More about CPR – an Advance Care Planning decision

The conversations we need to have when we are facing the death of a terminally ill relative or friend are the hardest ones we will probably ever have.

Conversations around deciding whether to have future CPR or not to have future CPR are no exception and you need to know what you are getting into before you make any decisions. There is some information on CPR in the Asking Questions booklet but as it's such an important and poorly understood issue, here's some more information if you need it.

What is CPR (Cardiopulmonary Resuscitation)?

Basically, CPR is the process of restarting the heartbeat and breathing after one or both has stopped. The first step involves creating an artificial heartbeat by pushing on the chest, and attempting to restore breathing by blowing into the person's mouth.

After that, a tube may be inserted through the mouth and down the airway to make the artificial breathing more efficient. Electric shocks may be given to the heart, and various drugs may be given through an intravenous line. If the heartbeat starts again but breathing is still not adequate, a machine called a ventilator may be employed to move air in and out of the person's lungs until they can breathe again on their own.

Does it work?

On television, CPR is often depicted as the ultimate life-saving technique. In real life the process is more harsh. Pushing the centre of the chest down about five centimetres 100 times a minute for several minutes, causes pain, and may even break ribs, damage the liver, or create other significant problems.

CPR may save a person's life, particularly in the case of some kinds of heart attacks and accidents in an otherwise healthy person.

BUT when a person is in failing health from a serious and progressive illness, including dementia, the heart and breathing will ultimately fail as a result of the effects of that illness on the body. In such a circumstance, there is little chance that CPR will succeed at all. Any success will be temporary, because the person's weakened condition will soon cause the heartbeat and breathing to fail again. The person may end up on a ventilator as they continue to deteriorate.

Survival rates after CPR vary from 5-23%. Survival for frail older people with multiple health problems or severe dementia is less than 1%.

Case Study

Judy's husband[1] has had Alzheimer's disease for eight years, and is now in the final stages of the illness. After a discussion of end-of-life issues with her family, Judy has decided to 'let nature take its course' if anything of an urgent medical nature happens to her husband. In other words, she does not want him to be put on life support. She has told her doctor of this decision, and he has agreed.

One night, Judy wakes up to find her husband having trouble breathing. Reflexively, without thinking, she calls 000. By the time the ambulance arrives, her husband has stopped breathing completely. The ambulance officers immediately administer CPR and take him to the hospital. By the time Judy arrives at the hospital, her husband is connected to a ventilator and intravenous fluids numerous IVs. Unfortunately, this is exactly what she did not want for him.

Calling 000

Calling 000 is a call for emergency help. This means that when the ambulance arrives, they are not there to talk about treatment options. They know that any delay could mean brain damage, so they may immediately start CPR and then take the person to the hospital.

When Judy called 000 in our scenario, the paramedics simply did what they are trained to do – they revived her husband. However, if Judy and her doctor had completed an Advance Care Plan with a No-CPR Order included and kept it in the home, her husband may not have been resuscitated and/or connected to machines when he got to the hospital.

What is a No-CPR Option?

The 'NO-CPR Order' is a document that allows medical teams not to perform CPR. The No-CPR Order would normally be made by a person's doctor after discussion with the family.

In light of this, the No-CPR Order should be kept near the ill person's bed, perhaps on the wall, so it will be easy to find in case of emergency. When emergency personnel see this Order, they will still do anything they can to make the sick person comfortable, but they may not perform CPR.

Why would you choose to have a No-CPR as part of an Advance Care Plan or Directive?

There are times when it may not make sense to perform CPR. When a person with dementia is reaching the end of their life, nothing will stop their decline. At this point, CPR may only prolong dying. Under these circumstances, you might feel there is little reason to attempt CPR.

A doctor will recommend a No-CPR Order when it is clear that CPR would be futile and lead to a reduced quality of life for the person who is dying.

Having a No-CPR Order option does not mean that other supportive treatments will not be continued!

Conclusion

When someone is suffering from dementia, the decline is gradual. As a result, both carers and those in their care often forget to talk about the choices the person with dementia would like to make regarding their health care. It is normal and instinctive to try to save life no matter what, and some people are concerned that not doing everything possible to preserve life is the same as 'killing' someone. It is not – it simply means respecting the end stage of a disease as the body shuts down.

There are no right and wrong answers to these questions, and until we face a situation like this, it is difficult to anticipate the kinds of choices we'd make. But the more we talk about these issues in advance of the need to make a critical decision, the easier it will be on both the person with dementia and those responsible for that person's care. It is never too soon to start the conversation.

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1 This story is adapted from the Family Caregiver Alliance of San Francisco, California.

This Fact Sheet has been developed in part with reference to the My Wishes Fact Sheet on CPR (ref) and the Family Caregiver Alliance of San Francisco Fact Sheet on CPR.

Accessing Palliative Care for people with Dementia and their families

Palliative Care is delivered in different ways and for varying amounts of time. **It is not only for people with cancer**. If your relative or friend has dementia you can ask your doctor to refer you to Palliative Care at any stage of the dementia and especially if treatment is not adequately controlling symptoms.

Your doctor may refer you to Palliative Care if s/he would like some advice on symptom management and supportive care. This referral may happen earlier in the dementia journey than you might expect but it's better to make those connections sooner rather than later.

Depending on your circumstances, Palliative Care can be delivered in your home or in the Residential Aged Care Facility (nursing home), in a general ward or specialised Palliative Care ward in a hospital; and/or in a specialised 'in-patient' facility (formerly called a hospice)'. For people with Dementia and their families, this place is usually going to be in a Residential Aged Care Facility.

Usually, there is no charge for Specialist Palliative Care services.

You can contact your local Palliative Care team for advice if you would like to know more about treatment options and the type of resources available in your area. Your local service will provide information on the resources available. Some services may require a referral by a doctor to formally admit someone with dementia while other services can accept a referral from you or a family member or friend, local community health centres and local hospitals.

For information about local Palliative Care services, please see the directory of NSW Palliative Care Service Providers on our website at **www.palliativecarensw.org.au.**

Sometimes people die without the benefit of Palliative Care because their doctor, their family or indeed, they themselves are reluctant to admit that the person is dying of their dementia. Sometimes people are afraid that referral to Palliative Care will hasten their death. Discussing these concerns with a member of your local Palliative Care service will help put your mind at ease.

Understanding the changes which occur before death

There will come a point in a person with dementia's life when death and dying are contemplated. This may be sooner or later in the disease but you will have to talk about it.

In order to reduce the anxiety that often comes from the unknown, this article describes some typical features of the prtocess of dying, whether from dementia or from another cause.

It anticipates questions you may want to ask and hopefully it will encourage you to seek further help and information.

The changes that occur before death

The dying process is unique to each person but, in most cases, there are common characteristics or changes that help to indicate that a person is dying.

Any one of these signs can be attributed to something other than dying, so remember that the events described here are happening to a person whose illness is already so severe that life is threatened.

The many changes that indicate that life is coming to an end fall into three main categories:

1. Diminished need for food and drink
2. Changes in breathing
3. Withdrawing from the world

Diminished need for food and drink

When someone stops eating and drinking, it can be hard to accept, even when we know they are dying. It is a physical sign that they are not going to get better. There is a separate fact sheet on this in this folder.

Initially, as weakness develops, the effort of eating and drinking may simply have become too much, and at this time help with feeding might be appreciated.

However, eventually there will come a time when food and drink are neither wanted nor needed. This can be very distressing for carers as food and drink are closely associated with nurturing.

Nevertheless, caring can be continued in other important ways such as spending time together, or sharing news of family and friends. Simply being together can be a great comfort to both of you. You might like to play some soft music and keep light and noise down.

Most importantly, being cared for in this way enables people to feel that their lives have been worthwhile and that they will be remembered.

Changes in breathing

People who suffer from breathlessness are often concerned that they will die fighting for their breath. Yet towards the end of life, as the body becomes less active, the demand for oxygen is actually reduced to a minimum.

This may be comforting to those who have had breathing problems, as carers often remark that when a loved one is dying their breathing is easier than it has been for a long time.

Of course, breathing difficulties can be made worse by feelings of anxiety. But the knowledge that someone is close at hand is not only reassuring; it can be a real help in preventing breathlessness caused by anxiety.

Occasionally in the last hours of life there can be a noisy rattle to the breathing. This is due to a build up of mucus in the chest, which the person is no longer able to cough up. Medication may be used to reduce this and changes of position may also help.

These measures may have limited success, but while this noisy breathing is upsetting to carers it doesn't appear to distress the dying person.

If the person is breathing through their mouth, the lips and mouth become dry. Moistening the mouth with a damp sponge and applying lip salve will give comfort.

Withdrawing from the world

'Withdrawing from the world' is a gradual process. The person will spend more time sleeping and will often be drowsy when awake.

This apparent lack of interest in one's surroundings is part of a natural process which may even be accompanied by feelings of tranquillity. It is certainly not a snub to loved ones.

Eventually the person may lapse into unconsciousness and may remain in this state for a surprisingly long time (in extreme cases many days) although for others it is shorter.

When death is very close (within minutes or hours) the breathing pattern may change again Sometimes there are long pauses between breaths, or the abdominal muscles (tummy) will take over the work – the abdomen rises and falls instead of the chest. If breathing appears laboured, remember that this is more distressing to you than it is to the person dying.

The skin can become pale and moist and lightly cool prior to death. Most people do not rouse from sleep, but die peacefully, comfortably and quietly.

This is a difficult and painful time for you. You are leaving those you love or losing someone you love and care for, and you may or may not know whether they can see or hear you. Touch is still comforting to both you and your loved one and is expecially comforting when words are hard to find. It is often hard to know what to say to each other at a time like this.

The Palliative Care Team along with other nurses, doctors and other staff are there to help you to work through your worries and concerns and to offer you care and support.

For more information about your role as a Carer contact Carers NSW.

Visit www.carersnsw.asn.au or telephone the National Carer Counselling Line on 1800 242 636.

Thank you to Irene Salmon RN, Catherine Griffiths PhD RN and John Bridson BA (Hons) MSc RN, practicing palliative care nurses, Liverpool Care Pathway for some of the content of this Fact Sheet.

End of life care: When your relative or friend refuses to or cannot eat

Difficulties with eating and drinking, refusing to eat, swallowing and chewing problems are common in end stage dementia, so common that about 86% (8 or 9 people out of 10) with end stage dementia have an eating problem.

Earlier in the course of the illness, the person with dementia needs help to eat and drink, because confusion and lack of coordination of the muscles stops the person getting enough food and fluids.

Eventually other problems with eating begin. The food is held in the mouth for a long time without swallowing, or the food is chewed and chewed, as if the person has forgotten how to swallow. Towards the end of life, a person with dementia may let the food fall from the mouth without any attempt to eat it, despite encouragement from carers. **Often when a person appears totally uninterested in food it is a sign that they are nearing the very last weeks and days of life**. Watching a loved one refuse to eat can be distressing for family members and carers.

If this happens to the person you know with dementia then talk it over with the carers and your family so that you get some support for yourself. A person with end-stage dementia usually eats and drinks a lot less than normal. As a result he or she may lose weight and become dry (dehydrated). The dryness in turn can cause other problems, such as constipation.

Swallowing problems

Swallowing problems are very common, and are one of the main signs of end stage dementia. A person with dementia who develops swallowing problems may have a very limited life span of only a few months, although this is not true in every case.

Signs of swallowing problems include appearing to choke when eating, and/or coughing after eating.

The medical term for swallowing problems is *dysphagia*. A Speech Therapist can assess dysphagia and provide detailed information to allow carers to feed the person correctly. If dysphagia is not managed, food and fluids may go down the wrong passage and enter the lungs. This can cause a condition called *aspiration pneumonia*, which is a type of lung infection caused by the food or fluid. Antibiotics and possibly admission to hospital are needed to treat aspiration pneumonia.

A person with swallowing problems can usually continue to eat, with the food mashed or pureed, and fluids thickened. Sometimes however, no matter how carefully the right-textured food and fluids are given, repeated bouts of aspiration pneumonia occur. One of these bouts will be fatal to the person. The options may be to continue feeding, knowing the high risk of death from pneumonia, or to stop feeding and maintain the person's comfort until natural dying occurs.

The comfort of the person with dementia is the most important factor in this difficult situation. Make sure the Palliative Care Team knows about the problem too.

Feeding Tubes

When a person has swallowing problems from dementia it is sometimes suggested that a feeding tube be inserted into the stomach to give the person nourishment through the tube. Recent expert opinion is that feeding tubes are not advisable for people with dementia. There is no evidence that they prolong life, prevent aspiration pneumonia, or improve the quality of life of the person with end stage dementia, which are the usual reasons for inserting them.

The decision about whether or not to use a feeding tube is very complex, and needs to be considered carefully for any person with dementia. Sometimes if tube feeding is started, a decision needs to be made, when the person is dying, to stop the feeds, because otherwise death will be more uncomfortable. The decision to stop feeding is often more emotional and difficult than the decision to start the feeds. Careful spoon feeding, with food and fluids of the right texture, allows a person living with dementia to enjoy the smell and taste of the food for as long as they are willing and able to eat.

Weight loss

Weight loss is commonly associated with the final stages of dementia. Earlier in the course of the illness weight is lost because the person is too restless to eat, or does not recognise the food and doesn't eat enough.

In the end stage of dementia, weight is lost **despite the person being given adequate amounts of food and fluids**. This is due to complex changes in the body due to advanced disease. This kind of weight loss also occurs when a person has advanced heart, lung or liver disease, or advanced cancer.

Weight loss due to advanced illness, including dementia, cannot be reversed, even if food supplements such as fortified drinks are offered.

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