

Providing Comfort Care to People with Dementia During Their Last Days of Life



A guide for family and friends

[United Kingdom version]

Last updated: January 2021



Throughout the guide we use the term ‘family carer’ to refer to a relative or friend who is providing support to the person with advanced dementia residing in a care home.

This guide is intended to provide information to the family carers of someone who is in the later stages of dementia and may be nearing the last days of life. We hope that you will find reading this information useful but realise that you may find some of the content upsetting. Please take your time to read the information and, if you have any questions, talk to your GP, nurse or another care professional e.g. staff at the care home.

In the later stages of dementia, your relative may have difficulty speaking or understanding what is going on around them and may not be able to communicate their needs or wishes in a way that we can understand. Family carers may be asked to act on their relative's behalf if they have lasting power of attorney. Otherwise, they may be asked to advise what care their relative may want and discuss their treatment with healthcare professionals. Some family carers report that they feel unprepared to undertake this role.

The purpose of this guide is to provide you with basic information so that you can better understand how advanced dementia may affect your relative. This guide provides information about challenges which may occur as your relative approaches the last days of their life and how these might be managed.

This guide is divided into a number of sections:

- Natural evolution of dementia
- Decisions about the last days of life
- Relief of symptoms
- The final moments
- After the death

At the end of each section, you will find a number of questions that you might wish to consider asking a health or care professional, to allow you to discuss these issues in more detail.

These questions have been suggested by other family carers of people with dementia based on what they think might be useful information for you, and having read this booklet themselves.

You may find that asking questions helps reduce your anxiety about things.



Natural Evolution of dementia

THE NATURAL EVOLUTION OF DEMENTIA

In the later stages of dementia there are signs that may suggest the person is nearing the last weeks or days of life. These include:

- ◆ Limited speech or complete loss of speech
- ◆ Needing help with washing and dressing
- ◆ Difficulty eating and drinking, including problems with swallowing
- ◆ Weight loss
- ◆ Bowel and bladder incontinence
- ◆ Being unable to sit up, walk or stand and becoming bedbound
- ◆ Having frequent infections

WHAT CAN FAMILY CARERS DO WHEN THEIR RELATIVE CAN NO LONGER EAT OR DRINK?

As dementia progresses the person's appetite reduces and they may develop difficulties swallowing safely. This increases the risk of food, fluids or saliva going down the windpipe and causing chest infections or pneumonia. The most common cause of death among people with advanced dementia is pneumonia.

The first thing that healthcare professionals do is try to work out why there is an eating problem and, where possible, attempt to improve it. In some cases, it may be possible to help your relative (e.g. when there is a mouth infection) with medication. However, in the advanced stages of dementia, some people experience difficulty swallowing for other reasons. For example, they may lose their appetite, food may taste unpleasant, or they may experience difficulty opening their mouths, chewing or swallowing.

The healthcare team use a number of approaches when dealing with eating problems. Often, to ensure someone is receiving adequate nutrition, they will advise puréed food or smoothies, or may recommend the use of dietary supplements (e.g. Ensure or Resource). These supplements may be easier to swallow and can replace a portion of a meal, although they may not be appropriate for everyone. Above all, dietary preferences, including modifications such as pureed foods, should always be individualised.

WHAT CAN FAMILY CARERS DO WHEN THEIR RELATIVE CAN NO LONGER EAT OR DRINK?

(... continued)

Often, people with advanced dementia can experience problems with their oral health or may develop dental disease (problems with their teeth). It is important that when your relative is eating and drinking less than usual, we encourage good mouth care and try to make sure that their mouth feels as comfortable as possible. Mouth care is very important, even for those people who wear dentures.

- ◆ Try to keep the mouth moist through regular gentle teeth cleaning or, if appropriate by providing small sips of water.
- ◆ You can clean the mouth with some water-moistened gauze or a clean wet flannel on the tip of a finger.
- ◆ Lip balm, or a similar lubricant can be used to reduce the risk of developing dried or cracked lips.
- ◆ Remember that many people with advanced dementia will need help to clean their teeth or look after their dentures. Try to make this part of their regular routine.
- ◆ If your relative wears dentures try to ensure that they are a good fit (particularly if they have lost weight) and make sure they are washed and stored correctly.
- ◆ Try to get into a good mouth care routine after every meal or at least before bedtime.

Where it is possible to manage, good mouth care can make your relative feel a lot more comfortable.

WHAT CAN THE CAREGIVING TEAM DO IF YOUR RELATIVE DEVELOPS PNEUMONIA?

When a person with advanced dementia develops pneumonia, each event is evaluated on a case-by-case basis. The doctor and family carers should discuss the most appropriate care to provide, keeping in mind the best interests of the patient. Best interest decision making is described later in this document.

The doctor may also prescribe an antibiotic if they believe your relative is suffering from pneumonia e.g. if they have a high fever or are coughing up mucus from their lungs. However, at the very end of life, antibiotics may not always be helpful. If your relative is not able to swallow antibiotics, the medicine may need to be given into a muscle or vein by injection. This might require a hospital admission. In the final phases of life, such injections may be more burdensome than beneficial.

In some instances, the healthcare team may decide to provide oxygen to help your relative feel more comfortable, though usually this would be for those in hospital.

WHAT CAN THE CAREGIVING TEAM DO IF YOUR RELATIVE DEVELOPS BREATHING PROBLEMS?

When a person with advanced dementia experiences difficulty breathing, it is helpful to adjust their positioning. It may be necessary to clear the back of their throat and their breathing passages. This helps to ensure that nothing is blocking the flow of air to or from the lungs.

SHOULD SOMEONE WITH ADVANCED DEMENTIA BE TRANSFERRED TO A HOSPITAL?

Hospitals are not the best places for someone with advanced dementia. The environment and focus of care is not geared towards their needs. Furthermore, hospitals can feel strange to people with advanced dementia, worsening their disorientation and confusion

Transferring someone with advanced dementia to a hospital may cause them a great deal of distress. Best available advice suggests that a transfer to a hospital should only be made when it is absolutely necessary, and if unavoidable, your relative should remain in the hospital for the shortest possible time.

A hospital admission may be useful under some circumstances, such as for painful fractures that can be stabilised through surgery. Most problems can be managed at home or in the care home and a transfer to hospital is not often needed.



CARDIOPULMONARY RESUSCITATION

Cardiopulmonary resuscitation (CPR) is an emergency lifesaving procedure that is carried out when someone stops breathing or their heart has stopped. A person's heart and breathing may stop in an emergency situation like a heart attack but everyone's heart stops as part of the natural and expected dying process.

CPR is often portrayed in the media as a simple technique that can return someone to full functioning quickly and with minimal side-effects.

However, if someone is seriously ill or very frail, or dying, attempting to restart their heart and breathing may lead to them experiencing more pain and suffering. Even if the CPR is successful, the majority will not regain consciousness.

As a family carer you may wish to consider what your relative would want in the event that their heart stops beating. Is CPR a treatment that you think they would agree to?

You may wish to discuss this with other family members, the nursing home manager or your relative's GP.



QUESTIONS TO CONSIDER

Can you tell me how much time they have left?

Can you tell me more about palliative care in dementia?

What do you want to know about my relative, so you can provide appropriate and quality care, now and later on?

What are the advantages and disadvantages of resuscitation in this case?

My relative has dementia but also other medical conditions. How might this affect their care at the end of life?

I would like to talk about how my relative would want to be cared for. When can I discuss this and with whom?



Decisions

about the last days
of life

HOW ARE MEDICAL DECISIONS MADE DURING THE LAST DAYS OF LIFE INVOLVING THE DOCTOR AND THE FAMILY?

It is recommended that you have an open discussion with the doctor and other family members about what care you think your relative would want.

Your relative may have completed an Advanced Decision to Refuse Treatment (ADRT) which is a written statement about care they do not wish to receive in certain circumstances. If your relative has nominated you in their lasting power of attorney, you may be asked to make decisions on behalf of your relative, taking into account what you think they would want.

Currently, if an adult has advanced dementia and is unable to make decisions for themselves and, has not completed documentation outlining their wishes, then medical decisions must be based on their 'best interests'. These decisions are the responsibility of a senior clinician or doctor, in consultation with family carers.

As a family carer you should always feel that you can discuss your relative's care with the healthcare team. You can discuss your preferences and what you believe your relative would prefer but legally, the decision rests with the senior clinician.

Everyone is aiming to achieve the best for your relative, and it's really helpful to share your understanding of what your relative would want as they approach the end of their life with the GP and other professionals and care home staff.

Your views will be taken into consideration when the medical team or doctors are making a decision regarding your relative's treatment. However, sometimes the doctor may choose a treatment option that is different to your wishes. In this situation, the healthcare professional is making a decision based on what they believe is in the best interests of your relative.

If you disagree with a decision or do not understand why the medical team have chosen a particular course of action, the healthcare professional should explain why they have made the decision and also inform you about the law around making best interests decisions.

IF THE MEDICAL TEAM ARE UNABLE TO PROVIDE A CURE, HOW WILL MY RELATIVE BE SUPPORTED?

In the past, doctors may have told a family that “nothing more can be done for their relative” during the end stage of their illness. Family carers could feel that their relative was abandoned and could become upset at this change in care.

This way of thinking no longer exists. Inspired by the success of palliative care teams working with cancer patients, today’s caregiving team will play an important role in providing maximum physical and psychological comfort to both your relative and the family carer as the last days of life approach. A number of ways are now available to make this possible, as will be described later.



SPIRITUALITY

Spiritual care may be important as we approach the last days of life. Providing person centred care means that it is just as important to meet someone's spiritual needs as it is to meet their physical needs.

Spirituality is a term used to describe a set of core beliefs that people use to gain a greater understanding of their lives and those things that give their life a deeper meaning, value or sense of purpose. For some people spirituality may be expressed through their religious beliefs. Other people may not believe in an organised religion and their values, sense of purpose and significance may be influenced by other things such as nature, family, friendships, music or art.

Religion or spirituality provides a set of beliefs that allow someone to make sense of their lives, cope with their experiences and maintain a sense of hope and peacefulness during their life, particularly during difficult times such as illness.

Your relative has the right to have their beliefs listened to, respected and acted on. Healthcare professionals should be made aware of any spiritual beliefs that they may have and they should respect and act in accordance with those beliefs. Your relative may find it helpful and comforting to talk to a leader in their religious community. Alternatively, some people may feel more comfortable talking to friends who are aware of their beliefs. Again, healthcare staff should try to accommodate these discussions.

ARE RELIGIOUS AUTHORITIES IN AGREEMENT WITH THE DECISION TO WITHDRAW OR NOT PROVIDE LIFE-PROLONGING TREATMENT?

For some people, faith is a vital aspect of how they live their life and how they die. It can have a strong influence on what they feel is the right thing to do about treatments as they become less well. The health care team supporting your relative will want to understand this, and build a plan for your relative that is in keeping with their faith practices.

Sometimes decisions need to be made about whether treatments that might prolong life are appropriate to use, because they may cause distress or reduce the quality of life of your relative.

To the best of our knowledge, all religious traditions who have addressed these questions consider it morally acceptable to refrain from using life-prolonging measures if there is little or no significant hope of improving the patient's quality of life.

If questions should arise, it is recommended that family carers discuss these with a representative of their religious or spiritual denomination. Priests, Ministers, Rabbis, Imams or spiritual counsellors will be able to talk through any concerns with family carers. The majority of care homes and hospitals will be able to contact these representatives for you.



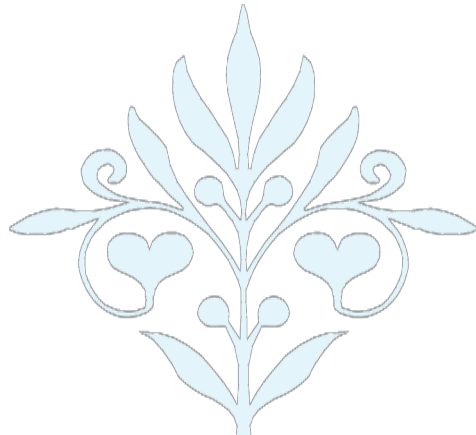
QUESTIONS TO CONSIDER

How can I make arrangements to meet with the doctor?

Can you arrange for me to talk with someone from my culture, someone who may understand me better?

Is it possible for me to see someone else if I don't get along with the nurse or doctor? How do I go about this?

Can I address questions or concerns about religion/spirituality at the end of life?





Relief of symptoms

WHAT ARE THE MOST COMMON CHANGES THAT OCCUR AS SOMEONE APPROACHES THE LAST DAYS OF LIFE?

The most commonly observed symptom during the last days of life is discomfort. Other symptoms include changes in breathing patterns, restlessness and agitation. Many people experience no distress, but if it arises, this can be readily managed with care and medicines, often given in injectable form.

HOW DOES THE CAREGIVING TEAM LOOK AFTER SOMEONE WITH BREATHING PROBLEMS?

It is normal for breathing patterns to change in the last hours and days, and this does not necessarily mean that your relative is experiencing breathlessness.

Breathing difficulties can have many causes e.g. lung infections, heart failure, inhaling particles of food into the lungs, and so on. Medications such as morphine may be used to reduce distress.

If your relative experiences problems with their breathing then certain medications, which can be inhaled and an inhaler or a mask will be provided as these can help air to flow more freely to the lungs.

SHOULD YOUR RELATIVE BE GIVEN ANTIBIOTICS WHEN THEY HAVE AN INFECTION?

Through discussions with the family, your relative's wishes will be identified in order to decide upon the most appropriate care to administer and to ensure a comfortable end of life experience. If there is any doubt, some doctors may decide to implement a treatment, and then stop it if it is not effective or if it is no longer desirable.

In the case of pneumonia, please see the relevant section earlier in this booklet. In the case of other infections which result in discomfort (i.e. bladder infection), antibiotic therapy may be the best way to provide your relative with rapid relief.

HOW ARE MUCUS SECRETIONS CONTROLLED WHEN THEY CAUSE DIFFICULT AND NOISY BREATHING?

When there is a large quantity of mucus at the back of the throat, healthcare providers will position your relative correctly and may administer medication to decrease the formation of new secretions and keep your relative comfortable.

The production of mucus may become too frequent in some people causing them to breathe noisily. For carers, this noisy breathing may be distressing. However, if your relative is unconscious or, if they are receiving appropriate medication, they will be comfortable and possibly unaware they are breathing differently. Sometimes it may be necessary to use a suction machine to help remove mucus from the mouth and airways. Since this can be unpleasant, it is only carried out when absolutely necessary, most likely in a hospital or hospice.

WHAT ARE THE SIGNS OF PAIN IN SOMEONE WHO IS UNABLE TO EXPRESS THEMSELVES?

It can be difficult to evaluate pain in someone who is no longer able to communicate clearly. The healthcare team will observe facial expressions, vocal sounds and the way someone moves to gauge if they are experiencing discomfort. You can help with this process and inform nursing staff if you feel your relative is in pain.

HOW CAN PAIN BE RELIEVED?

There are many possible causes of pain, thus it is important to identify the right one. It is especially important that the person is properly positioned in a comfortable bed.

Various medications are available for different types of pain, and sometimes they have to be combined in different ways to be effective. Pain relieving medications such as paracetamol may be used for mild pain or discomfort. Morphine may be used for moderate to severe pain. In order to control pain, medications may be administered according to your relative's assessed need.

Pain relieving medication may be given as tablets, patches to the skin, injections, suppositories or via a device known as a syringe driver which gradually administers small amounts of medication through small tubes under the skin. The use of a syringe driver can be beneficial to reduce the discomfort of repeated injections.

CAN MORPHINE END SOMEONE'S LIFE?

There are many fears and misconceptions about the use of morphine and other related medications in people who are at the end of life, such as a fear that they artificially speed up death or cause death. When used in appropriate doses for symptom control in a person at the end of life, there is much evidence that morphine enhances comfort and no evidence that it hastens death.

The aim of care at the end of life is neither to hasten nor postpone death, but to ensure comfort. Doses of morphine and other medications sometimes need to be increased to control symptoms as someone gets closer to death. If medication is increased in the hours before a person dies it is because they needed more medication to remain comfortable as they were closer to dying.

HOW CAN ANXIETY OR AGITATION BE RELIEVED?

It is not always easy to distinguish pain from anxiety when someone who has limited ability to communicate is agitated or unable to rest. That's why experts in palliative care prefer to administer medications for anxiety, in addition to morphine.

IS IT NECESSARY TO ADMINISTER OTHER MEDICATIONS OR TO VERIFY BLOOD PRESSURE, TEMPERATURE, BLOOD SUGAR LEVELS, AND SO ON?

The healthcare team also have to make decisions regarding other types of care and treatments. During the last days of life, when swallowing may become difficult, it may be necessary to stop taking medications orally. Instead, necessary treatments are administered through patches to the skin, injections or suppositories. Medications will be continually under review to ensure that only essential medicines are maintained, while others are stopped. The syringe driver can continuously administer the necessary medication to keep your relative as comfortable as possible.

As your relative approaches the last days of their life it becomes less important to undertake routine tasks such as taking their temperature or blood pressure; especially if undertaking these routine tasks disturbs them. Monitoring and control of blood sugars and blood pressure does not improve quality of life at this stage, but adds burden to your relative.

On the other hand, nursing care aimed at maintaining hygiene and care of the skin (to prevent skin breakdown) and mouth, needs to be carried out until the end of life because this contributes to the comfort and the dignity of the patient.

HOW DOES SOMEONE FEEL WHEN THEY ARE NO LONGER EATING OR DRINKING?

It is natural for people who are approaching the last days of life to lose their appetite and have little interest in eating or drinking. Most people refuse all or even small amounts of food that are offered to them and say that they feel a sensation of dryness in the mouth. That's why experts in palliative care have developed products that are effective for treating dryness of the mouth, lips and throat. In terms of nursing care, management of this symptom is given a high priority.

On the other hand, an overall lowering of body-fluid levels (dehydration of the body) is not painful in itself. The blood becomes more concentrated and the kidneys gradually slow down and then stop functioning. All these changes are generally good for your relative as the perception of pain is lowered. In addition, having a lower volume of fluids in the body also means a reduction in the quantity of mucus, thereby making it easier to breathe.

SHOULD INTRAVENOUS FLUIDS BE STARTED?

Some families believe that their relative would be more comfortable with intravenous (IV) fluids known as a 'drip'. However, experience and research has shown that providing fluids through an IV drip can lead to increased mucus production in the breathing passages, may put off the onset of unconsciousness and, can prolong the duration of discomfort experienced by the patient.

WHAT TO DO IF THE PERSON ALREADY HAS A FEEDING TUBE?

Even though some people may have trouble understanding this concept, experts in the field of ethics consider that the decision to stop tube feeding is essentially the same as not inserting a feeding tube in the first place. Thus, after consulting with family carers or next of kin, the healthcare team may decide it is appropriate to stop tube feeding in the best interests of your relative.

HOW LONG WILL A PERSON WHO IS NO LONGER DRINKING OR EATING LIVE?

When a person is no longer eating or drinking, they will usually live for a few more days. However, people who are physically stronger or ingesting liquids when they are receiving mouth care may live for a further one or two weeks. Each case is different, and it may be difficult for the healthcare team to estimate the amount of time remaining as someone approaches the last days of life.

QUESTIONS TO CONSIDER

What changes can I expect, such as worsening of symptoms or behaviour?

If equipment is needed, where will it come from and how quickly can it be obtained? (For example, wheelchair, mattress, syringe driver etc.)

Would you call in specialist services if required? (For example, palliative care, dentist, neurologist etc.)

How quickly can you get medication for when it's needed?

Will care staff be aware of how to relieve pain relating to muscles or joints (contractures) which might happen at the end of life?



The final moments

HOW SHOULD YOU BEHAVE WITH SOMEONE WHO APPEARS TO BE UNCONSCIOUS?

The type of care that appears to help someone as they approach the last days of life is simple. Touching and holding the person, speaking with a soft voice, or playing music that the person enjoys are some of the ways in which your relative can be comforted and helped to feel more secure.

Whenever possible, family carers may wish to make arrangements so that their relative is not left alone during the last days of their life. Care homes are increasingly helpful in accommodating family carers so that they can spend the night with their relative. When the family carer is older or unwell or, if only a few family carers are available, talking to the care home staff may identify alternative services such as volunteers in the community who can stay with the dying person and inform nursing staff if your relative appears to be uncomfortable.

WHAT ARE THE FINAL MOMENTS LIKE?

When the dying person receives comfort care, as described in this guide, death is usually peaceful. Breathing can become more shallow and irregular. The pauses between breaths become longer and longer. Eventually, the unconscious person will take one or two deep breaths before exhaling the final one. Many family carers and friends who have been present at this time have said that these final moments were much less difficult or upsetting than they had anticipated. Most were content to have been with their relative right up to the end.





QUESTIONS TO CONSIDER

Is it feasible for my relative to die at home?



After the death

WHAT HAPPENS AFTER DEATH?

A doctor will confirm the death and nursing staff will then prepare your relative's body before it is taken to the funeral parlour in accordance with the family's wishes. In occasional circumstances, nursing staff may be able to verify a death.


The doctor may seek your approval for a post-mortem, which is the examination of the body to determine the cause of death. This will usually have been discussed with the doctor at an earlier stage if appropriate, and is not common for people with advanced dementia.

The results of the post-mortem could be important especially if your relative had an illness that is known to run in families (such as Alzheimer's disease), and to contribute to ongoing research to better understand the disease.

After the death of your relative, you may experience grief in various forms, and grief reactions vary from person to person. Some people will be surprised to find that they feel more relieved than upset. This is a normal reaction when death is “timely” following a long illness. You may also feel angry, alone, exhausted or even guilty and need to give yourself some time or obtain support during this period.

If you need counselling or support, certain community services can be of assistance, such as the local Alzheimer’s Society or CRUSE Bereavement Care.





In this guide we have tried to provide some answers to the sensitive questions that arise during the last months, weeks or days of life for people living with advanced dementia. In order for this stage of the illness to take place in as peaceful a manner as possible it is important that the family carers have a good understanding of what the caregiving team must do. It is also essential that the doctor and nursing staff are available to provide the necessary information and take time to agree about the treatment that serves the best interests of the person with dementia and respects their wishes.

Given that the wishes of the person with dementia may not have been clearly expressed either verbally or in writing, we have recommended that, when in doubt, a palliative care approach based on physical, spiritual and psychological comfort be provided.

FURTHER QUESTIONS TO CONSIDER

Is it possible to record wishes regarding end-of-life care now? How and when will these wishes be reviewed?

If there is no solution for unpleasant symptoms such as pain or shortness of breath, will the doctor have other options so my relative is less aware of them? (For example, lowering the level of consciousness, or putting my relative to sleep by means of 'palliative sedation'). Can this be discussed?

Can my relative be admitted into a hospice?

Can someone help me to communicate with other members of my family about what is happening?

What training/support is given to care staff to enable them to support my relative?

How often do you use temporary staff? Will my relative receive care in the last days and hours from someone who knows them?

How can I support my relative to make a will?

Useful resources

Admiral Nurse Dementia Helpline:

0800 888 6678

helpline@dementiauk.org

Age UK:

0800 678 1602

<https://www.ageuk.org.uk/>

Alzheimers UK:

0300 222 11 22

<https://www.alzheimers.org.uk/>

Care Quality Commission:

03000 616161

<https://www.cqc.org.uk/contact-us>

Carers UK:

0808 808 7777

<https://www.carersuk.org/>

Cruse Bereavement Care:

0808 808 1677

<https://www.cruse.org.uk/get-help/about-grief>

Film about anticipatory grief:

<https://www.ucl.ac.uk/psychiatry/research/marie-curie-palliative-care-research-department/research/centre-dementia-palliative-care-23>

References

This booklet is adapted from:
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