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Let's talk about our wishes for our future health, care and treatment

How to have conversations with families and healthcare professionals about death and dying and making our future care wishes

Our society does not always feel comfortable talking about dying and death, with either healthcare professionals or with our own important people.

Introduction

This booklet will support you and your family to think about, and have conversations about your future health and care wishes. It includes why these conversations are important, who to involve, and how to record your wishes.

We hope this resource will help you to have a conversation with the important people in your life, about what your wishes are if you become so sick that you are unable to make your own decisions.

Age UK would like to thank all the older people, grown-up children, grandchildren, relatives, friends and healthcare professionals who have helped to co-design this resource.

Age UK found that the biggest barrier which prevented advance care planning conversations from taking place were the uncertainties older people had about cardiopulmonary resuscitation (CPR) and do not attempt cardiopulmonary resuscitation (DNACPR). Our co-designers have helped us to explain, in the resource, most of the concerns and questions that were asked.

What is advance care planning?

Advance care planning is a record of our care and treatment preferences and wishes for a future time when we may be too sick to make our own decisions. It can help to let people know what our wishes are, and it can reassure those around us that they are caring for us in the way we want.

An advance care plan is not legally binding but will always be part of the decision-making process for healthcare professionals. This is the focus of this booklet.

If you wish to, there are also formal legally binding choices, that can support you in your advance care planning:

- An advance decision to refuse treatment (ADRT): this is about refusing a specific medical treatment that you do not want to have in particular circumstances, for example, CPR or antibiotics at the very end of life.
- Lasting power of attorney for health and welfare: this allows others whom we choose to make decisions for us on our health and care when we are unable to.
- Lasting power of attorney for finance: this allows others whom we choose to make financial decisions for us when we are unable to

Further information can be accessed here

<https://www.ageuk.org.uk/information-advice/money-legal/legal-issues/power-of-attorney>

Personal choices

Throughout our lives, we have the opportunity to make choices about the way we live, and we make these choices based on what matters most to us. We are all different, and therefore our choices will be too.

As a society, we are getting better at planning for our future around pensions and making wills, with many of us arranging our own funeral and burial plots so that we get the send-off we want.

Some of us are even planning for the legacy of our social media. We do this because we do not want to leave this worry to our friends and family.

However, we are not so good at planning our future healthcare, particularly as we get to later life when we may start to experience health problems, get diagnosed with a terminal illness, long-term condition, or generally feel that we are moving towards the end of our natural life.

Not having these conversations may mean that the important people in our lives can find themselves overwhelmed if they are called upon to make a healthcare decision on our behalf. They may not be confident that they are representing our wishes.

It can be difficult to have a conversation with the important people in our life

Talking about becoming seriously ill, dying, and our future treatment wishes is never an easy conversation to start.

It is difficult and we may find that the important people in our life are resistant and might even try to shut these conversations down.

However, thinking about our own wishes, discussing our thoughts with others, writing it all down and sharing our wishes to ensure they are known by the people who matter to us as well as health care professionals is important.

Sometimes there may be an assumption that our loved ones know what we want, so no discussion is required.

That's probably not true, and sometimes many of us just never get around to having this essential conversation.

The important things here are about thinking and talking ahead of time and trying to avoid making emergency decisions.

When we do not have these conversations about sharing our wishes, fears, and worries with our nearest and dearest or with healthcare professionals, how will they be able to advocate and make the decisions that we want on our behalf?

What to include in conversations with families' friends and healthcare professionals?

It should cover a range of personal choices that reflect your wishes if you develop a serious illness and cannot make decisions or speak for yourself.

It's good to prepare to have a conversation

- Reading through this booklet will help.
- Consider what you want to discuss and think about the information you will need to help you.
- You may need to ask questions to a healthcare professional or other trusted source to ensure you have the information you need to make an informed choice.
- Thinking through your decisions to yourself first can help to build your confidence to talk about your thoughts and choices and think about the reasoning behind your decisions.

What should we include?

Anything that's important to you. This may include:

- Where would you want to be looked after if you became so ill or too disabled to care for yourself? Would it be in a hospital, at home, in a care home or somewhere else?
- Who would you like to help make decisions or choices about your care? This could be a range of different people, such as your spouse, your partner, a good friend, your children or other family members.
- Which people, such as close friends or family, would you like to be involved in helping look after you, perhaps providing personal care? Is there someone you would not like to be involved in looking after you?

Remember to include your personal choices and beliefs, such as:

- Do you prefer a shower instead of a bath?
- Do you like the television on or the radio in the background?
- Do you like a mug or a cup and saucer?
- Include practical issues such as who will look after your pet if you become ill.
- How do you want any religious, or spiritual or cultural beliefs you hold to be reflected in your care?
- If you are a carer, who would provide that care when you are no longer here?

How could these wishes be made to happen?

- Who would you need to involve and have a discussion with?
- Are there other arrangements that you would need to make? For example, if you require finances to pay for your care then you would probably need to seek expert advice. Age UK is a good starting point:

<https://www.ageuk.org.uk/information-advice/money-legal/end-of-life-planning>



Starting a conversation

The real essence of advance care planning conversations is to develop a plan that will cover our health and treatment preferences so that if we become seriously ill and may be dying, our wishes will be known and recorded.

An advance care plan becomes important to have in place in case we experience any of the following:

- When we are naturally ageing, perhaps becoming frailer, feeling that our batteries are running low and thinking ahead to what we may want to happen at the end of our natural life.
- We may be worried about losing mental capacity and thereby the ability to make decisions. Or, worrying about the difficulty in taking in information or weighing up the pros and cons and then communicating decisions.
- We have recently received a diagnosis of dementia and want to get our affairs in order.
- We have a life-limiting illness or a long-term condition that is progressing and getting worse over time, such as cancer, COPD, or heart disease and it is expected to lead to very ill health.
- If we are unconscious or unable to communicate because of a sudden event or accident.
- Wanting to be ready for the possibility of any sudden unexpected illness or injury.

Starting conversations about future care and treatment

- Sometimes these conversations are difficult to have and it's important these conversations are undertaken in a way that feels right for you, allowing you to comfortably express your wishes.
- You may want to think alone or prepare your thoughts in discussion with family or friends or health care professionals.
- You should include anyone whom you would name, rely on, or expect to decide on your behalf.
- You should also think about including your GP, consultant, or healthcare professional who can ensure your advance care plan is included in your healthcare records.

Sometimes families or healthcare professionals will start an unexpected conversation about your future health and treatment.

- Families and friends may start to discuss your future health plans because they have noticed that you are less able to manage, and they are worried about your condition deteriorating and if you are looking after yourself well.
- Health care professionals could start an unexpected conversation with you about your future healthcare plan because they understand the benefits of having early conversations about advance care. They will want to discuss with you, your prognosis and the future care and treatment options that may be available to you.

How to manage an unexpected conversation about future health and treatment wishes.

- You may be glad and feel relieved to have the opportunity, or you may feel upset. This is quite a normal range of feelings.
- You do not have to continue the conversation or agree to anything if you feel unprepared. You should not feel uncomfortable saying "please can we have this conversation later when I have had time to think about it?"
- It may be a good opportunity to ask any questions you may have but you do not need to make any immediate decisions.
- You may feel that you want to include someone important to you in the conversation. If this is the case, ask the healthcare professional to arrange a time when you all will be available.



Why are advance care planning conversations important to healthcare professionals?

All healthcare professionals know how important it is to have a conversation with you about your wishes for your future care and treatment and continually review them with you as your condition changes. These conversations help healthcare professionals provide ongoing care that's best for you.

- Healthcare professionals will start an advance care planning conversation with you to help you make decisions about your care and future treatment.
- This will be an ongoing conversation as your physical condition changes, healthcare professionals will review your treatment and support and update your care plan to ensure you receive the best care possible.
- You may want to take the opportunity to review any preferences and choices that you have previously made.
- They will share their clinical expertise and knowledge and will explain what you may expect with the progression of your illness and your prognosis.
- While these conversations are important to have so that your preferences are known, it's important to remember that these preferences are not legally binding, and a healthcare professional's clinical expertise and judgement can override them if it is in your best interests at that time.

What if we don't want to discuss advance care planning at all?

- You may only want to know some details about your illness, tell the healthcare professional what you want to know and what you don't.
- We should feel comfortable saying no and we should not feel under pressure to carry on a conversation. If this is your wish, healthcare professionals will record it in your notes.
- Keep in mind, that if you have not discussed your health and care wishes, then making decisions on your behalf becomes trickier. It could mean important people in our lives find themselves overwhelmed if they are called upon to make a healthcare decision on our behalf.
- It also means healthcare professionals who make treatment decisions for you will not have received guidance from you. This is okay as they will always use their clinical judgement to do the best for you.





Where is my advance care plan kept?

- If you have written your wishes for an advance care plan yourself, it is best to share it with your regular healthcare professional so that it can be recorded to your health care record.
- You can carry a My Wishes card which explains that you have made an advance care plan. It's a good idea to discuss and share your plans with people who are important to you and whom you would like or wish to help with the plan.
- If you have developed your advance care plan with your GP, community nurse, or health care professional and you live in your own home, sheltered accommodation, or in a care home, the health care professional involved will add a copy to your health care record.
- You should also keep a copy to share with other healthcare professionals, such as when you are attending an appointment or being admitted to hospital, including Accident and Emergency.
- When we are in hospital, at home, or in a care home and our physical condition is expected to get worse, our advance care plan may be added to a Treatment Escalation Plan also known as a TEP.

How does a Treatment Escalation Plan also known as TEP work?

- A TEP is used to record information discussed between you and your healthcare professionals. It creates a personalised recommendation for your clinical care in emergencies, where you are not able to make or express your wishes yourself.
- A TEP is important if you have a medical condition that may change quickly, or you are approaching the end of your natural life. It is a process that is used to help guide decisions made by healthcare professionals in discussions with patients and relatives.
- The TEP will use your advance conversation wishes to create a person-centred plan for your clinical care, ready for if your condition becomes worse.

Making choices

Deciding that you don't want to accept a treatment that could potentially keep you alive is not the same as asking someone to help you end your life, which is illegal in England.

Decisions

- Deciding about what future care we would want can be difficult. Sometimes our decisions can be hard for the important people in our lives to accept particularly when it's about stopping a treatment or not agreeing to treatments that may prolong our life.
- These decisions should be your own choice and one that you feel comfortable with. They may be made alone, or by discussing it with your important people or healthcare professionals. We should never feel under pressure to make health and treatment choices.

Some of these decisions could be:

- We may not want to be resuscitated by cardiopulmonary resuscitation or mechanically ventilated.
- We may not want to receive food or fluids by tube or drip.
- If we are in our own home or a care home and our condition deteriorates, we may not want to be admitted to hospital.
- Or we may want to receive every treatment that is available to us that can be given to prolong our life.

Remember that while individual preferences will always be considered, clinical judgment will be used to determine what treatment or care we receive.

We can refuse treatments, but we cannot demand treatments that are not clinically advised.





Treatments

There are many different types of treatment that can be used to keep people with serious or terminal illness alive. These are called life-sustaining treatments. They do not cure or treat underlying conditions.

Examples of life-sustaining treatments include:

- Artificial nutrition (feeding) and hydration (fluids) such as tube feeding or intravenous drip,
- Antibiotics to treat infections for example a urine infection,
- Cardiopulmonary resuscitation also known as CPR,
- Mechanical ventilation is where a machine takes over the person's breathing,
- Dialysis, where a machine takes over the kidney's functions.

Remember that while individual preferences will always be considered, clinical judgment will be used to determine what treatment or care we are offered. There may come a time when there's no prospect of recovery and life-sustaining treatments are prolonging the dying process. Your healthcare team will discuss this with you and those important to you.

Cardiopulmonary resuscitation also known as CPR

CPR is a treatment that can be given when you stop breathing (respiratory arrest) or your heart stops beating (cardiac arrest).

The process of CPR

CPR tries to get your breathing and heart going again. It can involve:

- Pressing down hard on your chest repeatedly (chest compressions).
- A machine to stimulate your heart using electrical shocks (sometimes more than once).
- Equipment that helps move oxygen around your body (artificial ventilation).
- Giving medicine by injection.

You have the best chance of CPR restarting your heart or breathing if:

- Your lungs, heart or other organs are healthy and working well before your heart or breathing stops.
- You are near a person trained in CPR.
- Any equipment that is needed, such as a defibrillator, is nearby.

What is the impact of CPR?

- CPR can sometimes get the heart and breathing going again, but only a few people will make a full recovery even if their heart or breathing can be restarted with CPR.
- The actions used in CPR, such as chest compressions, can cause bruising, broken ribs and punctured lungs.
- Your chances of CPR starting your heart and/or breathing are lower if your lungs, heart or other organs were struggling to work before CPR is needed.
- The chances of CPR being successful are also lower for people who are frail, who live with multiple long-term health conditions, are approaching the end of their life, or have a severe current illness.
- Fewer than 1 in 10 people survive an out-of-hospital cardiac arrest.
- Following CPR, you may still be unwell and need more treatment and you may never get back to the health you had before.

Older people's concerns and worries about agreeing to a DNACPR

Older people tell Age UK that sometimes they feel confused and anxious about agreeing to a DNACPR because of what they or people they know have experienced, heard, or read in worrying media stories of older people's poor experience with DNACPR particularly around the pandemic and beyond.

Some people think that DNACPR is code for do not treat. This is not true.

If we choose not to be resuscitated, this decision is only about whether to attempt CPR if and when our heart has stopped beating (cardiac arrest), or we stop breathing (respiratory arrest).

If you decide that CPR is not for you, it does not mean that you will not be offered other treatments and care.

We should never underestimate the negative impact CPR can have on a person's health, particularly someone who is ill, getting older, feeling frailer, and nearing the end of their natural life.

Why do healthcare professionals ask you if you want to be resuscitated?

- It could be because they are helping you to think ahead at a time when there is plenty of time for questions discussions and planning.
- Your doctor feels you are becoming so ill that they do not think in their clinical judgement that there is a realistic prospect of a positive outcome for you and attempting CPR would be in vain.
- This preference is an individual choice, one that you should feel comfortable with, and one that you have made alone or with your important people or health care professionals. You should never feel under pressure from family or healthcare professionals to decide your preference.
- DNACPR is a medical treatment decision that can be made by your doctor even if you do not agree. We must remember that doctors do not have to give you treatments if they think it will not work.
- If you disagree with a DNACPR decision that a doctor has made, you can ask for a second opinion and a review.



What happens when we decide not to be resuscitated?

- A DNACPR decision is usually recorded on a special form. There are a variety of different forms that may be used, but they all serve the same purpose. Some examples are a DNACPR form, a Treatment Escalation Plan (TEP), or a Recommended Summary Plan for Emergency Care and Treatment (ReSPECT) process.
- The form says that if your heart or breathing stops, CPR should not be tried. This means medical staff will not try to restart your heart or breathing.
- All these forms are easily recognised by doctors, nurses, health and social care professionals and ambulance crew. This helps everyone to know what to do for you in an emergency.
- This form is kept in your medical records. It may also be printed and kept with you if you are at home or in a care home.
- You and the people important to you should know that a DNACPR form has been put in your medical records.
- More information can be found here:

<https://www.nhs.uk/conditions/do-not-attempt-cardiopulmonary-resuscitation-dnacpr-decisions/>



The path to the natural end of our life

“You matter because you are you, and you matter to the end of your life.”

*Dame Cicely Saunders,
founder of the modern hospice movement.*

As we age, we expect our body to slow down, perhaps to become more unwell with several health problems. We may be diagnosed with a terminal illness, or we may find that we are just generally declining. We are gently moving along to the end of our natural life, when our physical condition is deteriorating so much, and we become sick enough to die.

Understanding the phrases used as we move towards the end of our life

Terminal illness

Refers to an illness that cannot be cured. Such illnesses may also be referred to as life-limiting.

Palliative care

The term used to describe the care we receive if we have an illness that cannot be cured. This could be from a few days to many months or years.

Palliative care aims to take a holistic approach, treating the whole person and not just the illness or symptoms.

The aim is to help make us as comfortable as possible by managing any pain and other symptoms as our condition progresses. It involves psychological, social and spiritual support for you and the people who support you.

The palliative care team

The team usually consists of different healthcare professionals who coordinate the care of people with an incurable illness.

They are specialists, they can be part of a multidisciplinary team and they advise other professionals on palliative care.

Virtual ward or hospital at home

Virtual wards (also known as hospitals at home) allow patients to get the care they need at home safely and conveniently, rather than being in a hospital.

The NHS is increasingly introducing virtual wards to support people at the place they call home, including care homes.

End-of-life care

End-of-life care is the care you receive when you are likely to be in the last 12 months of your life.

End of life care aims to help you live as well as possible and support you to die with dignity. Care focuses on the quality of the person's life and death. It also includes support for families, carers and those important to the person.

If you live at home or in a care home your GP has overall responsibility for your care, they may be able to signpost you to available local support.

At the end of the day.

Eventually, for some of us there will come a time when it's clear there's no prospect of recovery and it may be that the life-sustaining treatments that we are receiving are prolonging the dying process, this is the time that healthcare professionals will consider withdrawing or stopping life-sustaining treatments.

How do my wishes and advance care conversations help in this situation?

During conversations about your health and treatment wishes with your important people and healthcare professionals, it's quite likely that you will have discussed what you would want to happen in the last days or hours of your life.

Healthcare professionals and families will feel confident to make decisions on your behalf because you have expressed your wishes.

What happens when life-sustaining treatments are prolonging the dying process?

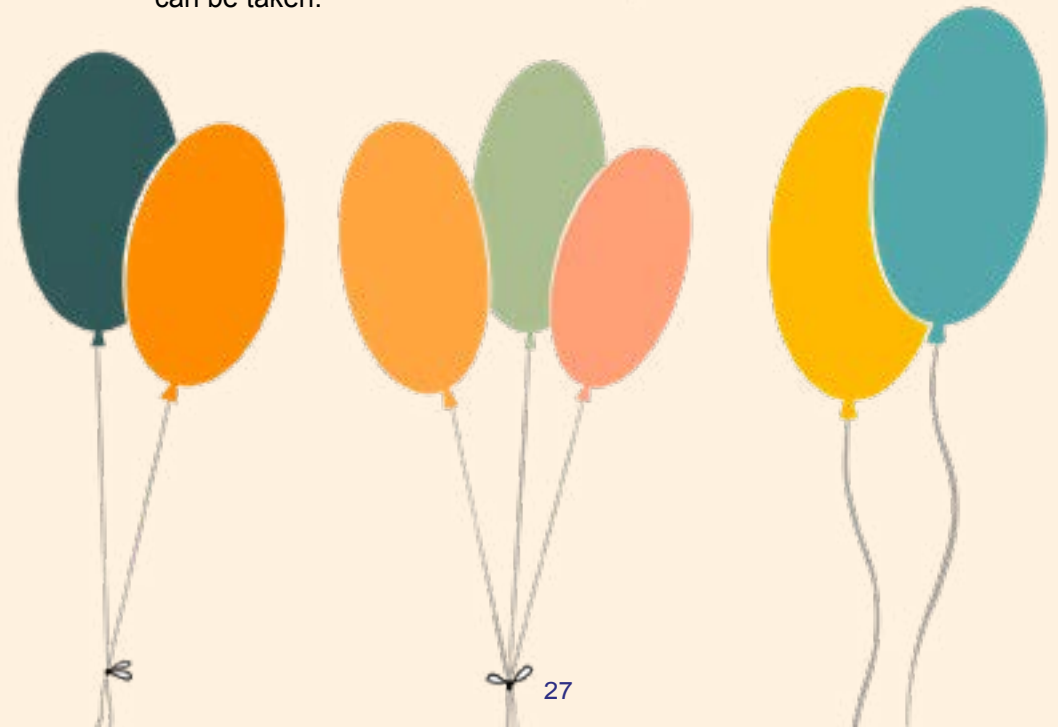
If it becomes clear that life-sustaining treatments are prolonging the natural dying process, healthcare professionals may discuss with you and those important to you that continuing with your current treatment may not be in your best interests.

In their experience and clinical judgement, they will make a clinical decision to withdraw active treatments. This means that you will be kept symptom and pain-free and supported to die peacefully.

The process of making the decision to withdraw treatment

The decision to withdraw treatment will be based on your best interests and your advance care plan and conversations with the important people in your life.

- Healthcare professionals will discuss this with you if you're able to understand and communicate.
- If you are not able to understand or communicate, they will draw on the discussions that have been made in any conversations with healthcare professionals and your family or important people during the course of your care and treatment.
- If you have a Lasting Power of Attorney (LPA) for health and welfare, your healthcare team will discuss this with your LPA representatives giving them time to consider all the implications.
- In exceptional circumstances, if an agreement cannot be reached, the case can be referred to the Court of Protection before any further action can be taken.





We hope that now you have reached the end of this booklet; it will help you to think about what you would like to do about planning your own health, care and treatment plan.

Your wishes are important and its vital that you set some time aside to make your decisions to share with your nearest and dearest people and healthcare professionals.

Remember, we are all different. Some of us will be sure

that we don't want some treatments. Others of us will be undecided and may need more information and time.

There will be many of us who want everything and anything that is going to help us to continue our life.

Whatever you choose, make your decisions and make sure that you let people know what your wishes are for your future care and treatment.

Glossary



A digital care summary record

- A digital care summary record is an electronic summary of key clinical information from your GP records. Hospitals, ambulances and 111 emergency departments, wards and intensive care units can access this helpful information and will know our wishes so that they can do their best to make care and treatment decisions by what we have said we would want. Whatever our decisions are, it's important that they are included.

A urine infection (UTI)

- A UTI is a urinary tract infection. UTIs affect your urinary tract, including your bladder (cystitis), urethra (urethritis) or kidneys (kidney infection).

Age UK Insight work

- This is research carried out by Age UK to understand what older people would like more information on and what is unclear to them. Age UK Insight work is based around the voices of older people.

Clinically appropriate

- If a decision is clinically appropriate then it is in accordance with clinically accepted standards of medical practice and is a tailored decision based on each patient and what is best for them at the relevant time.

COPD

- Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties.

Dementia

- A general term for the impaired ability to remember, think, or make decisions that interfere with doing everyday activities. Alzheimer's disease is the most common type of dementia. Though dementia mostly affects older adults, it is not a part of normal ageing.

Do Not Attempt Resuscitation orders

- A Do Not Attempt Resuscitation order does not mean that they will not treat you if you become unwell. It specifically means that CPR will not be carried out if your heart stops beating and you are unconscious, unresponsive, and not breathing.

End-of-Life Care

- The care you receive when you're close to the end of your life and is likely to be the last 12 months of your life. The aim of 'end-of-life' care is to help you to live as well as possible until you die and die with dignity.

Health care professionals

- Health care professionals are trained to provide evidence-based and caring services to people's health needs. These are the professionals who look after you and support you when you are unwell.

Heart disease

- A type of disease that affects the heart or blood vessels. The risk of certain heart diseases may be increased by smoking, high blood pressure, high cholesterol, unhealthy diet, lack of exercise, and obesity.

Holistically

- Holistic treatment means treating a person as a 'whole' rather than just the illness or symptoms.

Life-sustaining treatment

- Life-sustaining treatments (sometimes called life support) refer to actions and treatments that may help to prolong life when one or more body systems are not working. These treatments will not cure or treat underlying conditions. You can refuse a treatment that could potentially keep you alive, known as life-sustaining treatment. Life-sustaining treatment is sometimes referred to as lifesaving treatment.



Glossary

Mental Capacity

■ Mental capacity is the ability to make informed decisions. Under the Mental Capacity Act 2005, someone is capable of making their own decisions if they can:

- Understand the information they need to make their decision,
- Remember the information,
- Apply that information to making their decision using reasoning and analysis,
- Communicate what their decision is.

If someone is considered to lack capacity, at the time a decision needs to be made, it means that they lack the capacity to make a specific decision on a specific matter, or take a specific action for themselves at that time.

Palliative Care

■ Is the term used to describe the care we receive if we have an illness that cannot be cured. This could be from a few days to many months. The aim of palliative care is to take a holistic approach, treating the ‘whole’ person, and not just the illness or symptoms. The aim is to help make us as comfortable as possible by managing any pain and other symptoms as the condition progresses.

Prognosis

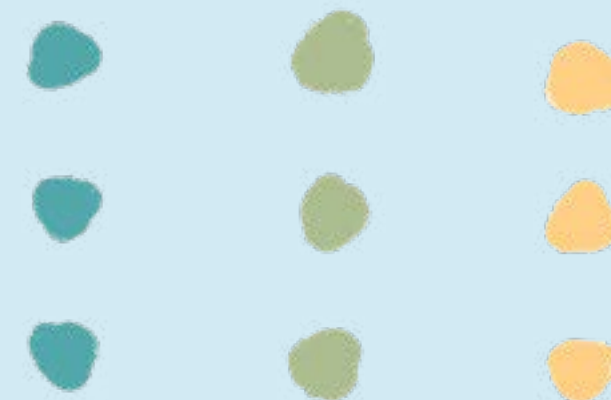
■ A medical prognosis is an informed medical guess as to the probable course and outcome of a disease.

Summary Care Records (SCR)

■ An electronic record of important patient information, created from GP medical records. They can be seen and used by authorised staff in other areas of the health and care system involved in the patient’s direct care.

Treatment Escalation Plan

■ This is a process that is used to help guide decisions made by healthcare professionals in discussions with patients and relatives. The TEP will use your advance conversation wishes to create a plan personalised for your clinical care ready for if your condition became worse and you were not able to make decisions or express your wishes yourself.





Useful organisations



Age UK

- Provides advice and information for people in later life through our Age UK Advice line, publications and website - www.ageuk.org.uk
- Age UK Advice: **0800 169 65 65**. Lines are open seven days a week from 8am to 7pm.

Malnutrition Task Force

- The Malnutrition Task Force provides a variety of different resources and information for older people on topics such as avoidable and preventable malnutrition, end of life care, and mental health.
- www.malnutritiontaskforce.org.uk/resources

Cruse Bereavement Care

- Offers information and support to bereaved people, both over the phone and face to face.
- **Tel: 0808 808 1677**
- www.cruse.org.uk

Digital Legacy Association

- Helps people manage their digital legacy, ensuring end-of-life wishes are met in both the real world and digital realm.
- **Tel: 01525 630 349**
- www.digitallegacyassociation.org

Dying Matters

- A Hospice UK campaign which aims to help people talk more openly about dying, death and bereavement, and make plans for the end of life.
- **Tel: 08000 21 44 66**
- www.dyingmatters.org

Gold Standard Framework

- Provides a database of care homes in England that provide high-quality end-of-life care.
- www.goldstandardsframework.org.uk/accredited-care-homes

Hospice UK

- The national charity for hospice care, supporting the work of more than 200 member organisations.
- **Tel: 020 7520 8200**
- www.hospiceuk.org

Macmillan Cancer Support

- Provides practical, medical and financial support for people facing cancer, and their carers and loved ones.
- **Tel: 0808 808 0000**
- www.macmillan.org.uk

Marie Curie

- Provides care and support to people with a terminal illness, and their carers and families.
- **Tel: 0800 090 2309**
- www.mariecurie.org.uk

NHS

- Find out about local NHS services in England and get information on end-of-life care.
- www.nhs.uk
- In Wales, contact NHS 111 Wales **Tel: 111** www.111.wales.nhs.uk
- In Northern Ireland, contact NI Direct www.nidirect.gov.uk

Office of the Public Guardian

- Provides information and guidance on appointing a Power of Attorney or applying to the Court of Protection.
- **Tel: 0300 456 0300**
- <https://www.gov.uk/government/organisations/office-of-the-public-guardian>