

Starting the journey: Care in the last year of life

When you are told there is no longer any appropriate treatment available to cure your illness, you will probably have many questions about what to expect in the weeks and months to come and what help you can expect to receive in the future.

The opportunity to decide how and where you are cared for is crucial.

The following are in place to help inform you about your care:

Nomination of a key worker

Once your needs have been identified you will be allocated a key worker who will co-ordinate your care. Your key worker may be your nurse, doctor, social worker or another professional responsible for your care. Your key worker will work with other services on your behalf to ensure your needs are met and will be your main point of contact for any worries you may have about your tests or treatment. If you are unsure who your key worker is, please speak to your GP or nurse specialist.

Patient held records - Information Prescriptions and Information Plans (IP's)

Professionals will offer an Information Prescription or Information Plan to you so you can select how much information you would like. The purpose of the Information Prescription is to initiate discussions between you and the healthcare professionals providing your care.

These discussions may include your concerns about:

- What is happening?
- What information is available to help you make choices and decisions?
- What your worries and concerns are?
- What are your preferences for care?

The following are in place to help you discuss and record your choices about your future care:

Advance Care Planning (ACP)

Advance Care Planning is optional and if the patient wishes, a discussion between them, family/carer and healthcare professional providing their care will take place. This process is intended to help the individual to plan their future care and make choices as end of life approaches, by giving them the opportunity to think, talk about and write down their preferences and priorities for care at the end of life. This may include preferred place of care and the types of treatment they would wish to receive. By recording these preferences in advance, health and social care staff will be able to support you during your illness to achieve your wishes.

Preferred Priorities for Care (PPC)

Preferred Priorities for Care is a patient held record, which has been specially designed to record any decisions, made as part of your Advance Care Plan. By keeping a written record of your choices your carers, family, friends and professionals can understand what is important to you when planning your care. If a time comes when, for whatever reason, you are unable to make a decision for yourself, anyone who has to make decisions about your care on your behalf will have to take into account anything recorded in your Preferred Priorities for Care record.

Expressing wishes and preferences about your future care can be done by discussing your wishes with your key worker (see fact sheet 3 for who a key worker is), GP or nurse.

Changes to your wishes

Over time, your wishes regarding your care may change. Throughout your journey, you will be encouraged by healthcare professionals to review any decisions made about your care as part of your Advance Care Plan in line with your changing needs. Any changes will be recorded and communicated to all care providers.

As part of the ACP process you may wish to discuss and include the following:

Advance Decisions to Refuse Treatment (ADRT)

An advance decision to refuse treatment (previously known as a living will or advance directive) is a decision you can make to refuse a specific type of treatment at some time in the future. Sometimes you may want to refuse a treatment in some circumstance but not others. If so, you must specify all the circumstances in which you want to refuse this particular treatment. There are rules if you wish to refuse treatment that is potentially life sustaining, for example ventilation. An advance decision to refuse this type of treatment must be put in writing, signed and witnessed.

If you wish to make an advance decision to refuse treatment you are advised to discuss this with a health care professional who is fully aware of your medical history. An advance decision will only be used if at some time in the future you lose the ability to make your own decisions about your treatment.

Do Not Attempt Resuscitation (DNAR)

Where an individual chooses to request that CPR is not attempted, this is known as a 'Do Not Attempt Resuscitation (DNAR)' request.

If CPR is an expected part of the dying process but will not be successful, making and recording an advance decision not to attempt CPR will help to ensure that the patient dies in a dignified and peaceful manner. It may also help to ensure that the patient's last hours or days are spent in their preferred place of care. In cases in which CPR might be successful, it might still not be seen as clinically appropriate because of the likely clinical outcomes.

Assessing your needs: Accessing care

Being told that your illness cannot be cured/treated does not mean that you are no longer entitled to receive care to manage your symptoms. All care and support is delivered in a 'holistic' nature including medical treatment, help with physical symptoms etc. To achieve this, health and social care professionals are responsible for determining the level of support needed by you and your family/carer, through an assessment of need and/or carer's assessment.

Other End of Life Care factsheets which may be of interest:

Factsheet 1: Care in the last year of life ▶	Factsheet 6: Care after death ▶
Factsheet 2: Support in the last six months ▶	Factsheet 7: Frequently Asked Questions ▶
Factsheet 3: At every step of the journey ▶	
Factsheet 4: Approaching the final few weeks ▶	
Factsheet 5: Care in the last few days ▶	