

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



A guide for family and
friends

Northern Ireland
Version



Throughout the guide we use the term ‘family carer’ or ‘carer’ to refer to a relative or friend who is providing support to the person with advanced dementia. We use the term ‘relative’ to describe the person who is living with dementia.

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 healthcare professional.

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. Family carers may be asked to act on their relative's behalf and discuss their treatment with healthcare professionals. Some family members 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 symptoms which may occur as your relative approaches the last days of life and how these symptoms may be managed.



Natural

Evolution of dementia

THE NATURAL EVOLUTION OF DEMENTIA

In the later stages of dementia there are symptoms that indicate the person is nearing the last days of life. These are:

- ◆ 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 recurring infections

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.

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

The first thing that healthcare professionals do is trace the cause of the eating problem and, where possible, attempt to correct it. In some cases, it may be possible to help your relative (i.e. when there is a mouth infection or a problem 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, they may be afraid of choking or, they may experience difficulty opening their mouths, chewing or swallowing. At this stage a referral may be made to a Speech and Language Therapist who can assess your relative's ability to swallow.

The healthcare team use a number of approaches when dealing with eating problems. Often, to ensure someone is receiving adequate nutrition, they will provide puréed food or smoothies or, may recommend the use of dietary supplements (i.e. Ensure or Resource). These supplements may be easier to swallow and can replace a portion of a meal.

However, as dementia progresses, these strategies may become less effective. The healthcare team may consider the use of a drip or inserting a feeding tube directly into your relative's stomach to provide nutrition. This decision will be made on the basis of balancing the potential benefits versus the burden of receiving the treatment. Although the use of a feeding tube reduces the difficulties associated with eating, research has not shown any benefits in terms of survival, nutritional status or quality of life.

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

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Often, people with advanced dementia can experience problems with their oral health or may develop dental disease. It is important that when your relative is eating and drinking less than usual that we encourage good mouth care and try to make sure that their mouth feels as comfortable as possible. Oral hygiene is very important, even for those people who may 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.
- ♦ Lip balm, or a similar lubricant can be used to reduce the risk of your relative developing dried or cracked lips.
- ♦ Remember that with advanced dementia many people will need help to clean their teeth or look after their dentures. Try to make this part of your 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 oral healthcare routine where mouth hygiene is considered after every meal or at least before bedtime.

Good oral hygiene will 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 experiences difficulty breathing it is 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.

In some instances, the healthcare team may decide to provide oxygen to help your relative feel more comfortable. The doctor may also prescribe an antibiotic if they believe they are suffering from pneumonia.

However, for someone with advanced dementia, the chances of making a full recovery from pneumonia are limited and, those who do recover, have an increased likelihood of getting pneumonia again.

When a person with advanced dementia develops pneumonia each event is evaluated on a case-by-case basis. The doctor and the family carer 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.

SHOULD SOMEONE WITH ADVANCED DEMENTIA BE TRANSFERRED TO A HOSPITAL?

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 your relative should remain in the hospital for the shortest possible time.

A short hospitalisation period is justified under some circumstances, such as for painful fractures that can be stabilised through surgery. Nevertheless, it is generally advised to not transfer someone to hospital if the problem can be adequately dealt with in the community or in a nursing home.



CARDIOPULMONARY RESUSCITATION

Cardiopulmonary resuscitation (CPR) is an emergency lifesaving procedure that is carried out when someone stops breathing or their heart has stopped. The purpose is to try to get the heart beating again. CPR is often portrayed in the media as a simple technique that can return someone to full functioning quickly and with minimal side-effects. Sadly, among frail elderly people or people with life-limiting illnesses, such as advanced dementia, this is rarely the case and the majority will experience discomfort, physical injury and may not regain meaningful consciousness.

A person's heart and breathing may stop as part of the natural and expected dying process. If someone is seriously ill or very frail, restarting their heart and breathing may lead to them experiencing more pain and suffering. 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?

Due to the likelihood that they may not experience a positive outcome it is usually not recommended that resuscitation procedures be carried out on people who have advanced dementia. You may wish to discuss this with other family members, the nursing home manager or the relative's GP.



Decisions

about the last days of life

WHO MAKES MEDICAL DECISIONS DURING THE LAST DAYS OF LIFE, THE DOCTOR OR FAMILY?

It is recommended that you have an open discussion with the doctor and other family members to share your views.

Your views will be taken into consideration when the medical team or doctor 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.

WHAT IS THE ROLE OF THE FAMILY?

Currently, in Northern Ireland, 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 the 'best interests' of the adult. These decisions are the responsibility of a senior clinician or doctor.

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.

You should share your questions with staff! When questions are not expressed, family members may be left with unnecessary distress.

WHAT TO DO IN CASE OF CONFLICT OR DOUBT?

Sometimes family members may disagree with the doctor's advice or may find it difficult to agree among themselves on what care is appropriate for their relative.

If this is the case it may be necessary to arrive at a compromise. The medical team will always make decisions based on what they see as your relative's best interests. For example, they may try out a treatment and evaluate its effects. If a family member is unhappy with the care provided they can ask for a second opinion from another doctor, hold a case conference, contact the Patient and Client Council or, complain to your local Healthcare Trust's Complaints Manager.

Fortunately, differing points of view between the medical team and the family are rarely settled in court. It is much better to find a friendly solution before resorting to a legal remedy.

IF THE MEDICAL TEAM ARE UNABLE TO PROVIDE A CURE, DOES THIS MEAN THAT YOUR RELATIVE IS LEFT ON THEIR OWN?

In the past, doctors may have told the family that “nothing more can be done for your relative” during the end stage of their illness. Family members 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.



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

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 members take the necessary time to discuss this matter with a representative of their religious or spiritual denomination. Priests, ministers or spiritual counsellors, who are aware of the situation and the concerns of the healthcare providers, are available in most nursing homes and hospitals to address family member's concerns.

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.





Relief

of symptoms

WHAT ARE THE MOST FREQUENT SYMPTOMS AS SOMEONE APPROACHED THE LAST DAYS OF LIFE?

The most frequent symptoms during the last days of life can be breathlessness and discomfort. Other symptoms include anxiety, agitation and nausea.

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

Breathing difficulties can have many causes (e.g. lung infections, heart failure, inhaling particles of food into the lungs, and so on). Treatment varies according to the cause of the problem.

Pain killing 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 through a pump, an inhaler or a mask will be provided as these can help air to flow more freely to the lungs.

Diuretics (medication to increase the amount of urine produced) may also be given to make sure that there is not an unhealthy build up fluids in your relative's body.

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

In the case of pneumonia, it may be necessary to administer antibiotics if your relative has high fever and is coughing up mucus from their lungs.

The medical team must then decide if the pneumonia should be treated or if it may be better to ensure that the patient has a comfortable end of life experience. Through discussions with the family, your relative's wishes will be identified in order to decide upon the most appropriate care to administer. If there is any doubt, or when family members cannot be located, some doctors may decide to implement a treatment, and then stop it if it is not effective or if it is no longer desirable.

On the other hand, in the case of certain 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 MUCOUS 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 administer medication to decrease the formation of new secretions and keep them comfortable.

Medication is usually helpful, however, 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.

IS IT HELPFUL TO PROVIDE OXYGEN?

If your relative has difficulty breathing, oxygen may help reduce certain muscular pains and breathing problems. However, when the end of life is near or, if they are unconscious, it is reasonable to remove the oxygen as, at this stage, it will not provide any additional benefit.

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 that your relative needs pain relief.

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. Analgesic 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 at this stage of the illness, medication will be administered according to your relative's assessed need. Pain killing medication may be given as tablets, injections, suppositories or via a device known as a syringe pump which gradually administers small amounts of medication.

CAN MORPHINE END SOMEONE'S LIFE?

Many family carers wrongly believe that it is the last dose of morphine that causes their relative to stop breathing, especially if the medical team have increased the dosage. This is not the case, if necessary the medical team may increase the dosage and people are able to tolerate heavier doses of morphine if the strength is gradually adjusted.

It is possible that high doses of morphine can sometimes lead to a premature death. Under such circumstances, it is generally understood that, if the medical team's intention was to provide pain relief and not to end life, it is morally acceptable to administer the necessary doses. Failing to respond to someone's needs and leaving them in pain would be immoral.

HOW CAN ANXIETY OR AGITATION BE RELIEVED?

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

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 injections or suppositories. In order to reduce the discomfort of repeated injections, nursing staff insert small tubes under the skin attached to a device known as a syringe pump. The syringe pump 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 completing these routine tasks disturbs them. 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?

People who are approaching the last days of life often 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 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 a 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 members or next of kin, the medical 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 caregiving team to estimate the amount of time remaining as someone approaches the last days 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 members may wish to make arrangements so that their relative is not left alone during the last days of their life. Institutions are increasingly helpful in accommodating family members so that they can spend the night with their loved one. When the family member is elderly or unwell or, if only a few family members are available, talking to the care home staff may identify alternative services such as volunteers in the community who can stay with the dying individual 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 becomes 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 members 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, and in turn they became reassured about their own eventual death. Most were content to have been with their loved one right up to the end.





After the death

WHAT HAPPENS AFTER DEATH?

A doctor will confirm the death and nursing staff will then prepare the body before it is taken to the funeral parlour in accordance with the family's wishes. The doctor may seek your approval for a post-mortem, although this will usually have been discussed at an earlier stage.

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 where treatments may be available to help other members of your family either now, or in the future.

After the death of your relative, you will experience grief in various forms. 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 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 members and/or next of kin 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 orally or in writing, we have recommended that, when in doubt, a palliative care approach based on physical, spiritual and psychological comfort be provided.

Useful resources

The Alzheimer's Society National Dementia Helpline:
Telephone: 0300 222 1122.

The Alzheimer's Society Northern Ireland.
Telephone: 02890 664100
www.alzheimers.org.uk/northernireland/

CarersNI: an organisation that provides general advice, information and support to people who are supporting a loved one.
Telephone: 02890 439843
www.carersuk.org/northernireland

CRUSE Bereavement Care: offer a range of advice and information services to children, young people and adults when someone close to them dies.
Telephone: 0808 808 1677
www.cruse.org.uk/

Bereavement Network NI: Offer information and guidance to people who provide palliative care.
<http://www.hscbereavementnetwork.hscni.net/>

Caring for Carers is a website developed by the All Ireland Institute for Hospice and Palliative Care. It provides information for family members and friends who are providing support to someone who needs palliative care.
<http://www.carers.thepalliativehub.com/>

Patient and Client Council: the Patient and Client Council will help you to complain about any part of health and social care.
Telephone: 0800 917 0222
www.patientclientcouncil.hscni.net/

References

Developed by Arcand and Caron (2005) *Comfort Care at the End of Life for Persons with Alzheimer's Disease or Other Degenerative Diseases of the Brain—A Guide for Caregivers*: Centre de santé et de services sociaux—institut universitaire de gériatrie de Sherbrooke.

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