



Planning care at the end of life – for patients and carers



Information for end of life

Caring for our loved ones at the end of their life is distressing and can be overwhelming for families, loved ones and carers. During this challenging period following the COVID-19 pandemic, and NHS pressures there is understandably increased anxiety. We would like to assure you that we are working hard to continue to offer the best possible palliative care and support services.

In line with Government and NHS guidelines, your GP, district nurse, care workers and others will not always be able to physically visit; however we will be using technology and alternative routes to reach and support you. We have developed this Information and Guidance booklet to help with questions or worries you may have. It includes practical advice contact details of organisations and websites for further information and support.

Planning ahead

If someone is approaching the end of life, they may want to record their views, preferences and priorities about their future care. Planning ahead like this is sometimes called **advance care planning**. It involves thinking and talking about your wishes for how you wish to be cared for in the final months of your life and when you are dying. No one is obliged to carry out advance care planning, but it helps to make sure your wishes are known and shared appropriately. Your health professional may ask whether you want to fill in an Advance Care Plan with them.

Examples of things you might want to include:

- the name of a person/people you wish to be consulted on your behalf at a later time
- where you would like to be cared for
- who you would like to be with you
- how your religious or spiritual beliefs are reflected in your care

If you have an Implantable Cardioverter Defibrillator (ICD) you may also wish to discuss and agree what would be the best time to deactivate the device. Your family and carers will know that a plan is in place and the healthcare professionals will be able to carry out your wishes as agreed. Deactivating the defibrillator at an earlier planned time does not mean that your heart will stop beating and cause death. This will reduce any distress, discomfort (painful electric shocks) and confusion if the ICD has to be deactivated in an emergency.

More Information and a template form can be found on the websites listed below:

[**www.advancecareplan.org.uk**](http://www.advancecareplan.org.uk)

[**www.england.nhs.uk/coronavirus/publication/advance-care-planning-guidance-and-template**](http://www.england.nhs.uk/coronavirus/publication/advance-care-planning-guidance-and-template)

[**www.compassionindying.org.uk/making-decisions-and-planning-your-care**](http://www.compassionindying.org.uk/making-decisions-and-planning-your-care)



An advance decision to refuse treatment

Sometimes called a living will or advance directive is a decision you can make to refuse a specific type of treatment at some time in the future.



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

The treatments you're deciding to refuse must all be named in the advance decision. You may want to refuse a treatment in some situations, but not others. You need to be clear about all the circumstances in which you want to refuse this treatment.

You should talk to your GP or nurse about the kinds of treatments you might be offered in the future, and what it might mean if you choose not to have them.

An Advance Decision to Refuse Treatment will only be used if at some time in the future you are not able to make your own decisions about your treatment.

More Information is available on the NHS website:

www.nhs.uk/conditions/end-of-life-care/advance-decision-to-refuse-treatment/

The charity Compassion in Dying has an advance decision form you can fill in online or by hand, with suggestions for things to think about. Visit:

www.compassionindying.org.uk/choose-a-way-to-make-an-advance-decision-living-will/

Planning ahead for your future treatment and care:

www.mydecisions.org.uk

ReSPECT



ReSPECT stands for Recommended Summary Plan for Emergency Care and Treatment. The ReSPECT process creates a personalised recommendation for your clinical care in emergency situations where you are not able to make decisions or express your wishes. It also includes your wishes on resuscitation.

Decisions Around Resuscitation:

Cardio-Pulmonary Resuscitation (CPR) is a treatment that attempts to restart 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 lung

In many cases CPR isn't successful at restarting a person's heart and breathing. If you have a long-term or chronic condition or a terminal illness, then it's much less likely to work. The methods used in CPR can have side effects such as bruising, cracked or broken ribs and/or punctured lungs.

Everyone has the right to refuse CPR if they wish. You can make it clear to your medical team that you do not want to have CPR if you stop breathing or your heart stops beating. This is called a DNACPR – Do Not Attempt Cardio-Pulmonary Resuscitation. This conversation may also form part of your ReSPECT conversation with your health care professional.

Once a DNACPR decision is made, it's put in your medical records, on a ReSPECT form that health professionals will

recognise. You should let your family or other carers know about your DNACPR decision, so it does not come as a surprise to them if the situation arises.

A DNACPR order is not permanent, and your DNACPR status can be changed - please discuss with your healthcare professional. Even if someone has agreed to a DNACPR this does not mean that they will not be offered other forms of treatment for example antibiotics and pain relief medication.

You can find out more in the Resuscitation Council's leaflet about CPR (PDF, 48kb). Visit: www.resus.org.uk/respect

Making a Lasting Power of Attorney (LPA)

You may choose to give another person legal authority (making them an 'attorney') to make decisions on your behalf if a time comes that you are not able to make your own decisions. This can be a relative, a friend or a solicitor.



A Lasting Power of Attorney (LPA) enables you to give another person the right to make decisions about your property and affairs and/or your health and care.

There are special rules about appointing an LPA. You can get a special form from the Office

Further information: www.gov.uk/power-of-attorney

End of Life

Support for people at End of Life in the community is available from a number of different health and social care partners as well as the voluntary sector. These include your GP, district nurses, your local hospice, Social Care's Intermediate Care Teams and the ambulance services.

Hospice contact details:

- **East Berkshire** - Thames Hospice day or night - 01753 848925 for support on palliative or end-of-life care. www.thameshospice.org.uk/
- **Surrey Heath or North East Hampshire and Farnham** - Phyllis Tuckwell Hospice - 01252 729400
OOH night service - 01252 729 440
www.pth.org.uk/our-care/

Community Nursing Teams contact details

- **Surrey Heath** - Mon-Fri 8am-8pm - 01276 539660
Weekends and bank holidays - 0300 6138000 opt 2
8pm-8am - 07815 991382
- **East Berkshire** - via Health Hub 365 days 24/7 - 0300 365 1234 Bks-tr.hub@nhs.net
- **North East Hampshire** - Mon-Sun (including bank holidays) 8am-11pm - 0300 003 0050
Out of hours 11pm-8am help via - 111 or 999
- **Farnham** - 8am-8pm - 01483 908169
8pm-8am - 0781 5991382 seven days a week

Everyone's experiences are different, but there are changes that sometimes happen shortly before a person dies. These include loss of consciousness, changes to skin colour and changes to breathing.

When someone's dying, the body slows down and shows signs that the person is approaching the end of their life, although not everyone will have these symptoms.

It's difficult to predict what will happen but knowing some of the possibilities provides a chance to think ahead and prepare.

Changes to appearance

Some people lose weight and muscle and look thin or frail. This can be caused by their illness, treatment or loss of appetite. Other people gain weight or have swelling or puffiness, sometimes called oedema (fluid build-up). This can be caused by their illness or sometimes by certain medicines.

Feeling weak and very tired

Some people may need to spend more time in a chair or in bed as everyday activities become too tiring. Needing to sleep more than usual is normal, and they may drift in and out of consciousness. Try to imagine what the person you are caring for would want. Provide familiar sounds and sensations, a favourite blanket for example, or piece of music. Keep the environment calm by not having too many people in the room at once and avoid bright lighting. This can reduce anxiety even when someone is unconscious. Even when they cannot respond, it is important to keep talking to them as they can most probably hear right up until they die.



Feeling too hot or too cold

This happens because the body isn't regulating temperature as well as it used to. People can be kept comfortable by making practical changes like using blankets or opening a window. They may have a fever. Fever is when your temperature goes above the normal range of 36-37degrees centigrade. You can help by turning down the heating, wearing loose comfortable clothing, cooling the face by using a cool flannel, and drinking fluids.

Normal body temperature: 37°C (98.6F)



Body fever temperature: > 37.7°C (100°F)



Eating and drinking

It is usually recommended that we drink about 6-8 glasses of fluid every day to stop us getting dehydrated. However, when someone is nearing end of life they may not want to eat or drink. There are some foods that can help keep them hydrated, such as custard, jelly, soup and fruit. You should always follow their lead – they will let you know if they want to eat or drink.



More Information at:

www.nhs.uk/live-well/eat-well/water-drinks-nutrition/

www.nhs.uk/live-well/healthy-weight/keeping-your-weight-up-in-later-life/

If people are still eating, their tastes can change and they may not want to eat at the same times every day. Some people have difficulty with swallowing, a sore or dry mouth, or feel sick. Smaller portions may help. If the person feels thirsty and has problems swallowing, taking small sips, sucking on ice chips or swabbing their mouth might help. It's important not to force food or drink onto someone who no longer wants it.

Mouth care

It is important to maintain good oral health and look out for any changes in a person's mouth. Gum disease and poor oral health may increase the risk of all kinds of other health complications, including lack of appetite or malnutrition.

The way to improve gum conditions is to gently brush the bacteria away. Frequent brushing of teeth is important for people who are unable to take any food or drink orally. It is better to spit out after brushing and not rinse, leaving a little toothpaste in the mouth. A soft headed toothbrush is recommended as it may be easier to tolerate. Sugary foods and drink should be reduced, and ideally kept to mealtimes.



People rarely complain of thirst at the end of life; however a dry mouth can be a problem due to breathing mostly through their mouth. It's important to keep lips moist with a small amount of un-perfumed lip balm to prevent cracking. Regularly wet inside their mouth and around their teeth with a moistened toothbrush whether he or she is awake or has lost consciousness. Check for sore areas and white patches on the tongue, gums and inside the cheek which can be sore. If this happens let the GP or district nurse know as this can be easily treated.

Coughs

Cover the nose and mouth with a disposable tissue when sneezing, coughing, wiping and blowing your nose.

Dispose of used tissues promptly into a closed waste bin.

To help settle a cough:

- Drink fluids
- Drink honey & lemon in warm water
- Suck cough drops / hard sweets
- Elevate the head when sleeping
- Avoid smoking

Wash hands thoroughly with soap and water for 20 seconds, especially between fingers and palms of hands.



1



Apply soap
on wet hands

2



Rub palm
to palm

3



Now, focus on
the back of
your hands

4



Interlace
your fingers

5



Clean thumbs

6



Rub nails and
fingertips against
your palms

Breathlessness

Some people feel breathless. It can be made worse if the person is anxious. Breathing may become loud if mucous phlegm has built up in someone's throat or airways. Changing the way someone is sitting or lying down can help with this. Leaning forward, sitting up straight, with legs uncrossed and keeping your head forward are positions that could help. Relaxation techniques and mindfulness breathing exercises can help with breathlessness. Before someone dies their breathing often becomes noisy. Try not to be alarmed by this, it is normal. It is due to an accumulation of secretions and the muscles at the back of the throat relaxing.

For more information on breathlessness visit:

www.nhs.uk/conditions/shortness-of-breath/

Forward lean 1



Forward lean 2



Adapted forward lean for lying



Adapted forward lean for sitting



Delirium

Delirium is when someone becomes very confused due to their illness. It can happen suddenly and can last for a few hours or days at a time. People may become agitated or withdrawn and this can be upsetting and distressing for their family and carers.

Help someone with delirium feel calmer:

- talk to them in short, simple sentences; check that they have understood you, repeat things if necessary.
- try not to agree with any unusual or incorrect ideas, but tactfully disagree or change the subject
- reassure them
- help them to eat and drink
- have a light on at night so that they can see where they are if they wake

Pain

Pain at the end of life is something that many people worry about. Not everyone gets pain and with the right treatment and support, pain can usually be managed. Your GP will prescribe pain relief and help you manage pain.



Your doctor or nurse will start using the weakest painkiller available that keeps you free from pain. In order of strength (starting with the weakest) these are:

- non-opioid painkillers, such as paracetamol
- weak opioids, such as codeine
- strong opioids, such as morphine

Some of these painkillers can cause constipation so your GP or nurse may also prescribe a laxative to soften stools.

The first step is to take them by mouth (orally). If this is not possible – for example, if you have difficulty swallowing or vomit – painkillers can be given:

- through an injection under the skin (subcutaneous route)
- through an injection into the muscle (intramuscular route)
- directly into a vein (intravenous route)

Sometimes a small battery-operated pump called a syringe pump (also known as a syringe driver) is used to give medicine continuously into your body just under the skin for a period of time, such as 24 hours.

There are also some strong painkillers that can be given through a patch on the skin.

Your GP, community nurses or the Specialist Palliative Care nurses at your hospice will be able to help you manage pain.

Hospice contact details:

- **East Berkshire** - Thames Hospice day or night - 01753 848925 for support on palliative or end-of-life care: www.thameshospice.org.uk/
- **Surrey Heath or North East Hampshire and Farnham** - Phyllis Tuckwell Hospice - 01252 729400 www.pth.org.uk/our-care/

Contact your GP if you need a prescription

Your GP may be able to send this through directly to a pharmacy of your choice or you may need someone to pick it up for you and take it to the pharmacy. You can ask a neighbour, family member or friend if they can pick up your medicines for you from the pharmacy. If you are in need of medication quickly, tell your GP and pharmacist – it may be possible for the pharmacy to deliver the medication. You or your nurse can also check with your pharmacy that they have your medication in stock. If they need to order it in, it may take longer. There are specific pharmacies that stock End of Life care medicines. Your GP or nurse may know which pharmacy local to you stocks end of life medication. This is called Just in Case Medication, and may already be in the home. Your district nurse will know if it is already there.



More information is available on the NHS website:

www.nhs.uk/conditions/end-of-life-care/controlling-pain-and-other-symptoms/

In an emergency situation, your pharmacy may be able to supply you with your ongoing medications, if you have already been receiving these. Some medications have extra rules and cannot be supplied in this way. Call your usual pharmacy for support and advice in the event of an emergency.

Helping someone with their medication

Managing medicines for a person you look after can be confusing, particularly if they are taking several different medicines.

Medication should always be given either according to the instructions on the label as prescribed or according to the instructions on the original packaging.

Not doing this could mean the medicine works less effectively. You also need to know whether or not the medicines should be taken before food, with food, or after food.



Further information for carers supporting someone with their medication: www.mariecurie.org.uk/help/support/being-there/caring/medication

Nausea and vomiting (feeling and being sick)

Lots of things might help with nausea including trying different foods or drinks, eating small portions, and activities that are distracting or relaxing. If the person is vomiting and unable to sit up, turn the person on their side to protect their airway.

Moving someone safely

When someone is very unwell, they may need help with getting in or out of bed, or turning over, and showering, bathing and using the toilet, or even getting up from a chair and walking about.

It is best to get someone to demonstrate the correct techniques. Contact your community nurse to ask for advice, they may signpost you to an occupational therapy service that will be able to recommend equipment and training to help you with lifting and moving safely. Also, the council may provide free equipment – such as stand aids, transfer boards or slide sheets – to make moving someone safer and easier.

The **Disabled Living Foundation (DLF)** has factsheets on how to move or lift someone safely.

More Information is available on the the NHS website:

www.nhs.uk/conditions/social-care-and-support-guide/practical-tips-if-you-care-for-someone/how-to-move-lift-and-handle-someone-else/

Washing

If it is too disruptive for the person to have a full wash, just washing their hands and face and bottom can feel refreshing.



To give a bed bath, use two separate flannels, one for the face and top half of the body and one for the bottom half. Start at the top of the body, washing their face, arms, back, chest, and tummy. Next, wash their feet and legs. Finally, wash the area between their legs and their bottom. Rinse off soap completely to stop their skin feeling itchy. Dry their skin gently but thoroughly.

Only expose the parts of the person's body that are being washed at the time – you can cover the rest of their body with a towel. Contact your district nurse to ask for advice on help with washing and dressing, they may signpost you to your local council providing health and care services.

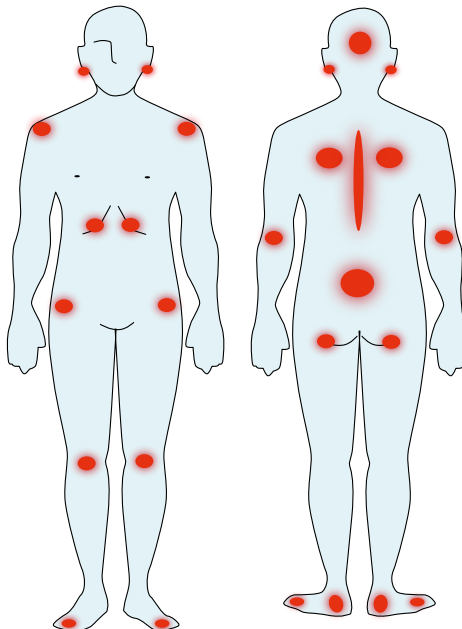


Preventing pressure ulcers (pressure sores)

Maintaining good skin condition is really important. The parts of the body that are at higher risk of developing pressure damage are shoulders, elbows, back of the head, rims of the ears, knees, ankles, heels or toes, spine and tail bone. Supporting and encouraging a person with regular changes of position (every 2-4 hours) is important to prevent and maintain good skin condition. You can use pillows or rolled up towels to support them and also to support under their arms and between and under their legs.

Wheelchair users are at risk of developing pressure damage on the buttocks, the back of arms and legs and the back of the hip bone.

For more Information visit: www.nhs.uk/conditions/pressure-sores



Incontinence

At end of life many people have symptoms of bladder or bowel incontinence. This can be embarrassing for people. There are a range of options to help you manage including incontinence pads you wear inside your underwear, absorbent pads for the bed, and catheters.

It is important to keep the skin clean and dry to prevent skin irritation or infection. The community nurse can give you more information on incontinence products, supply you with incontinence pads and recommend barrier creams and films.

Information on changing sheets if the person cannot get out of the bed can be found at the website below.

Even though we expect someone to go to the toilet less as they eat and drink less, contact the community nurse if they have not passed any urine for 12 hours or more as it can be uncomfortable.

www.mariecurie.org.uk/help/support/being-there/caring/moving-someone-bed

Bowel care

Constipation is a common problem for people at end of life. It can be either a direct effect of your illness, or a side effect of medications used to treat pain. Contact your GP if constipation persists for more than 4 days. If you're taking opioids – such as morphine, codeine or oxycodone – you should be prescribed laxatives at the same time, which you can take to prevent constipation happening as a side effect. If you're prescribed laxatives, it's important to keep taking them regularly, even after you have had a bowel movement. This helps to stop you getting constipated again. Diarrhoea can be caused by side effects of treatments or medications. If you see blood or pus in your stool, you should talk to your nurse or GP. You should not take anti-diarrhoea medicine without seeing a doctor or nurse first as, in some cases, it can make things worse.

Caring

You may be feeling anxious or worried about someone you know with a terminal illness or if you are responsible for someone's day-to-day care. Caring for a dying person can be exhausting both physically and emotionally. Take time out to eat and rest. Try to share the care with other people when possible and remember it is OK to leave the person's side.



There are things you can do which could help:

- Try to eat healthy, balanced meals.
- Spend time doing things you enjoy, like reading or watching TV.
- Open the windows to let in some fresh air.
- Reach out if you need support – connect with family, friends and neighbours.
- Connect with others in a similar situation on social media or an online community, like the Carers UK forum.

You can contact your local carers support service at:

- **Windsor and Maidenhead**
www.rbwm.gov.uk/info/200178/carers
- **Bracknell Forest** www.signal4carers.org.uk/
- **Slough** www.sloughcarerssupport.co.uk/
- **North East Hampshire and Farnham**
www.northeasthampshireandfarnhamccg.nhs.uk/support-and-services/advice-for-carers
- **Surrey Heath Action for Carers** - 0303 040 1234
- **Carers UK** www.carersuk.org/home

The charity Mind has information about taking care of yourself if you're feeling anxious, www.mind.org.uk/ and you can also contact your local Improving Access to Psychological Therapies (IAPT) team. You can refer yourself to this service without a referral from your GP. For contact details of your local IAPT team see page 32.

Make a plan so you are prepared if circumstances change. Write up the key health and care information of the person you are caring for. This will make it easier for other people to step in if you are no longer able to care for them.

Support from the council

It can be reassuring to have the local council involved in case other arrangements fall through or if you don't have a back-up carer. You can have a carer's assessment with the local authority to assess your needs. The Marie Curie website provides information on carer's assessments:

www.mariecurie.org.uk/help/support/being-there/support-carers/assessments

If you're not able to care for your friend or family member and there isn't a back-up carer, the Council should be able to help. They might arrange for a professional carer to come to your friend or family member's home, or they might arrange for them to go into a hospice or nursing home.



Staying safe

Infections can spread very quickly. When someone with a respiratory illness or other infectious diseases. Bacteria, viruses and large droplets can land on to objects and surfaces around them. It can then be passed on to another individual if they touch the objects or surfaces and then touch their mouth, nose and eyes.

Cleaning and disposal of waste

Use your usual household products, like detergents and bleach to clean, as these will be very effective. Clean surfaces frequently such as door handles, handrails, remote controls and table tops.

Personal waste (such as used tissues) and disposable cleaning cloths, from an infected individual, should be stored securely within disposable rubbish bags. These bags should be tied securely and placed directly into the bin.

Laundry

To minimise the possibility of dispersing bacteria and viruses through the air, do not shake dirty laundry.

Wash items as appropriate in accordance with the manufacturer's instructions. All dirty laundry can be washed in the same load.



Support from volunteers

There are lots of ways volunteers are supporting people who need help. Some of the ways volunteers are helping out include:



- helping with shopping and running errands for those who are self-isolating
- driving people to/from health appointments or other essential appointments
- helping to organise food deliveries from food banks and/or supermarkets
- running online wellbeing classes for people
- online or telephone befriending to those who need to stay indoors

If you need help with any of the above you can contact your local council or Council for Voluntary Services.

- **For Windsor, Ascot and Maidenhead**
www.rbwm.communitydatabase.co.uk/
- **For Slough** sloughcvs.org/residents/
- **For Bracknell Forrest** Involve Community Services - Making a Difference Locally involve.community/
Call Centre: 020 3514 8117
- **For Surrey Heath and Farnham** Find a Good Neighbour - Surrey Community Action
www.surreyca.org.uk/find-a-good-neighbour/
For deaf and hearing impaired residents only (Mon-Fri 9am-5pm)
SMS: 07860 053465 Brigitte Trust - provide practical, emotional and social support to people with life limiting illnesses.
07469 932192 Email: referrals@brigittetrust.com
www.brigittetrust.org
- **For North East Hampshire** Helpline - Hantshelp4vulnerable
0333 370 4000 (Mon-Sun 9am-5pm)

Signs that someone is close to dying

- Their pattern of breathing may change shortly before death, when they are already unconscious.
- There may be long gaps between breaths or between a run of breaths.
- Then the breathing stops completely.
- Their colour changes and they look very pale with a bluish tinge, and gradually their skin looks mottled.
- Their heartbeat is no longer felt by a hand on their chest.

What to do when someone dies at home

When you are able, write down the time you think they died. If you feel you can, put a pillow or rolled up towel under the jaw to support their mouth closed and close their eyes, by gently pressing the eyelids closed for 30 seconds. If you can, lie their limbs straight. There is nothing more you need to do.

When someone dies at home, the death needs to be verified, this is done by making certain checks to be sure that the person has died. If there is no healthcare professional with you, you will need to call your GP, or if it is out of hours (after 6.30pm Mon-Fri, weekends, and bank holidays) call NHS 111.

Health professionals will be wearing protective clothing and there will be additional precautionary measures in place to protect you and other family members living in the house, and themselves if deemed necessary.

Your GP will then complete a Medical Certificate of Cause of Death as soon as possible. This may be in person or carried out by video call. Once you have a medical certificate you will need to register the death with your local registrar. It is normally a family member who registers a death; however other people can also do this.

There are a number of documents you will need to help you provide information for registering the death, such as birth and marriage/civil partnership certificate and passport. The registrar will most likely communicate with you by phone and email rather than in person. The registrar will send you the information and forms you need to make the funeral arrangements. You cannot make any arrangements until you have completed all the necessary paperwork.

If the GP is unable to give an acceptable cause of death or has not seen the patient in person or by video within the last 28 days, and has not seen the patient in person or by video after death, the GP will report the death to the Coroner for investigation.

The coroner will carry out enquiries to try to find the cause of death. If the cause of death is not clear during the enquiries there may need to be an inquest. The coroner's office will answer any questions you may have and keep you informed of everything that is happening and after completion of the investigation, the Coroner will certify the cause of death, or may give permission for the GP to issue the death certificate.

You can find your local register office online:

www.gov.uk/register-offices

For more information visit: www.gov.uk/register-a-death

Further information about what you need to do when someone dies can be found at: www.gov.uk/after-a-death

Medicines

Any unused medication should be returned to the supplying pharmacy. When returning medicines to the pharmacy, place the unused medication in a bag and tie or seal the bag. Place this bag into another secure bag. Tell the pharmacy staff if the medicines belonged to a patient with COVID-19 so that infection prevention and control precautions can be taken.

If the person you looked after had any NHS equipment on loan, e.g. bed, crutches, wheelchair or medical equipment, you will need to arrange for this to be returned – your GP or local hospital will be able to tell you how to do this. If social services or another support service supplied the equipment, contact them to find out how it can be returned.

Bereavement

Bereavement, grief and loss can cause many different symptoms and they affect people in different ways. There's no right or wrong way to feel. These resources may be of help.

If you are bereaved and would like to speak with someone, you can call:

- **Cruse Bereavement Care**
Surrey Heath and Farnham - 01483 565660
Hart and Rushmoor - 01264 336006/01264 335569
Thames Valley Berkshire covering Wokingham, Bracknell, Slough, East & Central Reading, Windsor, Maidenhead and surrounding areas - 01344 411919
www.cruse.org.uk
- **Brigitte Trust**
07469 932192 (Surrey Heath & Farnham)
www.brigitte-trust.org referrals@brigitte-trust.com
- **Marie Curie**
0800 090 2309
To contact a nurse or trained staff member email: support@mariecurie.org.uk or contact them on web chat or visit: www.mariecurie.org.uk/help/support/bereaved-family-friends
- **Thames Hospice** provides pre and post bereavement services, including specific services for children and young people
www.thameshospice.org.uk/patients-emotional-support

- **Phyllis Tuckwell Hospice Care** provides a bereavement programme for people whose loved ones have died under the care of Phyllis Tuckwell
01252 729430 or
Email: pafs@pth.org.uk.
- **Independent Age** provides information and advice on a range of subjects including welfare, legal and financial
0800 319 6789
www.independentage.org/information/personal-life/grief-chat
- **A Child of Mine** provides emotional and practical support to bereaved parents and families
01784 283434
www.achildofmine.org.uk
- **Daisy's Dream** provides support and information to bereaved children and families, working predominantly in Berkshire and the surrounding areas
01189 342604
www.daisysdream.org.uk

Improving Access to Psychological Therapies (IAPT)

For East Berkshire

- Talking Therapies
talkingtherapies.berkshirehealthcare.nhs.uk/
0300 365 2000

For Surrey Heath

- www.healthysurrey.org.uk/mental-wellbeing/adults/local-services
0808 802 5000 open 24 hours, 7 days a week

For North East Hampshire and Farnham

- Talk Plus - offer telephone, video calls, instant messaging and webinars.

www.talkplus.org.uk

TalkPlus website has a range of resources including MP3 downloads for different types of relaxation exercises, video clips and leaflets on how to deal with anxiety, depression and worry.

Facebook: [@talkplusiapt](https://www.facebook.com/talkplusiapt)

Twitter: [@TalkPlusNHS](https://twitter.com/TalkPlusNHS)

Instagram: [@talkplus_nhs](https://www.instagram.com/talkplus_nhs)

Useful resources

www.helixcentre.com/project-end-of-life-toolkit

Comfort box checklist:

Below are suggestions of items that may be useful to have at home to help provide comfort and support.

Mouth Care/ Dry mouth
<ul style="list-style-type: none"> Baby (or soft, small adult) toothbrush This may be used with toothpaste to brush teeth or may be used moistened with water to wet the inside of mouth, lips and gums if dry. Please see Mouth Care on Page 11.
<ul style="list-style-type: none"> Non foaming toothpaste Reduces the amount of excess toothpaste needed to be spat out.
<ul style="list-style-type: none"> Lip Balm Use to keep the lips moistened and prevent cracked and sore lips. Unflavoured may be preferred, though a flavoured one could be used if preferred by the individual. If oxygen is being used, avoid lip balms or gels containing petroleum (such as Vaseline) as these would be a fire risk. Use water-based or non-petroleum containing ones, which are available from pharmacies, supermarkets or on-line. KY Jelly, a water-based lubricant, could also be used.
<ul style="list-style-type: none"> Ice cube/ ice chips/ice lolly Gently rubbing a small ice-cube around the mouth or using ice chips may moisten the area and may be soothing for some people. Sucking on an ice lolly could also be used.
<ul style="list-style-type: none"> Tinned pineapple cubes cut into small chunks A small chunk can be sucked and will give a feeling of cleaning the mouth at the same time
<ul style="list-style-type: none"> Drinking Straws (or teaspoon or plastic medicine syringe) Small sips of fluid can be comforting and help moisten a dry mouth, if the person can swallow safely.
<ul style="list-style-type: none"> Soap alternative (e.g. Zerolatum) or Baby wipes/ dry conti wipes Gentle use of a soap alternative or gentle wiping with wipes can help the person feel freshened up.
<ul style="list-style-type: none"> Hand lotion Some individuals may find it relaxing to have hand-lotion gently rubbed on their hands by a loved one; the gesture of the touch may bring comfort and closeness.
Toileting needs
<ul style="list-style-type: none"> Bed pans, bottles, commodes, incontinence pads, bed pads etc Many items are available from pharmacies, supermarkets, specialist mobility stores and on-line. Your nursing team could help you decide if any would be useful for you to have and may be able to supply some of these items; others may be purchased.





General

- **Disposable gloves and aprons**

If desired, gloves and aprons could be worn whilst performing care. If there is a risk of infection such as coronavirus, use disposable items carefully discarding after single use is advised; please follow the infection control guidance at the time.

- **Face masks/ eye protection**

Protective items such as face masks, eye protector goggles and face visors may be necessary as infection control measures, as recently seen during the coronavirus pandemic. Clear face visors would allow the face of the carer to be seen. Please follow the infection control guidance at the time.

Personalised items

- **Reading/music**

You could consider playing music in the background or reading out loud from books if this is something your loved one would enjoy.

- **Background sounds - music/radio/television**

Having some “noise” on in the background instead of total silence can be a useful distraction from what can be the fear or intensity of total silence. It can give something for the person to focus on rather than perhaps thinking in silence about their condition, and when family/visitors are present can provide a welcome alternative to talk about and prevent what can sometimes feel like too intense a focus on the person.

- **Religious/spiritual items**

If the individual has religious or spiritual beliefs, then having symbols of their faith present, or holding such items in their hands, could bring comfort and strength to them. These could be objects such as a religious book, rosary beads, a cross, comfort poems or other similar meaningful items for that person.

Leaflets

- **Various available**

There is information and advice available to help provide families with practical information and sources of support during the end of life. You may wish to have a look through and see if you feel it would be useful to have a few printed and ready to hand as reminders for when the person is nearing their final moments and after their passing.

Booklets and resources: mariecurie.org.uk

- **National organisations offer leaflets.**

Our local Phyllis Tuckwell Hospice Care has a wide range of leaflets including ‘What to expect when someone important to you is dying’ available here:

www.pth.org.uk/our-care/helpful-information/leaflets/

The information in this booklet has been collated from a number of different sources. The main source for the practical caring information is the Frimley Health and Care's Stop Look Care booklet.

Stop Look Care was originally devised jointly by Frimley Health and Care and Brighton and Hove CCG.

The booklet refers to a number of different websites which provide guidance and information.

Where we have taken information from a particular website, the link is provided at the end of the paragraph.

The websites used are:

Hospice UK - www.hospiceuk.org/

Gov.uk - www.gov.uk/

The NHS web-site - www.nhs.uk/

Carers UK Compassion in Dying - compassionindying.org.uk/

Resuscitation Council - www.resus.org.uk/

Marie Curie - www.mariecurie.org.uk

The Disabled Living Foundation - livingmadeeasy.org.uk/

Bladder and Bowel UK - www.bbuk.org.uk/

If you require translated copies of this booklet, please email: **frimleyicb.endoflifecare@nhs.net**

An electronic copy of this booklet can be found on the Frimley Health and Care website:

www.frimleyhealthandcare.org.uk/

Frimley Health and Care



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Frimley Health and Care website:
www.frimleyhealthandcare.org.uk

