

Comments, Concerns and Complaints

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

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 few days of life



Patient and Carer Information Leaflet

If you require a translation or an alternative format of this leaflet please call PALS on 01296 316042

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 to 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 providing food for our loved one is an important part of caring and there may be a concern about the person becoming dehydrated.

When a person is close to death, though it is possible to give fluids by a drip into the veins (IV) or under the skin (Subcutaneous), it is uncertain that this will prolong their life or help them feel better. The risks and potential benefits of fluids given at the end of life will vary from person to person and the team looking after your loved one will assess regularly.

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.

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 a member of staff who can assess them and reassure you or give analgesia if needed.

My loved one had talked about organ/ tissue donation. Is it possible and what do I need to do?

Lots of people are unsure about what they can donate. We have specialist nurses who can talk with you. If you think that this is something that you would like to discuss let the doctor or nurse know and they can contact the specialist nurse for you.

What if my loved one deteriorates when I'm not here ? If you are not around the nurses in the ward will call you to tell you so you can come in if you wish.

Care after Death

Everyone reacts differently to a death of a loved one and time will be given to you to be able to say goodbye to your loved one.

After death the person will be seen by a doctor or nurse to verify that death has occurred and then the person will still be cared for until they are taken to the mortuary.

When you are ready to leave the nursing staff will explain to you about collection of the medical certificate. If there is a need for a urgent release for burial due to spiritual, cultural or practical wishes this can be discussed and plans made to meet this need.

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. This is not a snub but is because of their low energy levels.

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.

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 used. 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. |

End of Life comfort measures

It is important to us to try and ensure that we meet you and your family's needs please let the staff in the ward know if there is something that is very important to you.

If possible a side room may be offered for privacy ,we will also place a purple rose on the door or curtain to ensure that your privacy is protected as this will indicate to other staff to check before entering your space. Loved ones can stay by the bedside and the ward staff will discuss with you about food and drink, parking etc.

Please feel free to bring in the persons own nightclothes, a special blanket for the bed, photos to help to make the space more homely.

Some families may want to be involved in assisting with their loved ones care, if you do please tell the nurses.

If you want to have a keepsake the nursing staff will be able to help you with this.

Spiritual, pastoral and religious care.

While support during this time can come from families and friends sometimes it helps to talk to someone who is independent.

The spiritual and pastoral team are very approachable and available to provide support to patients and their families and a member of staff would be very happy to contact them for you if you would like.