What is a Living Will?

Living Will

The technical term for a Living Will is an Advance Decision (sometimes known as an advance decision to refuse treatment (ADRT) or a living will). It is a decision that can be made to refuse a specific type of treatment at some time in the future.

It lets family, carers and health professionals know wishes about refusing treatment if unable to make or communicate those decisions yourself.

The treatments to be refused must all be named in the Advance Decision document.

It is possible that someone might want to refuse a treatment in some situations, but not others. If this is the case, they need to be clear about all the circumstances in which they want to refuse this treatment.

Deciding to refuse a treatment is not the same as asking someone to end life or help someone end their life.

An Advance Decision is not the same as an Advance Statement.

Advance Statement

An Advance Statement is a written statement, while a person has mental capacity to make decisions, that sets down personal preferences, wishes, beliefs and values regarding their future care. This could include: -

- where ideally would like to be cared for – at home, care home, hospital or hospice
- dietary requirements
- foods – likes and dislikes
- prefer baths or showers
- what kind of clothes preferred to wear
- type of music liked
- types of programmes watched on TV
- whether like to sleep with a light on
- the time to go to bed and whether an early riser or prefer a lie in
- religious, other beliefs and values
- who to be consulted about their care
- visitors would like to see

These wishes and preferences can be made known by talking about them to other relevant people. Better still written down to make everything clear to family, friends, carers, and anybody involved in providing care. It can be written with support from relatives, carers, health, or social care professionals. The key thing is to let others know where to find this statement when needed if not already held by a family member, friend, carer, or Attorney for a Lasting Power of Attorney

An Advance Statement is not legally binding, but anyone making decisions about the care for an individual must take it into account. An Advance Statement does not have to be signed but a signed document makes clear the wishes that have been written down by the person concerned. It does not need to be witnessed.

Life-sustaining treatment – Advance Decision

Someone can refuse a treatment that could potentially keep them alive, known as life-sustaining treatment.

This is treatment that replaces or supports ailing bodily functions, such as:

- ventilation – this may be used if someone cannot breathe unaided
- cardiopulmonary resuscitation (CPR)
  - this may be used if their heart stops
- antibiotics – this can help fight infection

It is sensible that the person concerned discusses such intentions with a doctor or nurse who knows about their medical history before they formally proceed to record such as Advance Decision. Explore with a doctor or nurse the various kinds of treatments that might be offered in the future, and what it might mean should the choice be not to have those treatments or interventions.

It is suggested that it is discussed with family and friends so that they understand the wishes.

It cannot be used to: -

- request certain treatment
- to ask for life to be ended

Wording of the Advance Decision

A decision to refuse life-sustaining treatment in the future needs to be: -

- written down
- signed and dated by the person to whom it relates
- signed and dated by a witness

If it is intended to refuse life-sustaining treatments in given circumstances then the document must also include a statement that the Advance Decision applies even if their life is at risk: -

- a statement such as ‘even if life is at risk as a result’

The charity Compassion in Dying has an Advance Decision form that can be filled in online or by hand, together with suggestions for things to think about.

An Advance Decision does not need to be in writing if not refusing potentially life-sustaining treatment though it makes sense to do so in writing.

Who should see the Advance Decision document?

The person who makes the Advance Decision is free to choose who can see it. It is essential that certain people know about such a decision and where to find the document. Better to have several copies of the document signed and dated including the witnesses' signature so that in the event it is needed it can be quickly provided.

Advance Decision legally binding?

It is provided it: -

- was made by a person aged 18 or more
- complies with the Mental Capacity Act – had mental capacity at the time it was done
- was made freely of their own accord without any harassment by anyone else
- applies to the situation
- specifies the situations when treatment is to be refused and acknowledges that death could follow from such refusal of life saving treatment
- the person making that Advance Decision has not said or done anything that would contradict the Advance Decision document since it was made

If the Advance Decision is binding, it takes precedence over decisions otherwise made by other people in the best interests of the person concerned. However, it will only be used if the person concerned has lost the capacity to make or communicate decisions about their treatment.

CPR and a 'do not attempt CPR' decision

CPR (cardiopulmonary resuscitation) is a treatment that attempts to start breathing and blood flow in people: -

- who have stopped breathing (respiratory arrest), or
- whose heart has stopped beating (cardiac arrest)

CPR can involve: -

- chest compressions (pressing down hard on the chest repeatedly)
- electrical shocks to stimulate the heart (sometimes more than once)
- injections of medicine
- artificial ventilation of the lungs

According to the NHS website, in hospital, around 2 out of 10 people survive and leave hospital after having CPR. Survival rates are usually lower in other settings. Of course, the individual chances of CPR can be better or worse than that. For some people, there will be no chance of benefit from CPR. It depends on why the heart and breathing has stopped, any pre-existing illness or medical problems, and overall health.

The healthcare team can discuss the likely chance of CPR working in the individual case.

Even when CPR is successful, a person can develop serious complications, such as: -

- fractured ribs
- damage to the liver and spleen
- brain damage, leading to disability

People who survive after having CPR may need high-intensity medical support afterwards. A small number need prolonged treatment in an intensive care unit (ICU).

Refusing CPR in advance

Everyone has the right to refuse CPR if they wish. This can be made clear to the medical team that it should not be undertaken should breathing or the heart stop.

This is known as a *'do not attempt cardiopulmonary resuscitation' (DNACPR) decision, or DNACPR order.*

Once a DNACPR decision is made, it is placed in that person's medical records, usually on a form that health professionals will recognise.

It is advisable to let family or other carers know about a DNACPR decision so it does not come as a surprise to them should the situation arise when CPR might otherwise be undertaken.

Where someone has a serious illness or are undergoing surgery that could cause respiratory or cardiac arrest, a member of the medical team should establish the patient's wishes regarding CPR if they have not done so previously.

Where someone does not have mental capacity to make decisions about CPR when a decision needs to be made and they have not made an Advance Decision to refuse treatment, the healthcare team may consult with their next of kin about what they might know of any wishes to decide in their best interests.

The Resuscitation Council website has a useful section on FAQs: Decision making (CPR).

Sources of help and information

Age UK

Advance Decisions (living wills)
https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/advance-decisions/

https://www.ageuk.org.uk/globalassets/age-uk/documents/factsheets/fs72_advance_decisions_advance_statements_and_living_wills_fcs.pdf

Alzheimer's Society

How to make an Advance Decision
https://www.alzheimers.org.uk/get-support/legal-financial/how-to-make-advance-decision
Advance Statement
https://www.alzheimers.org.uk/get-support/legal-financial/advance-statements-dementia

Cancer Research UK

Advance care planning
https://www.cancerresearchuk.org/about-cancer/coping/dying-with-cancer/making-plans/care-planning

Compassion in Dying

Making decisions and planning your care
https://compassionindying.org.uk/making-decisions-and-planning-your-care/

Dying Matters

Legal and ethical issues around advance care planning, including Advance Decisions
https://www.dyingmatters.org/page/legal-and-ethical-issues
https://www.dyingmatters.org/sites/default/files/user/Planning_for_your_future_care_FINAL_010212.pdf

healthtalk.org: videos and written interviews of people talking about making an Advance Decision
https://healthtalk.org/living-dying/advance-decision-to-refuse-treatment

Macmillan

Advance Decision to refuse treatment
https://www.macmillan.org.uk/cancer-information-and-support/treatment/if-you-have-an-advanced-cancer/advance-care-planning/advance-decision-to-refuse-treatment

MedicAlert

Non-profit, membership organisation that offers a way for emergency services to access medical information from a secure database when unable to share this information with them personally. Medical ID jewellery points towards the person's full MedicAlert record, containing their vital medical information, so first responders can make appropriate care decisions based on their individual needs
www.medicalert.org.uk

Resuscitation Council UK

Frequently asked questions: Decision Making (CPR)
https://www.resus.org.uk/home/faqs/faqs-decision-making-cpr

Sources: Age UK and NHS websites