

# Caring for someone with advanced dementia

This leaflet has been compiled by nurses from the Care Home Project Team at St Christopher's in collaboration with nurses from dementia care units to help support relatives of people with advanced dementia living and dying in care homes

## Coping with advanced dementia

Many people do not realise that dementia is a progressive disease. This leaflet outlines some of the changes you may see as the health of a person with dementia deteriorates. Care home staff will be able to help you understand and cope with the symptoms experienced by your relative or friend with dementia. The leaflet also suggests where you can find more information.

“You matter because you are you. You matter to the last moment of your life, and we will do all we can, not only to help you die peacefully, but also to live until you die.”

**Dame Cicely Saunders**

Founder of the modern hospice movement

## Symptoms of advanced dementia

People are unique individuals and so the disease of dementia may well affect each person slightly differently. The symptoms of advanced dementia occur because of damage to areas of the brain that not only affects the memory, but also how the body itself works, for example, movements and reflexes. The damage to the brain cannot be reversed.

Although there are many different types of dementia, some common symptoms that are an inevitable part of dementia help us recognise when someone is in the later stages of the disease.

- Severe memory loss sometimes resulting in not recognising family members
- Difficulty with communication and finding the right words
- Changes in behaviour such as increasing anxiety
- Loss of mobility and even becoming bedbound
- Loss of control over bladder and bowels
- Jerking movements and sometimes fits
- Problems with eating and drinking often resulting in weight loss
- Swallowing difficulties – food and fluids going down the wrong way and making them cough
- Frequent infections and fevers which may eventually not respond to antibiotics.

These symptoms may develop very slowly over months and years, but for some people the onset is rapid and takes place over weeks and months.

## Comfort care

At this stage in the illness, care is focused on providing comfort and quality of life. It is often painful and distressing for family and friends to see this happening to a person they love. Care home staff will work to keep the person warm and comfortable and maintain their dignity at all times.

Comfort and safety in a familiar environment are most important. If family and friends are able to take part in helping and giving care this can enhance the person's quality of life and is often comforting and rewarding for both the resident and family.

The following advice may be helpful.

- Establish a regular routine as this often makes a person feel safe
- Furnish their bedroom with items that have meant a lot to them, for example family pictures, paintings, photos, small items of furniture, ornaments and china pieces
- Use a favourite drinking cup or mug
- Have their favourite music playing in the room
- Give them a tin of their favourite biscuits or sweets
- Provide them with clothes that are familiar and comfortable in their favourite colours
- Ensure that everyone is aware of their likes and dislikes in all areas of their lives.

## Visiting

It is sometimes extremely difficult to know what to do when visiting someone with very advanced dementia. Some of the following tips may be useful.

- Bring scented flowers
- Play familiar music
- Use scented creams to massage their hands and feet.

## Planning future care for your relative or friend

Planning ahead for someone who no longer has the capacity to make their wishes known can be difficult. If you hold Lasting Power of Attorney (LPA – Health and Welfare) your decisions about the person's care are legally binding. Where there is no LPA then decisions have to be made in the person's 'best interest' by health and social care staff.

Health and social care workers have a duty to consult with relatives and friends in order to learn about the person's values and previously expressed wishes. It is likely that what you know about your relative or friend would be very helpful in supporting the decisions that have to be made to ensure good end of life care. You may be able to help answer important questions.

- Has your relative or friend ever spoken about where they would like to be cared for at the end of their life?
- Do they have any faith or beliefs that we should know about?

- Have they ever expressed strong feelings about going into hospital?
- Do they have any likes or dislikes that would be helpful for others to know?

Most people would choose to die in their own bed, and in their own home with people they love around them. We know from experience that people with advanced dementia rarely benefit from hospital admissions at the end of their lives, and find them very traumatic. Cardio-pulmonary resuscitation (CPR) is almost never effective or appropriate in frail older people with advanced disease.

## Support for carers

It is often painful and upsetting to see the person you love losing their memory, their strength and appetite. It can be worrying and frightening. Care staff can help you understand what is happening now and what to expect as the condition deteriorates. They will spend time discussing this with you and answering any questions and concerns you may have.

If you would like to talk with the doctor, care home staff can arrange a meeting for you.

It is important to look after yourself, physically and emotionally and to seek help if you feel unsupported. Care home staff may not know how you are feeling unless you tell them.

# Helpful information

Helpful information can also be obtained from the following organisations.

## **Alzheimer's Society**

Telephone 020 7423 3500

Email [enquiries@alzheimers.org](mailto:enquiries@alzheimers.org)

[www.alzheimers.org.uk](http://www.alzheimers.org.uk)

Alzheimer's Society is the charity working to improve the quality of life of people affected by dementia in England, Wales and Northern Ireland

## **Admiral Nursing DIRECT**

Telephone 0845 257 9406

Email [direct@dementiauk.org](mailto:direct@dementiauk.org)

[www.dementiauk.org/what-we-do/  
admiral-nursing-direct/](http://www.dementiauk.org/what-we-do/admiral-nursing-direct/)

Telephone information and support line for people with dementia and their family, carers and professionals, supported by the charity Dementia UK

## **Carers UK**

Telephone 0808 808 7777

Email [info@ukcarers.org](mailto:info@ukcarers.org)

[www.carersuk.org](http://www.carersuk.org)

A charity which provides information, advice and support for carers, and campaigns on their behalf



### **St Christopher's Hospice**

51-59 Lawrie Park Road, Sydenham, London SE26 6DZ  
Telephone 020 8768 4500 Fax 020 8659 8680

### **St Christopher's Bromley**

Caritas House, Tregony Road, Orpington BR6 9XA  
Telephone 01689 825755 Fax 01689 892999

**[info@stchristophers.org.uk](mailto:info@stchristophers.org.uk)**

**[www.stchristophers.org.uk](http://www.stchristophers.org.uk)**

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