

## Pain

Pain is not always experienced when someone is dying but we must ensure that the patient is comfortable. You may be worried that there are signs of pain if the patient is restless, calling out or grimacing. Please let the nurses know as we will have pain relieving medicine already prescribed 'just in case'. This will be administered as an injection under the skin. If the symptoms recur we may suggest giving the medicine continuously using a pump. The ward staff may also ask the Supportive and Palliative Care Team to review your loved one's condition to give advice on this medication if it is needed.

## Agitation

It is natural for dying patients to become sleepier and less aware of their surroundings as things progress. Sometimes patients may become agitated or constantly restless. Your voice and touch will help to soothe and reassure your loved one and this is very important. The nurses can also administer further medications under the skin to alleviate restlessness if needed. It is also important that the nurses reposition your loved one and check the bed clothes are not soiled or causing discomfort. They will also check for other conditions such as urinary retention (when a patient is unable to pass urine properly resulting in an uncomfortable swollen bladder) to make sure your loved one is as comfortable as possible.

## Breathing

The pattern of breathing may change as death gets closer. It may become irregular with longer gaps in between. There may also be a noise due to secretions and fluid building up in the air passages. The nurses may wish to reposition your loved one

as well as to give medication under the skin to help to ease this symptom. At this stage if fluids are still being given by a 'drip', the team will talk to you about stopping or slowing the fluids to reduce the fluid build-up and ease the symptoms. As the breathing pattern changes you may also notice that the colour of the skin around the mouth and hands may become darker and their extremities such as hands and feet may feel cold to touch.

## Final moments of life

Not all patients show the changes described above (such as breathing changes, restlessness or much in the way of noticeable changes in their observations). This may make death appear sudden or without warning. This may also make it difficult for the hospital team to contact you if you are not present at the bedside when we do recognise that your loved one is about to die. We aim to do our best to keep you fully informed about your loved one's condition, but on occasion things can change quickly and without much warning. For most patients the final moments are very peaceful. Breathing stops altogether and often the body relaxes completely.

Following death the nurses will need to attend to your loved one and a doctor or senior nurse will need to examine them but we also wish to offer you comfort and support at this time and to ensure that before you leave the hospital, you feel that have had time with your loved one and that you know what to do next.

If you require this information in another format, such as a different language, large print, braille or audio version please ask a member of staff or email [patientexperience@uhb.nhs.uk](mailto:patientexperience@uhb.nhs.uk).



University Hospitals Birmingham  
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# Information for you when your loved one is dying

**Notes:**

The medical and nursing teams caring for your loved one have discussed with you that their condition has changed and despite all efforts, recovery is not thought possible and sadly your loved one is dying.

We hope this leaflet helps to support you during this difficult time. It is not meant to replace the face-to-face discussions you may wish to have with nursing and medical staff.

At this time it is crucial that the care your loved one now receives is focused on comfort and control of symptoms. There may be many concerns that you may wish to discuss with us. Please do request to speak to a nurse or doctor if you have any questions.

## **As a family member or friend, what can we do to help?**

You may wish to help with your loved one's care and worry that moving them may cause distress. Please talk to us about this so we can answer your questions and include you in care planning if that is what you would like. As your loved one becomes less responsive it is important for them to still hear your voice, so please carry on talking to them and to each other. If possible we will offer you a camp bed to rest on as it is important that you try and rest yourself, especially if you are spending long periods of time at the bedside. We will also try and offer you a single room so that you and your loved one have private family time together. Please tell us about your loved one's life as we may not have known them when they were well.

## **When can we visit?**

You can visit at any time so you can be there to

support your loved one, but please respect that staff may ask you to leave the room on occasions, if they are offering intimate personal care to your loved one. We will offer you refreshments whenever possible however there is also refreshment facilities within the hospital that offer meals and drinks for relatives and visitors. Please ask a member of the ward team for further information.

## **Preferred place of care?**

It is important that we discuss with you any preferences that you or your loved one may have with regard to where they wish to be cared for at this time. It may be possible for the hospital team to explore continued care at home. Alternatively, your loved one may have already had contact with a hospice team and may prefer to be cared for in a hospice setting, if this can be arranged. Any decisions about moving your loved one to their preferred care setting will be discussed fully with you and the ward team may refer to other specialists to help co-ordinate this.

## **Emotions and feelings**

Many of us find it difficult to talk about dying but we would like to listen to any thoughts you want to share with us. Crying is natural and normal, as are feelings of anger and frustration. We may suggest that other specialists come to see you to help you at this time. If, whether you are religious or not, you would like a visit from a member of the multi-faith Chaplaincy Team for some support, please ask a member of staff to make contact with that team for you. The Chaplaincy Team are also available out-of-hours in urgent situations.

## **Fluids and food**

The intake of fluids and food is often of great concern to relatives and carers and we recognise this. As end of life gets closer the need for fluids and food lessens, especially as the body may no longer be able to absorb or digest them. The nurses will support the patient to take food and fluid by mouth for as long as possible and whilst it remains safe to do so. As your loved one becomes weaker and less awake, you may be worried that they may be feeling hungry or thirsty. However because the body is slowing down, this is not necessarily the case. Fluids via a 'drip' will not necessarily reduce thirst and in some situations may cause more harm than benefit. Regular mouth care, including moistening of the mouth and lips, can help to give some relief and the nurse will show you how to provide this aspect of care, if you would like to help do this for your loved one. At this point the medical team will review any medication and regular tablets will stop being administered if they are no longer of benefit to your loved one, or if they have difficulty swallowing them. Other medication will be made available 'just in case' usually as an injection in case of any sign of pain, restlessness, sickness or 'noisy' breathing. In some cases these medications may be administered as a continuous injection using a pump if required.

## **Observations**

At this time we do not wish to cause distress by repeatedly taking blood pressure measurements, but we do need to monitor pulse and breathing rate as these observations help us to monitor comfort of your loved one. These observations will be taken at least once a day.