NHS
Hounslow
Clinical Commissioning Group

My Care Ahead

NHS Hounslow Clinical Commissioning Group
Green Zone (Pavilion CG)
Ground Floor
Civic Centre
Lampton Road
Hounslow
TW3 4DN

Telephone: **020 8538 2400**
Email: **HOUCCG.communications@nhs.net**
Website: **www.hounslowccg.nhs.uk**
Twitter: **@HounslowCCG**

Date published: September 2018

My Care Ahead

None of us know what the future holds. We should all think ahead to consider the possibility of becoming seriously ill or disabled and the impact it would have on how we would want to live our lives. At a time of ill health, or a life changing event for you, or a loved one, the relevance for planning ahead for your future may feel even more important.

Making an **Advance Care Plan (ACP)** gives you the opportunity to think about, talk about and communicate your preferences and priorities for your future care and important health decisions. These preferences would be especially important if you were to lose the ability to communicate your wishes for yourself. This is sometimes described as losing your capacity.

Some examples of where capacity can be lost are:

- if you were to develop a brain injury, stroke or neurological condition
- if you became unconscious as part of a severe illness
- dementia or Alzheimer's, which can affect your ability to make decisions

Making an advance care plan now, will allow you to continue to influence your health care choices in the future. The information you provide, can support your family and health care team to make the right decision for you, if there becomes a time when you are no longer able to make those decisions for yourself. Many people feel reassured with the knowledge, that they will still have control over their future care and the choices made on their behalf.

We anticipate and understand that people's wishes and priorities may change over time and your ACP can be updated at any point, to reflect these changes.

The ACP is a statement of wishes and not a legal document. If you would like to consider a more formal plan to refuse treatment (Advance Decision to Refuse Treatment) or give someone you trust the legal power to make health and welfare decisions for you, if you were to lose capacity in the future (Lasting Power of Attorney for Health and Welfare), please look at the links at the end of this leaflet or speak to your GP about options available to you. Like an ACP it is important that these plans are made at a time when you have capacity. It is not possible for a person who has already lost capacity to make one.

Talking to Family and Friends

When thinking about your future care, you may find it helpful to talk about it with your family and friends. Sometimes this can be difficult. It may be emotional for family members to discuss your future or they may find it difficult to accept your care decisions. However, most people find the process very helpful and it can be a relief to get these issues out in the open.

It is well recognised that the burden of making medical decisions for loved ones at the end of their lives can cause significant stress. An Advance Care Plan, and prior conversations with your family, so they know what your wishes for the future are, can considerably reduce this distress at an already difficult time.

What should I include in My Advance Care Plan?

Identify your wishes and preferences

- The wishes you express during advance care planning are personal to you and can be about anything to do with your future care.
- You may want to include your priorities and preferences for the future, for example:
  - How you might want any religious or spiritual beliefs you hold to be reflected in your care?
  - The name of a person/people you wish to be consulted on your behalf at a later time; this could be a close family member but can be anyone you choose
  - Your choice about where you would like to be cared for if possible, for example at home, in a hospital, nursing home or a hospice.
  - Where you would like to be cared for at the end of your life and who you would like to be with you.
- Your thoughts on different treatments or types of care that you might be offered
- How you like to do things, for example preferring a shower instead of a bath or sleeping with the light on.
- Concerns or solutions about practical issues, for example who will look after your pet should you become ill.

If you become unable to make a decision yourself, the information in your ACP will help those caring for you to identify what is in your best interests and make decisions on your behalf.

Documentation and Communication of Your Advance Care Plan

We often hear from patients and their families that important communication does not always happen well.

An ACP can be documented in different ways and a number of paper versions are available (some are listed below). However in the event, that something was to happen to you, it may be that the paper copy is not seen by the right health care team, at the right time.

In London we are lucky to have access to an electronic record called **Co-ordinate My Care (CMC)**. This means your plan can be seen by your primary care team, district nursing, hospitals, the ambulance service and out of hour GP service. This record will contain some information about your medical history and decisions you have discussed with your health care team. If you need help in an emergency, all patients on **CMC** will be given priority when they or a carer phones NHS 111 or 999 Their notes will be flagged so their call will be fast tracked to a clinician, without triage, and as a result their management and care from the most appropriate source will be arranged as soon as possible.

This includes Preferred Place of Care and Preferred Place of Death, and also if a decision has been made about the patient's resuscitation status. These are two crucial pieces of information for 111 doctors and the London Ambulance Service when called to a home for urgent care.

If you feel a **CMC** record is appropriate for you / someone you care for, or is something you would like to discuss further, please ask your GP practice, who will be able to arrange it for you.

If you have access to the internet at home, it may be helpful for you, your family and your GP if you visit the website **www.mycmc.online**.

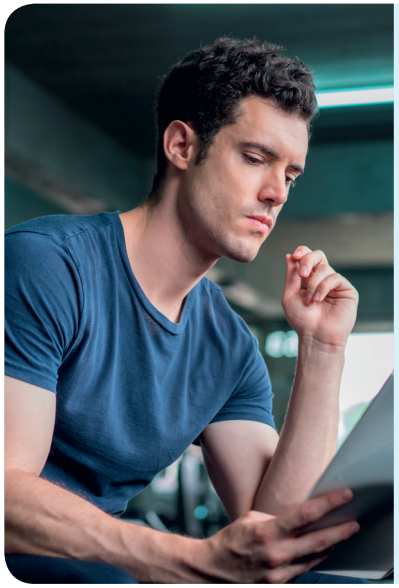
Mycmc not only allows you to start your record at home, but it also has many useful videos and resources about **CMC**, advance care plans and also helps you to understand some of the decisions you may be asked to consider as part of your ACP.

Have you thought about CPR?

As part of an Advance Care Plan some patients are keen to discuss and document their wishes about CPR (cardio-pulmonary resuscitation). This is a voluntary part of your care plan and not everyone feels comfortable thinking or talking about this. Please don't feel you have to read this section or talk about it if you don't want to. Any choice you make now, can always be revisited and updated on your ACP in the future.

What is CPR?

Cardiopulmonary arrest means that a person's heart and breathing has stopped. When this happens it is sometimes possible to restart their heart and breathing with an emergency treatment called CPR.



CPR can include:

- repeatedly pushing down very firmly on the chest
- using electric shocks to try to restart the heart
- 'mouth-to-mouth' breathing; and artificially inflating the lungs through a mask over the nose and mouth or a tube inserted into the windpipe.

CPR was first introduced in the 60's to restart the heart when it had stopped due to a problem with the heart, such as a heart attack. It is in this context that CPR is still most effective. However in many people, their heart and breathing stop, as part of the natural process of dying from a long term medical condition or increasing frailty. We know in these situations CPR is very unlikely to be successful or result in a return to your normal life.

In hospitals only around 2 out of 10 patients survive and leave hospital after having CPR. For patients whose heart stops beating in the community, with underlying medical conditions, these figures are much lower still.

Many people in their last years of life, or who have chronic health problems, have made the decision that they would like to be 'Allowed a Natural Death' rather that have CPR if their heart were to stop beating.

If you feel CPR would not be appropriate for you, or is not something you would like to happen, please discuss it further with your healthcare team. If it is appropriate a DNACPR (Do Not Attempt Cardio Pulmonary Resuscitation) form can be filled out for you and the ambulance service notified.

A DNACPR form is only made in reference to the use of CPR if the heart if it stops beating. Making this decision will not affect any other medical treatment decisions or admission to hospital if required.

Additional resources For Advance Care Planning, Advance Decision to Refuse Treatment and DNACPR

www.coordinatemycare.co.uk

www.nhs.uk/Planners/end-of-life-care/Pages/advance-statement.aspx

www.ncpc.org.uk/publication/planning-your-future-care

www.compassionindying.org.uk

www.macmillan.org.uk/information-and- support/organising/planning-for-the-future-with-advanced-cancer

www.mariecurie.org.uk/globalassets/media/documents/how-we-can-help/a027-planning-ahead-a-w-15.03.16-a.pdf

www.ageuk.org.uk/information-advice/money-legal/legal- issues/advance-decisions/

www.alzheimers.org.uk/info/20032/legal_and_financial

www.dyingmatters.org/sites/default/files/DNACPR%20Patient%20leaflet_A4.pdf