

Advance Decision to Refuse Treatment



EasyRead Version



What is an Advance Decision to Refuse Treatment?



An **Advance Decision** is a choice you make now about something in the future.



To refuse treatment means that you say “no” to having something that might make you better if you become unwell.



An **Advance Decision to Refuse Treatment** is when you decide now that you do not want certain types of treatment in the future.



We call this an **Advance Decision**. We sometimes also call it a **Living Will** (but we do not use this term very often anymore.)



It is **your** choice to have treatment or not.

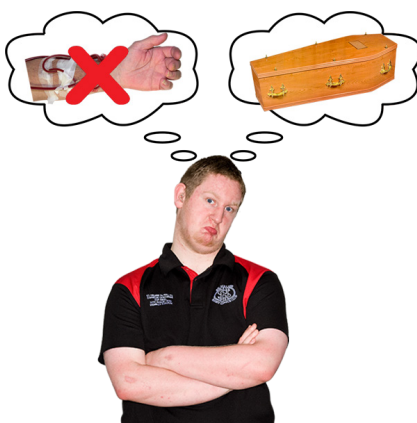


You can talk to doctors, nurses, friends and family about getting treatment.



You have a right to refuse treatment.

This means you can say what treatment you do not want.



You should tell people why you do not want this treatment.

This will help them to understand your Advance Decision.



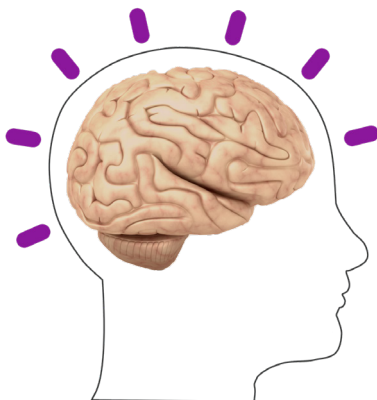
Your doctor and care team must follow your Advance Decision.



As you get older, you are more likely to become ill.

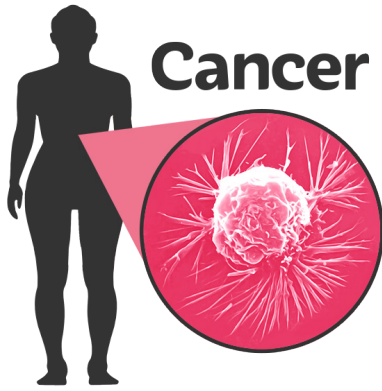


If you become ill you may need treatment to manage your illness.



These are some examples of serious illnesses:

- Brain injury such as stroke



Cancer

- Cancer



- Dementia



- Parkinsons



If you got an illness like these the doctor might want to give you **Life Sustaining Treatment**.

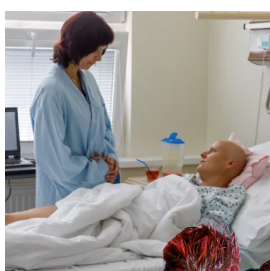
This is treatment to keep you alive.

Reasons why you might not want Life Sustaining Treatment



Some treatments can have unpleasant **side effects**.

Side effects are unwanted symptoms caused by medical treatment.



For example, Chemotherapy is a useful treatment for cancer but it has unpleasant side effects. These include:

- Feeling sick



- Hair loss



- Feeling very tired





These unpleasant side effects might put you off having the treatment.



If you do not have Life Sustaining treatment you will continue to be unwell and you might die.



You can choose to refuse treatment because:

- You would prefer to be unwell or let yourself die.
- You do not want to suffer unpleasant side effects.
- You do not want to take the risks that come with treatment.

When do you make an Advance Decision to Refuse Treatment?



You do not know what will happen to you in the future.



Something might happen which makes you unable to make choices about some things.



You can make an Advance Decision to Refuse Treatment now about your treatment in the future.



This lets your family, carers and health workers know if you want to refuse specific treatments in the future.



When you make an Advance Decision to Refuse Treatment you must list the treatments you want to refuse.



Doctors cannot use your Advance Decision to Refuse Treatment if you are still able to make decisions.



You may only want to refuse treatment in some situations, but not in others.

In this case you must be very clear about which situations.

What you need to do



If you want to refuse Life Sustaining Treatment, you must write it down. Someone can help you write it down.

This makes your Advance Decision clearer.



You must sign your Advance Decision to Refuse Treatment.

Someone else needs to watch you sign it and then sign it themselves.



The person who witnesses you sign your Advance Decision to Refuse Treatment must be a health or social care worker.

They must know you and understand your condition.



You must say clearly that you want this choice in the future, even if it means you might die.



An Advance Decision to Refuse Treatment is a **legally binding** document.

Legally binding means that the law says it must be obeyed.



It must follow the Mental Capacity Act (2005)



It must be **valid**.

Valid means that you followed the rules when you wrote the document.

These rules are written on page 13.

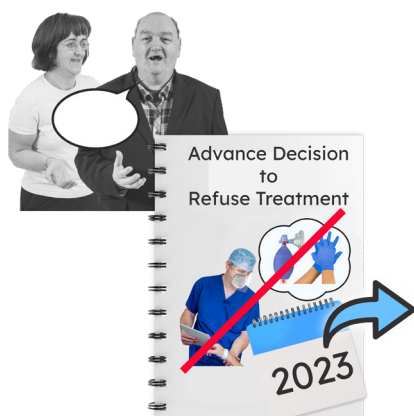


It must apply to your situation.

This means that it talks about you and your wishes.



A **Best interests** decision is made by someone else on your behalf for your benefit.



Your Advance Decision to Refuse Treatment takes the place of **best interest** decisions.



This means that doctors will not be able to give you Life Sustaining Treatment even if someone else wants you to have it.

What makes an Advance Decision to Refuse Treatment valid?



For an Advance Decision to Refuse Treatment to be valid:

- You must be 18 years or older.



- You must have **capacity** to make, understand and communicate your decision when you make it.

Capacity means that you understand information to make a decision and that you can tell someone about your decision.



- You must write clearly what treatments you wish to refuse. Someone can help you do this.



- You must explain in what situations you want to refuse treatment.



- You must sign the document.



- A witness must watch you sign the document and then sign it themselves.

This must be a health or social care professional who knows you and understands your condition.



- You chose to make an Advance Decision to Refuse Treatment on your own.

Nobody else told you that you must refuse treatment.



- You haven't told anyone that you want to change your mind since making the decision.

It is important to discuss the options with your doctor or nurse.

How does an Advance Decision to Refuse Treatment affect Lasting Power of Attorney?



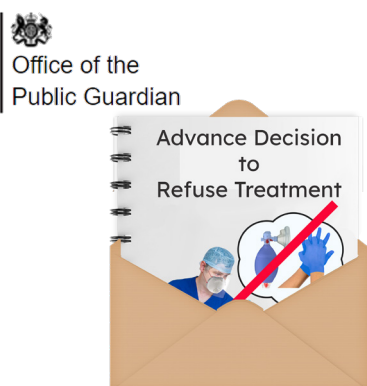
If you have made an Advance Decision to Refuse Treatment, you can still make a **Lasting Power of Attorney** for health and care.



Lasting Power of Attorney (LPA) means giving another person the right to make decisions about your health and care.



When you apply for a LPA you should write in the ‘extra instructions’ section that you wish for your Advance Decision to Refuse Treatment to be followed.



You must then send a copy of your Advance Decision to Refuse Treatment to the Office of the Public Guardian.



If you make a LPA for health and care you must decide if the doctor or your **attorney** should make decisions about life sustaining treatment.

Your **attorney** is the person you have chosen to make decisions for you.



If you choose to let your attorney decide about life sustaining treatment then your LPA will take the place of your Advance Decision to Refuse Treatment.



An **Advance Statement** tells people involved in your care about your wishes for the future.



An **Advance Decision** tells people involved in your care what treatments you do not want to have.

It is a legally binding document.



You can make both an Advance Statement and an Advance Decision.

Summary



You have a right to refuse treatment.



You must have the capacity to understand what might happen if you refuse treatment.



You must write your decision down and you must sign it.



Someone must witness you signing your decision and then sign it themselves.



The person who witnesses you sign your decision must be a health or social care worker.

They must know you and understand your condition.



You should review your decision from time to time to make sure that this is still what you want.

You should write the date you reviewed your decision.



You must share your decision.



Your Advance Decision to Refuse Treatment document will then be legally binding.



Produced by

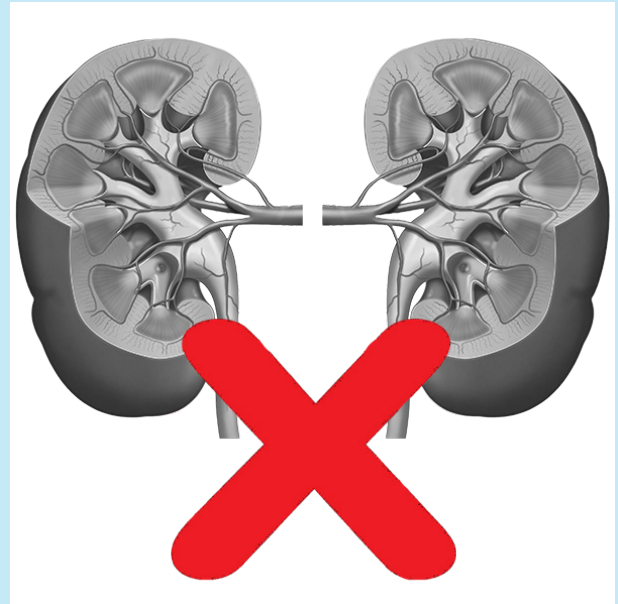


Inclusive Communication
Essex

Case Study 1 - John's Story



This is John.



John's kidneys do not work properly.



John needs help to remove waste and water from his blood. This treatment is called **dialysis**.



To stay healthy John needs dialysis 3 times a week.



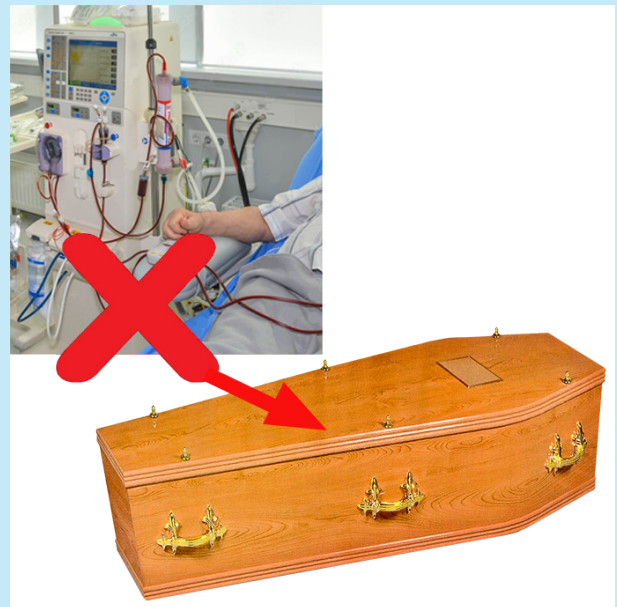
John does not like dialysis. He finds dialysis boring.



Dialysis also makes John feel sick and dizzy.



John chooses not to go for dialysis.

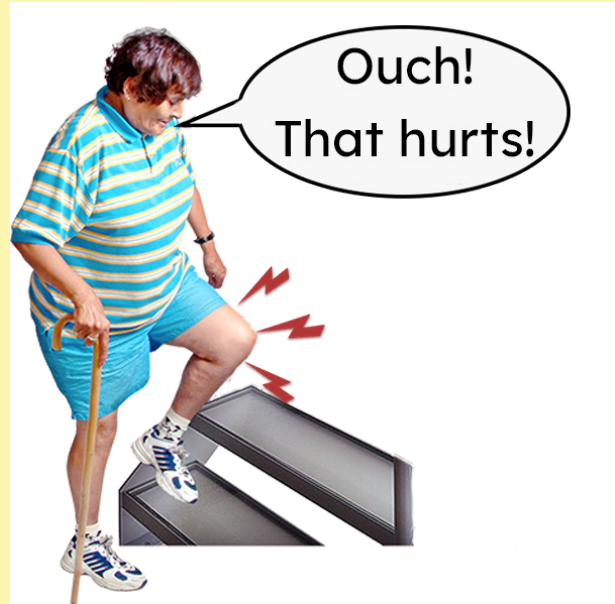


John knows that if he does not have dialysis he will become very ill and die.

Case Study 2 - Mary's Story



This is Mary. She is 83 years old.



Mary has arthritis. This means she suffers a lot of pain.



Mary also has an illness that makes it difficult for her to breathe.



To help her breathe Mary sometimes has to wear an oxygen mask.



Mary does not like wearing the oxygen mask. She finds it uncomfortable.



Mary is also tired and is fed up of being in pain all the time.



Mary asks doctors not to give her emergency treatment to save her if she stops breathing or her heart stops.



Mary understands that without emergency treatment she will die.

This information is issued by:

Essex Learning Disability Partnership
Lexden Hospital
London Road
Colchester
Essex
CO3 4DB

Telephone: 01206 366653

Essex Learning Disability Partnership is provided by Hertfordshire Partnership University NHS Trust and Essex Partnership University NHS Trust

 [HPFT.NHS](https://www.facebook.com/HPFT.NHS)

 [@ELDP_NHS](https://twitter.com/ELDP_NHS)

The information in this document can be translated, and/or made available in alternative formats, on request.

Published May 2023