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What to expect when someone is approaching the end of their life

Information for families and friends





When someone becomes less well, everything is done to promote their comfort and to make life as normal as possible.

Everyone is different and will experience this part of their life in an individual way. The end of life can be a highly emotional and incredibly difficult time for all of those involved; however it is a really important part of life which needs thoughtful planning and care to ensure that this experience is as comfortable as it can be.

Some days will be different than others, so taking each day at a time is important. These are guidelines only, and the person you care for will not necessarily experience all of the symptoms discussed or in the order they are written. The aim of this leaflet is to answer some of the questions

you may have about why they are experiencing these changes and offer some solutions which will help provide comfort to the person you are caring for. However, if you have any further questions, please do not hesitate to ask those who are caring for your relative or friend.

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Food and drink

People who are approaching the end of their life are supported to eat and drink as long as they wish. As time goes on you may find that they do not want to eat or drink. This can be a sign that they are less well. You may find this difficult but it is perfectly normal and struggling to get someone to eat and drink can be more distressing.

Tastes may change, so that food they once liked may now be unpalatable. They may ask for breakfast at teatime. It doesn't matter what is eaten – whatever is fancied is fine. Eating small snacks during the day may be easier than attempting normal meals. Sometimes people are able to manage softer foods.

Drinking is more important than eating. Gradually though, people

stop drinking and this can be a further indication of the time they have left. Whilst it is still possible, small sips of fluid can be encouraged, but this should not be forced. This is a natural course of events when someone is becoming more poorly. Your community nursing team can offer advice.



Mouth care

If you feel able, we would encourage you to become involved in your loved one's care. One way of making them more comfortable is to carry out their mouth care.

If you notice they have dry lips you can apply Vaseline or lip balm to their lips.

A dry mouth may be helped by having cold, unsweetened drinks, or frozen fruit juices. Fizzy drinks are often appreciated as are any other tippie or beverage that is requested as this can be pleasurable and normal. Frequent sips of fluid should be provided if tolerated well or they may be able to suck on an ice cube.

If your loved one is unable to swallow, you can freshen up their mouth with a soft toothbrush or mouth swab dipped in any of the above.

Their tongue may appear coated and this can be cleaned using a soft toothbrush or swab with a small amount of toothpaste or mouthwash. If this is painful just use tap water. If possible do this after meals. Your nurse will explain and demonstrate how to do this.

A coated tongue may also be a sign of oral thrush and your nurse will check regularly for this and will treat as necessary. This unfortunately can be very common.



Medications and managing symptoms

When someone is reaching the end of their life it is best to minimise disturbance and distress. Your doctors and nurses will advise on any interventions required and those that are not. It is likely that many of the medications your relative or friend may have been taking will be stopped at this stage as they will no longer be of benefit and may be difficult to take.

Common symptoms may include breathlessness, pain, nausea and agitation. Your nurse will ask about any symptoms you and your relative or friend have been aware of and medications can be given to alleviate these symptoms. Whilst the person is still able to swallow, tablets or liquid medicine will continue to be prescribed by the GP. However, if they are unable to manage these, there are other ways in which medicines can be given.

Medications can be administered by a small injection, or perhaps by a syringe driver. This is a small electronic pump which holds a

syringe containing the medications required to keep symptoms under control. Attached to the syringe is a long piece of plastic tubing with a small needle on the end, which is inserted under the patient's skin and secured by a see-through dressing. The medications will be delivered very slowly into their arm or other suitable site. It is safe and comfortable to lie on the area where the needle is positioned. The community nurses will check the syringe driver each day and will replace the syringe with a new supply of medications.

Toileting

Even if people are not eating or drinking at all, our bodies still make waste matter. It will therefore still be necessary for your relative or friend to have their bowels opened, though probably not as often as before. Lack of food, reduced mobility and some types of drugs being taken may also contribute to constipation. The nurse will monitor any bowel movements and decide if it is necessary to start a laxative whilst they are still able to swallow.

As people begin to drink less, they need to pass less urine. The urine may appear quite dark and strong and sometimes the person you are caring for may stop passing urine in which case it may become necessary to pass a catheter into the bladder to drain the urine for their comfort. You may find it necessary to use pads to collect urine; if this is the case please speak to your community nurse.

Maximising comfort

Whilst able to do so, most people prefer to be up and about. Gradually, they will be able to do less, perhaps walking for only short periods or maybe only sitting in a chair. Whilst they are still able, it is usually good to encourage them

to get dressed and tend to their own personal needs. As the person becomes weaker and less mobile they often spend more time in bed and it will become necessary to offer help with washing, bathing and cleaning teeth.

Resting and sleeping

Becoming sleepier is usually a sign that they are becoming more poorly. People get tired very easily so short visits and conversations are better. They may begin to fall asleep during a conversation. Just sitting with them and not talking at all may be more relaxing. Holding hands or resting your hand on them can also be comforting to you both.

Gradually sleep will occur for longer and longer periods

and the person may become unconscious. It is known that even when unconscious, people may be aware of those around them, so if you feel able and comfortable doing so, we would encourage you to talk to them as normal. Don't say things which you would not want them to hear. Physical contact is important, touch in general is a way of letting your relative or friend know you are there.

Feelings and emotions

It may be hard for you to come to terms with all the changes happening. There may be a mixture of emotions which are hard to cope with and understand. It may help to talk, share your feelings or to cry.

You may prefer to find someone else to talk to; don't hesitate to seek them out or to ask someone. You may want others around you or you may find you prefer some privacy.



When death is imminent

You may notice that their breathing pattern has changed - it may become more laboured or shallow, with long pauses between each breath. Often the person may feel cool to touch and their skin colour may become very pale or slightly blue. Sometimes it may sound as if they need to clear their throat and while this may sound distressing to you, it is not usually distressing for them. A drug may be administered by the community nurse to try to dry up the secretions causing this rattling or bubbly noise. A change of position may also help.

However, it is impossible to say exactly when someone will die, as the signs described above are only an indication that someone's life is drawing to a close and this happens more quickly with some people than with others.

As the person nears the end of their life you may wish to be present, but if you do not, that is fine. You will feel a mixture of many emotions and although you may have felt prepared for your loved one's death, you may experience a lot of unexpected feelings.

What happens when my relative or friend has died?

You may be with them when they die. Stay with them for a while if you would like to, either on your own or with someone else. If you have

never seen someone after death, you may wonder what to expect. They will look very pale and their skin will gradually feel colder.

Who should I contact when my relative or friend has died?

When someone has died at home, you will need to contact the GP or your community nursing team who may then visit to verify the death. If you have been supported by the community nursing team and/or a care agency, you may wish to call on them so they can offer you some support at this time.

The nurses will be able to offer you a booklet which has been produced to provide you with all the information and contact details that you will need.

When you are ready, you may want to contact your chosen funeral

director, who will arrange to collect your relative or friend from home. If you want to arrange the funeral without the support of a funeral director you can contact your local authority for guidance.



Useful contact numbers and websites

Brigitte Trust
Supporting people facing life-threatening illness and their families with emotional and practical help
www.brigitte-trust.org 01306 881816

Crossroads Care Surrey
Providing support and respite for unpaid carers and end of life services
www.crossroadscaresurrey.org.uk 01372 869970

East Surrey Macmillan Cancer Support Centre
Located at East Surrey Hospital offering support and advice to people with cancer and their families and friends
www.macmillan.org.uk 0808 808 00 00

Jigsaw South East
Supporting children, young people and families facing the death of a family member
www.jigsawsoutheast.org.uk 01342 313895

Marie Curie
Providing care and support to people with any terminal illness and their families
www.mariecurie.org.uk 0800 090 2309

St Catherine's Hospice
Hospice care in West Sussex and East Surrey on our wards or in your own home
www.stch.org.uk 01293 447333

The information in this leaflet has been adapted from “Information for families and carers when a person is less well” with kind permission of St Catherine’s Hospice.

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