

We continually evaluate our service to enable us to improve its quality for our patients and their families if you would like to be involved we have a small questionnaire for you to complete.

If you have any compliments, comments or complaints please tell a member of staff involved in your care at the time. If you prefer to talk to someone who is not involved in your care, please contact patient and liaison service (PALS) on:

Wycombe Hospital: 01494 425882

Stoke Mandeville Hospital: 01296 316042

Alternatively, you can email: [pals@buckshealthcare.nhs.uk](mailto:pals@buckshealthcare.nhs.uk)

### How can I help reduce healthcare associated infections?

Infection control is important to the well-being of our patients and for that reason we have infection control procedures in place. Keeping your hands clean is an effective way of preventing the spread of infections. We ask that you, and anyone visiting you, use the hand sanitiser available at the entrance to every ward before coming in to or after leaving the ward. In some situations hands may need to be washed at the sink using soap and water rather than using the hand sanitiser. Staff will let you know if this is the case.

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## Care in the last days of life



**What to expect when someone is close to death  
and what to do when they die at home.  
(expected death)**

**Safe & compassionate care,  
every time**

Many people worry about what changes to expect when someone is close to death, having more detailed information may help to reduce anxiety and allow for planning of care.

If you still have questions after reading this information, or simply want to be able to talk this through in person. Please do not hesitate to ask your Health Professional who will be happy to answer your questions and support you throughout this time.

### **Changes That Can Occur Before Death**

Everyone is unique but there are some common symptoms and changes that help to indicate that a person may be entering the last days of life.

These may include:

### **Reduced Interest in Eating and Drinking**

As people approach the end of their life and become weaker the desire to eat and drink reduces. Often small, easily, digested meals are all that can be managed, for others it may only be sips of fluids. However, there will come a time when the desire and need for food and drink stops altogether and the person may become unable to swallow

This can be difficult for families and carers, as we believe eating and drinking will help our loved ones get better. We may think that providing food for our loved one is an important part of caring and that they will become dehydrated. However, it is a normal part of the dying process that people will only be able to manage very small amounts of fluids and will eventually stop drinking altogether.

At this time your loved one may get a dry mouth, and this can be relieved by gently moistening their mouth with a small sponge on a stick. Your Healthcare Professional can provide these and will show you how to use them.

If the person still needs to take medicines at this time then these can be given either as an injections or via a syringe pump.

At busy times, there can be a considerable delay between your telephone call and the doctor's visit. We are aware that this delay can be distressing but ask for your understanding that the visiting doctor needs to balance the needs of all the patients who need visits for any reason.

The doctor cannot issue a Medical Certificate of Cause of Death as they do not know the person's medical history. However, they will inform your own doctor's surgery and you will then need to call the surgery the next working day to find out when the Medical Certificate of Cause of Death can be.

We recommend checking the Medical certificate of cause of death for accuracy before proceeding further.

### **Contacting the Undertakers**

Once the doctor has visited and verified the death, you can then phone the Undertaker or Funeral Director of your choice (if you have chosen to use one).

If there was a syringe pump in place when the death occurred, the Community Nurse will need to come and remove it, after the doctor has visited, but before the Undertaker comes.

The number to call will be in the community notes which were kept at the house. Alternatively, the Doctor may contact the Community team for you.

Once you have called the Undertaker, they will visit and will remove the body to their Chapel of Rest. Undertakers will visit at any time by arrangement, but some may charge more for visits made out of normal office hours.

The Undertaker will be able to give you more support and information about the process of registering the death, and also about what to do next.

## **What to do when someone dies**

When someone dies, there are a number of formalities that need to be completed. At this highly emotional time, it is entirely understandable that you may feel confused or anxious about what you need to do. This is a brief guide that outlines who you must tell, and how to register the death.

## **Informing The Doctor**

When someone dies at home, the first step is to inform a doctor in order for them to be able to verify the death. If it is an Out-Of-Hours doctor who does not know the deceased, then they will not be able to issue a Medical Certificate of Cause of Death, but they will still visit your home in order to confirm the death.

Please remember that, at this difficult and upsetting time, there is no rush to do anything and you may want to call a friend or relative to come and be with you.

If the death happens in the middle of the night, then you may decide to wait until your own GP surgery opens on the next day and then to call them directly.

If the death occurs within normal surgery hours, then simply phone your own family doctor, who will come and visit you and explain to you about the process for collecting the Medical Certificate of Cause of Death from the surgery when completed.

If the death occurs outside normal surgery hours, then you should call 111. You will speak initially to a Call Handler, and it is important at this point to inform them that the death was expected, otherwise they will assume that it has been an unexpected death and will call the emergency services.

Once you have spoken to the Call Handler, you will be called back by an Out of Hours clinician who will confirm all the details and make arrangements for a doctor to visit you at home.

## **Withdrawing From the World**

Over time, dying people become more drowsy and may spend more time asleep than awake. They will have little energy, and may take less interest in what is going on around them.

Eventually, the person may be unable to communicate and may become unconscious. We believe, at this time, that people can still hear, so talking to them or playing their favourite music may be comforting to them.

## **Changes in Breathing**

People who are short of breath are naturally very worried so the knowledge that a loved one is close at hand can be comforting. If needed, medicines are available which can help with the anxiety.

In the last few days or hours of life, the breathing patterns may change and sometimes long gaps between breaths can occur. You may hear a noisy rattle when the person breathes. This is the moisture in our lungs which we need to be able to absorb oxygen. When we become immobile and weak, we are unable to cough effectively and so moisture or mucus can build up and it is this which causes the “rattling” sound.

When needed, medication can be used to reduce the amount of mucus produced and changing the person’s position may also help. Sometimes however, once the mucus has built up, these measures do not relieve the problem completely. Usually, noisy breathing does not distress the dying person, but it can be upsetting for loved ones and carers.

When people are dying they often breathe through their mouth, causing their mouth and lips to become dry. Moistening the mouth with a small sponge on a stick and applying Lip balm or Vaseline can help to soothe the dry lips

Oxygen requirements may be reassessed and whilst it may be useful for some patients, for others, it may no longer be needed.

## **Changes In Appearance**

There may also be changes which occur to the person's skin near the end of life. It can become pale, moist and slightly cool before death. There may also be colour changes apparent, especially on the arms and legs.

## **Changes In Behaviour**

Sometimes, in the last few days of life, people may become muddled and confused. This is a normal part of the dying process. If necessary, they can be given some medication to help with this. However, most people become increasingly sleepy and die very peacefully.

## **Giving medicines – using a syringe pump.**

Often in the last days of life a syringe driver will be commenced. This syringe pump is used to deliver a constant dose of medicines usually over 24 hours. A small needle will be inserted just under the skin in the arm or tummy which the pump will be connected to.

A syringe pump means that the person can have the medicines they need and do not need a lot of injections.

Common Medicines used to relieve symptoms in the last days of life

Medicine	Reason for use	Notes
Morphine	Pain or Breathlessness	Alternatives for pain relief used are Oxycodone and Alfentanil.
Midazolam	Agitation and restlessness	
Haloperidol	Nausea and Vomiting	
Hyoscine	Chest secretions	Sometimes secretions will persist even when the medicine has been given.

## **How do I know if my loved one is in pain or distressed when they can't tell me?**

For lots of relatives there is a worry about whether their loved one has pain. Lots of patients can make a moaning or sighing noise when unconscious which is probably due to their breathing as a lot of people do when they are asleep. A good indication that someone may have some pain is a furrowing of the brow. If concerned call your health professional who can advise you.

## **I'm a Health Professional can I give my loved one an injection if they are in pain or distressed?**

We recognise that it can be difficult when watching your loved one in pain or distressed when you have the skills to help but it is also important for you to be the relative not the nurse or doctor.

If it is something that you are considering please talk to the nurses as they can talk you through the paperwork to help ensure that everything is recorded so that everyone knows what has been given. Also they will ensure that you have the correct numbers so that you can talk through these decisions with a health professional to give you some support.