hospital admissions do not offer a guarantee to get them better if they become more unwell, and would prioritise comfort by choosing to stay at home in certain circumstances.



It is worth noting that this is not a wish list exercise, and some treatments you may wish to have may not be clinically appropriate for you. Neither is it necessary to consider all possible scenarios, better to focus on those that worry you the most, those common problems in society (eg infection, stroke, heart attack) and those specifically most likely to impact you based on your existing health conditions.

Other considerations

- Advanced Decisions to Refuse Treatment
- Power of Attorney
- If you would like more information about either of these, Lindsey Lodge has some additional leaflets that
- explain these in more detail.
- Writing a will
- Funeral planning
- Organ donation or donation of body to science

If you would like more information on these, please contact your healthcare provider.

For more information on organ donation go to:

<https://www.organdonation.nhs.uk/helping-you-to-decide/about-organ-donation/what-can-you-donate/about-tissue-donation/>

The above lists are not exhaustive and you may have some other personal circumstances to consider.



My relative/loved one lacks mental capacity for making decisions about their care

It is still possible to have discussions regarding advance care planning and decisions may still be made on behalf of the individual who lacks mental capacity. This is done using a process called 'Best Interest' decision making. Best Interest decisions involve those close to the individual and clinical professionals involved in their care, taking into consideration the individual's pre-held health beliefs and values to arise at a plan that would be in keeping with how they made decisions prior to losing mental capacity.

I have considered my wishes, what should I do now?

We would recommend that you discuss these with your loved ones or those close to you.

We would also recommend you put something in writing. My Future Care Plan is a locally developed document for people to complete about their wishes and is available on request or can be downloaded from the hospice website. Once completed, we suggest you offer a copy to health providers and you advise your loved ones where the original is kept should it be needed in the future.

In addition, we suggest you discuss with your health provider (e.g. GP, community nurse, hospital doctors, hospice team) those considerations regarding your health. Your preferences for emergency care may then be recorded on a ReSPECT form (Recommended Summary Plan for Emergency Care and Treatment). This form will also be where decisions regarding CPR (cardiopulmonary resuscitation) are recorded. With your permission we wish to create an EPaCCS (Electronic Palliative Care Co-ordination System) record for you, in order to share those wishes for emergency and non-emergency care with a variety of health professional teams who may become involved in your care in the future.

I'm not sure I want to do this, or have further questions

If you do not feel it is the right time for you to consider advance care planning, that is okay. This is a voluntary process and not everyone chooses to do it. Simply keep this information handy for some time in the future when you do feel ready.

If you wish to discuss any of the issues raised or you have further questions, then do contact your healthcare provider (e.g. GP, community nurse, hospital doctors, hospice team).

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