

Thinking Ahead Information Booklet

YELLOW FOLDER

All important information to go in your yellow folder:

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Separate Documents to include in your yellow folder: tick

Completed ReSPECT form and ReSPECT leaflet	
Advance Care Plan	
Lasting Power of Attorney (LPA)	
Advance Decision to Refuse Treatment (ADRT)	
WILL	
Discharge Letters	
Care plans eg. Wound care, diabetic care plan, risk feeding	
Community Prescription form with Anticipatory Medications prescribed	



Thinking Ahead Information Booklet

Useful Contacts for Families and Patients

Community Nursing Team

If you have concerns around symptoms (pain, breathlessness, nausea, restlessness) then please contact your community team. They can administer the injectable anticipatory (just in case) medications. Community Nurses also support with catheter care, pressure area care, wound care etc. Community Nurses aim to arrive within two hours for urgent calls, however this is not always guaranteed.

Single point of contact (8am-6pm) - Norfolk - 01603 518444

Great Yarmouth and Waveney (7am-8pm) - 01493 809977

Out of hours Norfolk, Great Yarmouth and Waveney - 01603 481234

Community Specialist Palliative Care 24/7 Advice Line (Patients and Carers)

Norfolk: Norfolk Community Health and Care: 03301588011 - OPTION 2

Great Yarmouth and Waveney: St Elizabeth East Coast Hospice: 0800 5670111

West Suffolk and Thetford: St Nicholas Hospice: 01284 766133

NHS Continuing Healthcare - Fast Track Provision

Available 09.00- 17.00

If care or placement has been funded by the Fast Track Pathway you will have a case manager overseeing your care. If you need to provide feedback or ask for increased package of care, then please use the numbers below. (You may have to leave a message, but they will get back to you as soon as possible).

Norfolk - 01603 257159

Suffolk - 01473 770198

Great Yarmouth - 01502 719590

SWIFTS (Norfolk only)

0344 800 8020

24hr voluntary service. Emergency care provision, who may be able to provide practical support following a fall. This will depend on capacity.

Medequip

01603 511124

If there is an issue with equipment that requires repairing, if any equipment needs collecting then please contact. If you need therapist support around equipment, then please call the single point of contact number as well (see community nurse section for number)

NNUH Integrated Discharge Team

01603 289 899

Adult Social Services – Available 24 hours

For care that is not on the fast track or continuing health pathway, community therapy teams, any safeguarding or welfare concerns.

The Care Act Assessment:

If you have care and support needs you are entitled to a care act assessment, and if you are a carer, the carers assessment.

Norfolk - 0344 800 8020 Suffolk - 0800 917 1109

Carers Matters Norfolk - 0800 083 1148

Marie Curie - End of life advice and information

Support line - 0800 090 2309

Website - <https://www.mariecurie.org.uk/>

Continence Products

Community Nurses can refer you on to your local continence service to provide continence products however there can be a waiting time of a number of weeks.

Website for advice- <https://www.continenceproductadvisor.org/>

Most items can be bought in pharmacies and supermarkets.

If you are concerned about your relative/ friend please contact the community nurse team, their GP or 111

Thinking Ahead Folder

Introduction

Health and care organisations across Norfolk and Waveney have worked together to develop some documents to help you to plan your current and future care. The documents have been given to you in a yellow 'Thinking Ahead Folder'.

Included in this folder are an Advance Care Plan and ReSPECT form. Your health or care team will discuss these with you in the coming weeks. It is important that you keep these documents safe and available to any health or care teams who may help to care for you. The documents should be kept in your yellow Thinking Ahead Folder and taken with you to appointments or to hospital should you need inpatient care.

What should I do now?

Although it can sometimes feel upsetting, it can be helpful to talk to your family and loved ones about your wishes. Documenting your thoughts is important so those close to you know what your wishes are for now and for your future care.

The ways that you can record your wishes include:

- An Advance Care Plan
- A ReSPECT form
- An Advance Decision to Refuse Treatment (ADRT)
- A Last Will and Testament
- A Lasting Power of Attorney (LPA)

Advance Care Plan

An Advance Care Plan is a record of your wishes, feelings, beliefs and values which can be used if you later become unwell and need care or medical treatment. An advance Care Plan is not legally binding. This means that a healthcare professional does not have to follow the instructions that are in it. However, what you write in your Advance Care Plan is still important because your wishes must be taken into account when decisions need to be made for you.

Advance Care Planning is a voluntary process of person-centred discussion between an individual and their care providers about their preferences and priorities for their future care. The process may involve a number of conversations over a period of time with a healthcare professional such as your GP, consultant or nurse as well as with your family and loved ones.

By recording your wishes, you will give those around you a clear idea of what is important to you if you are unable to tell them.

The Advance Care Plan is included in the yellow folder. You may want to start filling in some of the sections such as the key information on the first page. You can then talk to your health and care team about who might be able to help you to record your wishes and complete the rest of the form.

There are lots of people that you can get help from to complete your advance care plan:

- Community nursing team
- General practitioner
- Specialist care team in the hospital
- Palliative care team in the hospital
- Palliative care team at the hospice
- Marie Curie companion at home service

What if I change my mind?

You can change your mind about what is recorded in your Advance Care Plan at any time. You can ask your health and care team to review and rewrite your plan regularly, and you can also update the plan yourself as and when you want to.

Where should the form be kept?

The Advance Care Plan should be kept at home with you in the yellow folder so that you or your carer can show it to health or care professionals in an emergency.

Emergency care and treatment plan (also known as ReSPECT)

In a crisis, healthcare professionals may have to make rapid decisions about your treatment, and you may not be well enough to participate in making decisions. The ReSPECT process empowers you to guide health and care professionals on what treatments you would or would not want to be considered for.

Many life sustaining treatments involve risks of causing harm, discomfort and loss of dignity, or the risk of dying in hospital when you may have wanted to be at home. The ReSPECT form can record preferences and recommendations for emergency situations, whatever stage of life you are at.

Your views are crucial. The health and care professionals will make every effort to come to a joint agreement with you, however it is important to understand that the ReSPECT form cannot be used to demand treatments that are not likely to benefit you.

What should I do now?

The ReSPECT form is included in the yellow folder. If it has not already been completed, you can talk to your healthcare team to request that this is done. After talking to you, the doctor or nurse will complete the ReSPECT form summarising personalised recommendations of your clinical care in a future emergency where you may be unable to express your choices.

What if I change my mind?

If your condition or circumstances change, or if you want to change your mind for any reason then the ReSPECT form can be changed.

Where should the form be kept?

The ReSPECT form should be kept at home with you in your yellow folder so that you or your carer can show it to health or care professionals in an emergency.

Advance decision to refuse treatment (ADRT)

An Advance Decision to Refuse Treatment is a decision you can make now to refuse specific treatment in the future and is legally binding. An ADRT is very specific and is used in situations when you would want to refuse particular treatments.

Anyone deciding to draw up an Advance Decision to Refuse Treatment should seek advice from their health care team. The ADRT is legally binding and as such should be written and witnessed. You may choose a solicitor to do this.

What should I do now?

The ADRT is not included in the yellow folder. If you would like to consider this, you should speak to your healthcare team. It is very important that your healthcare team know your wish to refuse treatment so this can be documented in your medical notes.

What if I change my mind?

If your condition or circumstances change, or if you want to change your mind for any reason then the ReSPECT form can be changed.

Where should the form be kept?

The ADRT should be kept at home with you in your yellow folder so that you or your carer can show it to health or care professionals in an emergency.

Last Will and Testament

Your Will lets you decide what happens to your money, property, and possessions after you die. If you die without a Will, there are laws that will determine how your money, property and possessions are distributed. There is no legal requirement for a Will to be drawn up and witnessed by a solicitor, if you want to make a Will yourself you can do so but it is advisable to use a solicitor or chartered legal executive unless the will is going to be straightforward. You will need to include details of executors in your Will. Executors are the people who are responsible for carrying out your wishes and sorting out the estate following your death.

What should I do now?

If you do not already have a Will, or if you have a Will that you think needs changing, you should think about if you are able to write the Will yourself or if you need legal assistance to do this. If you need legal assistance, you will need to contact a solicitor, chartered legal executive or Will writing service. You should remember that a solicitor will charge for their services in drawing or changing a Will.

What if I change my mind?

You can change your mind about what is written in your Will at any time. If you used a solicitor to write your will then you will need to ask the solicitor to help you make changes.

Where should the form be kept?

You can choose to keep your will in a safe place at home. You can also choose to keep your Will with the solicitor who has helped you. You should let your loved ones know where your Will is kept.

Lasting Power of Attorney (LPA)

A Lasting Power of Attorney is a legal document that appoints someone – your ‘attorney/attorneys’ – to make decisions on your behalf.

There are two types of LPA: one for making financial decisions and another for making health and care decisions. You can set up LPAs for both types of decisions.

An LPA for health and care decisions can only be used if you lose mental capacity. An LPA for financial decisions can also be used while you still have mental capacity if this is what you’d prefer, but you need to choose this option when setting it up.

You can only create an LPA if you have mental capacity to do so and you haven’t been put under any pressure to set it up.

What should I do now?

You should choose someone that you are close to, such as family members or friends to be your attorneys. You can apply for an LPA directly, or you can use a solicitor. It is more costly if you use a solicitor rather than filling the forms yourself, but you might find that the reassurance of having professional advice is worth it. <https://www.gov.uk/power-of-attorney>

What if I change my mind?

An LPA isn’t necessarily permanent. You can cancel it at any time while you have mental capacity by writing to your attorney or attorneys and the Office of the Public Guardian and advising them of your decision.

Where should the form be kept?

You can choose to keep your Lasting Power of Attorney in a safe place at home. You should let your loved ones know where your LPA is kept.

Financial Support

You could get money to help with living costs if you're nearing the end of life because of an illness.

If your doctor or a medical professional has told you that you might have 12 months or less to live, you might be able to:

- get benefits at a higher rate or get extra money
- start getting payments quicker than usual

This is sometimes called 'special rules for end of life'.

You should ask a medical professional to fill in form SR1 so you can get the benefit you applied for under special rules. They will have the form.

Medical professionals include:

- GPs
- Hospital doctors
- Registered nurses (for example, Macmillan nurses or specialist nurses)

They will send the form to the Department for Work and Pensions (DWP) to support your benefit application.

You only need one SR1 form, even if you apply for more than one benefit.

If you have reached state pension age you can apply for attendance allowance

If you are under state pension age you can check if you are eligible for these benefits:

- Employment and Support Allowance (ESA)
- Universal Credit
- Personal Independence Payment (PIP)

Also consider calling Adult Social Services, if you need support claiming any benefits or finding out what other financial support is available.

If you are Caring for Someone

You may be eligible for financial support if you care for someone who is nearing the end of life.

If you care for someone for at least 35 hours a week, check if you can get Carer's Allowance.

If you care for someone at least 20 hours a week and you're under State Pension age, check if you can get Carer's Credit.

Further Help and Support

If you need further help or support with financial matters you can get help from the following:

- **Macmillan Cancer Support** - practical and emotional support at the end of life - **0808 808 00 00**
- **Carers Matters Norfolk** - **0800 083 1148** Mon - Fri 9 to 5pm
- **Carers UK** - support and advice for carers - **020 7378 4999**
- **Citizens Advice** - for financial advice and support - **0800 144 8848**
- **Money Helper** - advice on money and benefits
- **Big C** - welfare advice **0800 092 7640** (free to call Monday to Friday, 9am - 5pm)
- **Age UK** - Advice on managing money and benefits - **03005 001217**

Mouthcare at the End of Life: Ensuring Comfort, Cleanliness and Dignity

At the end of life, mouthcare becomes an important part of maintaining comfort and dignity. As people become more fatigued and unwell, they may need extra support with their oral care. The following provides simple steps to help care for the mouth during this sensitive time.

Why Mouthcare is Important

- **Promotes Comfort & Dignity:** Regular mouthcare helps keep the mouth clean, comfortable, and moist, which can reduce discomfort and prevent infections.
- **Prevents Dryness & Soreness:** People may breathe through their mouths more as their condition deteriorates, leading to dryness, discomfort, and soreness. Simple mouthcare can relieve this.

Mouthcare Tips for Comfort

- **Using a Soft Toothbrush:** A soft toothbrush with a small amount of low-foaming, Sodium Lauryl Sulphate (SLS)-free toothpaste (e.g., Oralieve) can help gently clean the teeth and mouth. This promotes comfort and reduces irritation.
- **For Drowsy or Unconscious Patients:** If the person is drowsy, unconscious, or unable to swallow, it is important to provide mouthcare more frequently - every 1-2 hours if needed. Regular care prevents the mouth from becoming dry or uncomfortable.
- **Moistening the Mouth:** A circular mouth brush, like a Moutheze brush, can be used to apply a moisturizing oral gel (e.g., Oralieve or Bioextra) to the inside of the cheeks, tongue, and roof of the mouth. Gently massage the gel in a circular motion from front to back, ensuring it is fully absorbed. This helps keep the mouth hydrated and comfortable.
- **Removing Food and Debris:** The circular brush can also be used to gently remove any food particles, debris, or dry saliva that may build up in the mouth. A pen torch can help you check the mouth thoroughly.

Caring for Dry Lips

- **Moisturising Lips:** To prevent dryness and cracking, apply a water-based balm, such as Oralieve or beeswax lip balm, to keep the lips moist. Avoid petroleum-based products, as they can be a fire hazard when used around oxygen or open flames.

Caring for Dentures

- **Cleaning Dentures:** If the person wears dentures, remove them regularly to clean and rinse thoroughly. If the person is drowsy or unconscious, consider leaving the dentures out for their comfort.

Additional Tips for Mouthcare

- **Use a Towel for Protection:** Place a clean towel over the person's clothing to keep them dry during mouthcare.
- **Check Frequently:** Look for signs of dryness, soreness, or buildup in the mouth, and offer care as often as needed.

Supporting Dignity at a Sensitive Time

Providing mouthcare is a small but important way to maintain comfort, cleanliness, and dignity during the final stages of life. By following these steps, you can help ensure the person you care for is as comfortable as possible.

Information for Patient's Relatives and Carers who have been supplied with Anticipatory Medicines

Just in case medications

Just in case medications are also known as 'anticipatory medicines', these are medicines which are prescribed for you and are usually given by injection. They are given to you to be kept in your home 'just in case' you need them. This means you can be given a medicine to help relieve pain or other symptoms if you need it, especially during the night or at the weekend.

What are the medicines for?

You may not need any of these medicines right now however they have been prescribed for you because your healthcare team think that they may be needed at some point in the coming days or weeks to help with:

- **Morphine, Oxycodone or Alfentanil** for pain/breathlessness relief
- **Levomepromazine or haloperidol** for sickness/nausea
- **Hyoscine butylbromide** to help reduce phlegm that may build up in your throat (that you cannot clear yourself) when you are dying
- **Midazolam** for anxiety/restlessness/breathlessness.

When will I need to take the just in case medications?

When you have symptoms that are not being controlled with your usual medication, you or your carer can phone your GP, community nurse or the out of hours community nursing service to come to the house to see you. The GP or community nurse will discuss your symptoms with you. They may ask you to take an extra dose of your usual medicines if they think that this is what is needed. If you're unable to swallow your oral medication, are being sick or the medicine isn't getting to where it needs to work (due to problems with absorption) then the GP or community nurse may give you an injection from your 'Just in Case' medicines.

Who gives the just in case medications?

These medicines are given by injection, by your Health Care team; community nurse, specialist palliative care nurse or doctor. A medication chart will be provided, which must be kept with the medication, to enable the health care team to prepare the medication and use the chart to record what they have given. This is to make sure your treatment is effective and safe.

If you or your carer are administering the “Just in Case” medicines, you will have a plan available in your house about your care with instructions on what you should do if you have to give the medicines. You will also be provided with the equipment required to give an injection (needles, syringe, sharp item disposal - ‘sharps bin’).

Storage Guidelines

‘Just in case’ medications should be stored at room temperature in a secure location, away from the reach and sight of children and vulnerable individuals.

Requesting More Medication

If you need additional supplies, your nurse will coordinate with your doctor to obtain a new prescription. Please note that nurses are unable to pick up medications from community pharmacies. It’s advisable to have a friend or family member available to collect your medication (remember to bring a form of ID), or you may inquire if the pharmacy offers home delivery.

Disposing of Unused Medications

When medications are no longer required, please take them to any community pharmacy for safe disposal. We encourage you to do this promptly. While nurses cannot return medication to the pharmacy, a friend or family member can assist you with this task.

More information will be given to you if you need just in case medications to be prescribed.

What to Expect in the last Weeks and Days of life

Thinking about the last weeks and days of life is hard, but knowing what to expect may ease some of the worries you may be having.

Everyone's experiences are different but there are changes that often happen near to someone's death that may be signs the person is going to die soon.

Loss of Appetite

When someone is at the end of their life they may no longer wish to eat and drink, as their need for food and drink reduces. If they stop drinking and their mouth looks dry, this does not necessarily mean they are dehydrated.

It might be too much effort to eat and drink. If this is the case you can offer sips, ice chips or small bites, *provided the person is conscious and can still swallow*.

You can also help someone with a dry mouth by:

- applying a water-based lip balm such as Oralieve or Nivea as often as needed
- using a small headed soft bristled toothbrush and a mild non foaming toothpaste such as Oralieve or TePe to clean the teeth
- moistening the mouth with water or a water-based mouth gel or spray such as Oralieve or Biotene regularly. Gels should be massaged into the soft tissues of the mouth using a soft toothbrush and can be provided on prescription
- Mouth rinses and washes can be used to provide freshness provided the person has the ability to swish and spit out the mouthwash.

Needing More Sleep

When someone is at the end of their life, they are likely to spend more time sleeping, and will often be drowsy even when they are awake. They may also drift in and out of consciousness. Some people become completely unconscious for periods of time before they die - this could be for a short period or as long as several days.

They may seem less interested in what is going on around them, and have less energy to take part, but this does not mean they can't hear you.

You can carry on speaking quietly and calmly to them. You could also try letting them know you are there in other ways, for instance by holding their hand, reading to them, or playing their favourite music.

Restlessness/Agitation

Some people can become restless in the last few days of life. They will usually become calm again before they die.

They may appear confused and not recognise familiar faces, and even see or hear people or things that are not actually there - for instance, they may see pets or people who have died.

While this can be upsetting, it is very common, and it is not a sign that they feel differently about you. The restlessness can be caused by medicines or changes in the chemical balance of the brain, or as a result of drifting in and out of sleep so they are unable to clearly distinguish between what is real and what is not.

If they are agitated, often just sitting with the person can help to calm them down. You can also help by:

- speaking clearly, calmly, and audibly
- reminding them who you are (and being prepared to do so repeatedly)
- keeping their surroundings calm with a few changes like noise or light levels
- trying not to correct them if they say something wrong, or insist on them getting things right, as this may be upsetting for you and for them
- Agitation could also be a sign of needing the toilet, constipation or difficulty passing urine.

Ask the nursing or medical team if you have any concerns so they can rule out any underlying causes and if necessary, prescribe medicine.

Loss of Consciousness

Many people lose consciousness near the end of life, this is very common. But they may still have some awareness of other people in the room. They may be able to hear what's being said or feel someone holding their hand. Remain calm and you may wish to ensure that the room is peaceful and not too brightly lit.

Changes to Skin

The person's limbs, hands, feet, ears and nose may feel colder. This is because the blood circulation is slowing down.

People with lighter skin tones may look slightly blue or their skin can become mottled (have different coloured blotches or patches).

On people with darker skin tones, blue can be hard to see. It may be easier to see on their lips, nose, cheeks, ears, tongue, or the inside of their mouth. Mottling is also harder to see on darker skin tones – skin might look darker than normal, purple or brownish in colour.

Toilet Concerns

Some people may at this stage experience a loss of bladder and bowel control. This may happen earlier for some people. Your nursing team can offer support and advice should this happen. All main supermarkets sell products to help maintain dignity and hygiene if required.

Noisy Breathing

Noisy breathing in the days before a person dies can be frightening but is completely normal. Breathing may become loud and noisy if mucous has built up in the airways. This is because the person isn't coughing or clearing their airways. Some people call this type of breathing the death rattle because it can happen in the last days or hours of life. This is not a medical emergency, but a normal part of the dying process.

It can be upsetting or worrying for those around the person to hear their noisy breathing, but it's unlikely to be painful or distressing for the person who is dying. Often they will be unconscious or won't be aware of it. Looking at the person's face may reassure you that they are not distressed, if the face appears relaxed it is likely that they are not distressed by the noisy breathing.

If you are concerned about noisy breathing you can discuss this with your nursing team and medications may be prescribed alongside repositioning of your loved one. Sometimes it is not possible to alleviate the noisy breathing however the nurses will always ensure that your loved one is comfortable.

Shallow or Irregular Breathing

As the moment of death comes nearer, breathing usually slows down and becomes irregular. It might stop and then start again or there might be long pauses or stops between breaths. This is known as Cheyne-Stokes or agonal breathing. This can last for a short time or long time before breathing finally stops. Some people may switch between Cheyne-Stokes breathing and a more regular breathing pattern. This is not unusual.

Physical Signs of Dying

The following symptoms are often a sign that the person is about to die:

- They might close their eyes frequently or they might be half-open. Eyes may become less clear and may not focus on anything as they appear to look beyond you
- Facial muscles may relax and the jaw can drop
- Skin can become very pale
- Breathing can alternate between loud rasping breaths and quiet breathing.
- Towards the end, dying people will often only breathe periodically, with an intake of breath followed by no breath for several seconds. This can be upsetting to witness as the person seems to stop breathing only to start again. There might be one or two last gasps a minute or so after what seemed like the last breath, before breathing eventually stops. This is all completely normal.

Moment of Death

It's not always clear when the exact moment of death occurs.

When a person dies, those around them may notice that their face suddenly relaxes and looks peaceful. If the death isn't peaceful, it's unlikely that the person will have been aware of it. If anyone around the person finds it distressing, they can speak to a doctor, nurse, or bereavement counsellor.

The moment of someone's death is often very profound, even when you have expected it for a long time. You might want to talk to someone or call family and friends to let them know. You might prefer to be alone.

You may find comfort from just sitting with your loved one. Do not be afraid to hold their hand and talk to them if you wish.

If you have been caring for the person you might feel exhausted, and the relief and finality of the moment of death can take you by surprise.

Some people feel overwhelmed with sadness, for others it can take days, weeks, or months to process how they feel.

Every person's experience of dying and bereavement is unique.

Things you can do

- Sit with the person
- Hold their hand
- Moisten their mouth
- Play music/television quietly if these are things they enjoyed previously
- Read favourite books/poems/bible
- Look after yourself by eating and drinking regularly and getting some rest.
- Sharing the care enables everybody to get some rest.

What to do when someone dies at home

Even though you know the person is dying, and you can try to prepare yourself, it is hard to know how you might feel when they actually die. Some people feel shocked or numb, while other people might feel overwhelmed with sadness, or even anger.

It is also normal, particularly if it has been a long illness to feel a huge relief. You may find it helps if you have already thought of someone you can call who can be with you and support you at this time.

Confirming the person has Died

Although this is likely to be a very emotional time, there are still some formal things that need to happen. The first is confirming that the person has died. This is called verifying the death.

Following a death at home, please call the community nurse team, the contact number is in your yellow folder booklet. There is no rush to do this, take the time you may need to say important things and have those last special moments together. The Community Nurse will come as soon as possible to verify that the person has died. You are not required to call 999.

Verification of Death

There are some things that need to be done to verify the death, and some people prefer to leave the room when this is happening. This includes checking the person's pupils for any reaction, checking for breathing, and listening for their heart sounds with a stethoscope.

Now a Registered Nurse has visited and verified the death, they will fill in a Verification of Death form and send this to the GP of the person who has died. There is no formal documentation given to the family at this time as evidence of the death but the funeral directors will be aware that nurses are able to verify death in the community.

Once the GP receives the documentation for the verification of death from the Nurse, they complete a Medical Certificate of Cause of Death. This is a legal document which can only be completed by the GP.

This is then sent to the Medical Examiner who will be in contact to explain the cause of death and to answer any questions you may have. There may be delays in this process, it is advised to contact the funeral director who will be able to speak with the Medical Examiner on your behalf to follow up, if required. Once the Medical Examiner has approved the details they will send this to the Registry Office. Then an appointment will need to be organised with the Registrar to arrange collection of the formal Death Certificate.

The time of death will be when the nurse formally verifies the death. You do not need the Death Certificate immediately to begin arrangements for the funeral. The funeral directors will be able to offer ongoing general advice and guidance.

Return all medications back to a pharmacy at a time convenient to you within the next week. This includes controlled drugs. Some pharmacies will also take sharps boxes. If they are unable to they will advise where this can be taken.

You may have some medical equipment in the property, this can be returned by phoning Medequip. Contact details for this will be found on the yellow sticker on the equipment. They will be able to advise when they can collect this.

If there is oxygen in use in the home this will need to be collected, there will be details on the oxygen tanks of who the provider is.

The Nurse will have asked to see the RESPECT form. You can keep this for your own records if you wish to do so. If there is a chart used for anticipatory medications, this will be taken by the Nurse and scanned onto the patient's medical record.

Registering the Death

Registering your loved one's death is one of the first things you need to do after you have received the medical certificate of cause of death (MCCD). You can start planning their funeral beforehand, but you will not be able to actually hold it until you have registered their death. Legally, you need to do this within five days of receiving the medical certificate of cause of death (MCCD).

You can register a death at any register office, but if you use the one in the area where the person died you can receive the documents you will need on the day. If you use a different register office, the documents will be sent to the office in the area where the person died before they are issued to you. This means you will usually wait a few days. The one thing you absolutely must take with you is the medical certificate showing the cause of death.

When you register their death, you will be given:

- Death Certificates – These are all certified copies of the original entry which stays with the Registrar and are usually a light green colour. You can request as many of these as you wish, though there will be a charge for each copy. If anyone asks you for an original Death Certificate, this is what they mean.
- Certificate for Cremation or Burial – Commonly referred to as the "Green Form" this allows the Funeral Director to officially go ahead with the funeral arrangements.
- BD8 - Registration of Notification of Death – DWP – You might not need this if you are offered the **Tell Us Once** service (Tell Us Once-GOV.UK) to notify the Government organisations of the death, but please note this service is not available in all areas. The Registrar will be able to tell you whether this is available.

Arranging a funeral

If you have not already organised/planned the funeral, it is worth doing a little bit of thinking and planning to give you confidence and reassurance.

Check if the person who died left any instructions about what they wanted - some people leave instructions in their Will, or they may have left some informal notes, or simply have talked it through with someone close to them.

They may have left instructions on whether they would like to be buried or cremated. There might also be a particular place where they would like the service to be held. They may have chosen readings or music that they would like to be played. If they have not left any instructions, you may want to talk with family members about these different choices.

You do not need to wait until the person has died to start planning their funeral. Sometimes it can give the person approaching the end of their life reassurance to know that some of the arrangements are already in place.

The funeral director will need the Certificate for Burial or Cremation (the 'green form') and the MCCD in order to start organising the funeral.

You can arrange a funeral without the help of a funeral director. If you wish to do this, contact the Cemeteries and Crematorium Department of your local authority for advice and guidance. www.norwich.gov.uk/cemeteries

Informing Organisations about the Death

The Registrar Offices operate an appointment only system.

To make an appointment you can either phone Norfolk County Council Customer Service Department 0344-800-8020 (9am to 5pm, Monday to Friday) or via their website www.norfolk.gov.uk/registrationservices

When someone dies, you must contact certain organisations to let them know as soon as possible. There is a service called **Tell Us Once** (Tell Us once-GOV.UK) which will contact several government departments about the death in one go.

You will need to return the person's drivers licence to the DVLA and their passport to HM Passport Office.

How to register a death: <https://www.gov.uk/register-a-death>

What to do when someone dies: Step by Step: <https://www.gov.uk/when-someone-dies>

Tissue Donation Enquiries: 0800 432 0559

Stair lifts: Please contact original company who installed stair lift for details on how to get it removed.

You may need to contact other organisations as well, such as:

- Personal or occupational pension scheme providers
- Insurance companies
- Banks and building societies
- An employer or trade union
- A mortgage provider, private landlord, housing association or council housing office
- Social services if the person received community care
- Utility companies
- Their GP, dentist, optician and anyone else providing medical care
- Any charities, organisations or magazine subscriptions the deceased person made regular payments to.

Dealing with the Persons' Estate and applying for Probate

What you need to do to deal with the estate – the money, property, and possessions – of the person who has died depends on whether they made a valid will and, if they did, whether you are named as an executor in that will.

If they did make a valid will and you have been appointed as an executor, then you will need to apply for a grant of probate to deal with the estate. Probate is the legal process of distributing someone's estate after they die.

Getting Support with Bereavement

People experience loss and grieve differently; it is entirely individual. You might not need bereavement support now; however, you might need it later or another member of your family may need some support.

Information on bereavement support can be found on the Norfolk and Waveney knowledge NoW website <https://nwknowledgenow.nhs.uk>

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