

Advance care planning

Information for patients, relatives and carers

This leaflet aims to answer common questions about why you may choose to make decisions about care and treatment in advance and the different ways this can be done.

Why does thinking ahead matter?

Serious illness and ageing bring challenges that many of us prefer to avoid thinking about. At the same time many of us fear loss of control about decisions relating to our health care. If there comes a time when you are unable to speak for yourself and nobody is aware of what is important to you, your preferences and choices may not be taken into consideration.

What is advance care planning (ACP)?

ACP is a voluntary discussion about possible future treatments and care between you and your health care team. Ideally this would also include those important to you. ACP discussions may take place when you are diagnosed with a life limiting condition, when your condition begins to deteriorate or when you are in good health but thinking about what treatment and care you might need in the future.

What types of things are included in ACP?

ACP may include decisions about which offered medical treatments you may want balanced against those you would prefer not to have, as well as aspects of care that haven't yet been considered. The discussion will vary depending upon your individual situation, but may include:

- cardio-pulmonary resuscitation (CPR)
- admission to intensive care or a higher dependency environment
- continued treatment of infection
- giving food or fluids via a tube or a drip if you cannot eat and drink for yourself

ACP also includes discussion about your future wishes and preferences, for example:

- what is important in your day-to-day life
- where you would like to be cared for if you become less well
- information about others who are involved in your care, such as relatives/carers
- values and beliefs
- priorities in relation to maximising your quality of life e.g. spending time with family

Not all aspects of ACP have to be considered at once. It is important you take time to discuss your wishes and preferences, involving those important to you, and your healthcare team. Once you are happy with your wishes and preferences it is important they are recorded. This will ensure that anyone who provides care for you in the future is aware of them.

Where are ACP's recorded?

Universal Care Plan (UCP)

The UCP is an NHS service that enables every Londoner to have their wishes and preferences for care digitally shared with healthcare professionals across the capital. Any healthcare professional that is involved in your care will be able to see your care plan, this includes paramedics and other staff who may be involved during an emergency. Other professionals such as a nurse or doctor will also be able to see and help create or update the care plan as needed. Information documented on a UCP does not have any legal standing but can be used as an expression of wishes, if you are unable to speak for yourself, to guide care.

Please be aware that currently the UCP is only available for those residing in London but other similar systems are in use in other areas of the UK.

Other documents to consider

Advance decision to refuse treatment (ADRT)

An ADRT can be made by anyone over the age of 18 who has mental capacity (e.g. is able to make decisions about their own care). It is a legally binding document which sets out the medical treatments you may wish to refuse in the future and the specific circumstances in which you want to refuse them.

To be valid an ADRT must be:

- written down
- signed by the person in the presence of a witness
- signed & dated by the witness
- explicitly state which treatment the person wishes to refuse and in which situation
- include a statement that says "I refuse this treatment even if my life is at risk as a result" if this is what you wish

An ADRT will only be used when you no longer have the ability to make decisions for yourself. It is important you consider any decisions carefully and talk to your doctor or nurse. They will be able to help discuss the benefits and risks of the decision you are considering.

Lasting power of attorney (LPA)

An LPA is a legal document that lets you nominate representative(s) to make decisions on your behalf. An LPA is not valid and has no legal standing until it has been registered with the Office of the Public Guardian. <https://www.gov.uk/government/collections/lasting-power-of-attorney-forms>. Registration must take place while you have the mental capacity to do so.

There are 2 different types of LPA:

- 1) Property and financial affairs - this covers money and property. You can choose when this is active, either as soon as it's registered or only after you have lost mental capacity.
- 2) Health and welfare – this covers personal and health care decisions including refusing any medical treatments you may need to stay alive. It only becomes active once you have lost the mental capacity to make decisions for yourself.

Can I change my mind once my wishes have been recorded?

Of course. Wishes and preferences should be reviewed regularly with those close to you and your health care team. You can change your mind at any time.

What do I do next if I am interested in ACP?

Please talk to your hospital team or GP who will support you with the advance care plan and can signpost you to the other documents mentioned in this leaflet if required.

Additional information and support

Chaplaincy service

The chaplaincy team is made up Anglican, Hindu, Jewish, Muslim, and Roman Catholic chaplains, and has contacts in the community to provide for the needs of other religious communities. The team is happy to make contact with and arrange a visit by a representative of a community known personally to the patient or those who are close to them.

We offer confidential religious, spiritual and pastoral care to all patients and visitors between 09.00 and 17.00 with a 24/7 urgent out-of-hours on-call service. To request a visit, speak to a member of your care team and ask them to contact the on-call chaplain. Patients can also call directly on **020 3312 1508** where you can leave a message but please be aware you may not receive a response until the next working day.

Interpreting services

Discussions and decisions about treatment options can be challenging, especially if English is not your first language or if you don't have good support networks. If you need a language or British Sign Language interpreter please let your care team know and they will organise this.

This leaflet can also be provided on request in large print or easy read, as a sound recording, in Braille or in alternative languages. Please email the communications team:

imperial.communications@nhs.net

Patient advice and liaison service

If you have any suggestions or comments about your care or that of your loved one, please contact a member of ward staff or the Patient Advice and Liaison Service (PALS) on:

- 020 3313 0088 for Charing Cross, Hammersmith and Queen Charlotte's & Chelsea hospitals
- 020 3312 7777 for St Mary's and Western Eye hospitals
- Via email at imperial.pals@nhs.net

Alternatively, you may wish to complain by contacting our complaints department:

Complaints dept, 4th floor, Salton House, St Mary's Hospital, Praed Street, London W2 1NY
Email: ICHC-tr.Complaints@nhs.net Telephone: **020 3312 1337 / 1349**

Free will writing service

The hospital's official charity, Imperial Health Charity, offers access to a free will writing service. This means you can have a simple will written or updated by a solicitor and the charity will cover the cost. You will be under no obligation to leave a gift to the charity or to the hospital. However, if you'd like to take this opportunity to support our hospitals, the charity can provide information to help you make your gift. For more information about making a will for free, you can email the charity at legacy@imperialcharity.org.uk or call 020 3640 7766. If you prefer, you can ask a member of hospital staff to contact the charity on your behalf.