



PACIFIC  
· CARE ·

DEMENTIA IN DETAIL



# THREE STAGES OF DEMENTIA

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It's quite common to hear the dementia journey described as a series of stages in which different symptoms and challenges can emerge. Dementia is a progressive condition which slowly gets worse. The crucial word here though is slowly. The dementia journey usually lasts several years.

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## EARLY

1

Symptoms are mild and, despite being quite forgetful, most people are still living relatively independently. They might also still be driving or working. Loved ones may begin to notice subtle changes and signs that something 'isn't right'. They might be frequently losing their purse, or keys or forgetting appointments. If they seek advice from a doctor at this point, they could be told they have mild cognitive impairment.

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## MIDDLE

2

This is often the longest stage and can last many years. Forgetfulness and confusion gradually becomes more pronounced, loved ones might become withdrawn, depressed or moody, and need an increasing amount of help with daily life. Whilst they can probably still bathe and take care of other personal needs on their own (such as using the toilet), they may find it difficult to dress appropriately or may forget simple facts about themselves, such as their address or phone number. However, they usually recognise family and friends and can recall events from decades ago (especially their childhood) with great clarity.

## LATE

3

Most people at this point become increasingly frail, they may not talk or communicate very much and can appear to be in a world of their own. They often need round-the-clock care. You might need to help them with bathing and they may also become incontinent. You could notice changes in their personality and behaviour – such as anger and aggression – which can be upsetting and difficult to cope with. However, although they might be very confused, they often still know and recognise the people closest to them.



# GOOD TO KNOW

Everyone's dementia journey is unique – some people will move slowly through some dementia stages and quicker through others. It's important to make the most of where the person is now, and to focus on what they can do, rather than worry about what they may, or may not, be able to do later down the line.



Eventually, you may not be able to go on looking after your loved one with dementia at home. Perhaps they have become so ill they need a team of people to care for them. Or perhaps your own health has changed. Not everyone can be a carer and not everyone can go on caring as long as they wish they could. It is important to understand and accept what you can and can't do. Most people with dementia are likely to need to move into long-stay care in the later stages of their illness.



**CARE**



**SUPPORT**



**NURTURE**



**COMFORT**



Try not to take this difficult decision on your own. Involve the person as much as you can, and take into account any wishes they may have expressed in the past. But remember that things change, and sometimes it may be in the person's best interest to move into a care home, even if that isn't what they would have hoped for. Involve other family members too if you can. Professionals such as the social worker, doctor, nurse or other care workers can help you. It may help to also talk to other carers who have had to make a decision about long-stay care.

The late stages of dementia can undoubtedly be harrowing for loved ones, it's important to remember that the person with dementia may not experience it in the same way, since they no longer really understand what's happening. Providing everyone does their best to keep them comfortable and calm, there's every chance this stage can end peacefully for them – and for you.



# THE MOVE & AFTER

1

## PLAN AHEAD

Spending time planning before the person moves can help to make it easier for both of you. You will have to cope with practical issues as well as with your emotions.

2

## GETTING TO KNOW YOU

The care home will put together a care plan for the person with dementia. You can give them important information about the person's needs, likes and dislikes. If the person has a "life story book" make sure they take it to the care home, so that staff can learn about their life. You can also say if you would like to be involved with ongoing care; but don't feel that you should do anything more than you would like to do.

3

## READ UP

The booklets "Letting Go Without Giving Up" and "Continuing to Care for the Person with Dementia" are available from the Dementia Helpline and are for carers who want to continue to be involved in the life of the person they have cared for. They look at the impact of the move on the carer and on the person, and practical ways of staying involved and making visits more enjoyable.

4

## ADJUSTMENT

Personalise the person's room with familiar things. Talk to the care home about how the person is settling in, and about the care plan. Give it time – both you and the person with dementia will need time to adjust.





5

### SETTLING IN

Most people find that the person settles in with time, and visiting gets more enjoyable. Your relationship may even improve now that you don't have to deal with day-to-day caring.

6

### VOICE YOUR CONCERNS

If you're not happy about the person's care, talk to the care home first, and make a complaint if you are still not satisfied.



# COPING WITH YOUR FEELINGS

It may be very hard for you to accept that you can no longer provide care for the person with dementia. You may feel guilty or think that other people will disapprove. It may be hard to know what you will do with all the spare time you suddenly have. You may feel lonely without the person you were looking after and feel a sense of loss. It's probably impossible to avoid difficult and painful feelings which is why it's important to talk to others about how you are feeling.



Talk to friends or professionals about how you feel, or call the Dementia Helpline. It can also be helpful to talk to other carers at a carers support group. In time you will probably realise that your decision is for the best. It can be a comfort to see the person settle in and enjoy your visits. Although the care home will cope with the day-to-day caring, you can still be involved. Taking the person out for a walk, a run in the car or a day at home may still be possible. You may also be able to help with personal care, if you want to.

## END STAGE DEMENTIA CARE

It can be traumatic to watch a loved one with dementia nearing the end of their life. But knowing what to expect in the end stage of dementia may bring you some comfort.

Dementia is not a terminal illness but it does tend to shorten lives. However, none of us are immortal and no matter how well you care for a person with dementia or how much you love them, at some point their dementia journey will reach its end.

As difficult as this may be to accept, many people do find the final stage of the illness easier to handle if they are prepared and can do their best to allow a loved one to experience a peaceful and dignified death.



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🌿 **What are the warning signs that life is nearing an end?**

Generally speaking, as your loved one reaches the end of their life the symptoms of dementia may become increasingly pronounced which can be very upsetting to witness.

🌿 **Why does this happen?**

As they become increasingly frail—physically and mentally—you may find that your loved one succumbs more easily to infections, or is more likely to have a fall or accident which leads to a hospital stay and can, in turn, cause further decline until they become very weak.

🌿 **You aren't alone**

Watching a loved one die is undoubtedly painful and harrowing, however you should both receive support from professionals. They will receive care which manages their pain and symptoms and provides psychological, spiritual and social support.

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**RESPECT THEIR WISHES**

Hopefully you will already have given end of life care some thought and have some idea of what the person you're caring for would like to happen. Perhaps you've encouraged them to make an advanced decision or to have a Do Not Attempt Resuscitation Order in place. Ideally, they will have told you their views about important issues such as whether they'd like to remain at home and who they may want to visit, including spiritual advisors.



## WHAT YOU CAN EXPECT



### NURSING

Your loved one should have regular visits from their GP and sensitive nursing care from nurses skilled in palliative care.



### EQUIPMENT

Palliative nursing often requires specialised equipment such as adjustable beds and lifting aids.



### MEDICATION

A wide range of pain relief medication is available to people in the last days of life, to make sure they are as comfortable as possible.

## Letting go

Maybe you don't know what to do or how to behave? Here are a few ideas:

Sit quietly with your loved one, hold their hand gently. Just being there at the bedside can be very peaceful and you don't have to talk all the time.

If they're awake, do they have something pleasant to look at? Can they see the garden, favourite photograph or painting, or a flower arrangement?

Make sure their room has soft lighting and have some favourite calming music playing quietly in the background. Arrange a visit from a spiritual advisor or member of the clergy, if you feel it would bring comfort.

## Good to know

Caring for someone in the final hours of their life is often a very intense and intimate experience which allows a carer to feel close and connected to their loved one. Helping a person with dementia to experience a peaceful death may be, after all, the final gift you give them. Many carers say that knowing they did their best, right to the end, brought considerable comfort in the months ahead.

# PUBLICATIONS



## 1. ALZHEIMER SCOTLAND BOOKLETS

All available in full text online at [alzscot.org](http://alzscot.org). Free to carers in print or on tape from the Dementia Helpline.

## 2. DEMENTIA

Money and legal matters – a guide for carers.

A comprehensive guide to planning for the future, benefits, community care rights and financial assessments.

## 3. DON'T MAKE THE JOURNEY ALONE

Written by three people with dementia, this booklet offers personal thoughts, support and practical advice.

## 4. GETTING HELP FROM YOUR DOCTOR

A guide for people worried about their memory, people with dementia and carers.

Looks at how dementia is diagnosed, treatments, getting help and support, keeping well and when the person with dementia should see the doctor again.

## 5. LETTING GO WITHOUT GIVING UP.

For people who have been caring at home for family, partner or friend going into a care home.

## 6. CONTINUING TO CARE FOR THE PERSON WITH DEMENTIA.

For people who have been caring at home for family, partner or friend going into a care home.

## 7. LOOKING AFTER YOURSELF

This booklet encourages carers to look after themselves as well the person with dementia.

## 8. A POSITIVE CHOICE

Long-stay care for a person with dementia.

A helpful booklet by Alzheimer Scotland. Based on the experiences of carers, this booklet gives practical information on long stay care and help to deal with the emotional aspects. Includes information on help with care home fees and a checklist of what to look for when choosing a care home.

## 9. AGE SCOTLAND FACTSHEETS

Wide range of fact sheets available online at [ageuk.org.uk/scotland](http://ageuk.org.uk/scotland)

## 10. HEALTH SCOTLAND BOOKLETS

Available free to carers from the Dementia Helpline and local health promotion departments.

## 11. WORRIED ABOUT YOUR MEMORY?

This booklet looks at what can cause forgetfulness and when to see the doctor if you are worried.

## 12. FACING DEMENTIA

Information for people with dementia and their carers, looking at practical arrangements and coping skills.

## 13. KEEPING SAFE

A guide to safety when someone with dementia lives alone.

Also useful for carers of people with dementia who do not live alone, this booklet looks at how to assess what is a risk, balancing risks and independence for people with dementia and practical steps.

## 14. UNDERSTANDING DEMENTIA

A guide for young carers

A colourful booklet for 12 to 18-year-olds who are close to someone who has dementia.

## 15. SCOTTISH GOVERNMENT GUIDANCE

GUARDIANSHIP & INTERVENTION ORDERS:  
Making an application – a guide for carers

Available on the Scottish Government website at [scotland.gov.uk/publications](http://scotland.gov.uk/publications)

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For these publications  
and more contact:

**Dementia Helpline:**

**08088 08 30 00**

**Alzheimers Scotland:**

**08088 083 000**

**Age Scotland:**

**08001 244 222**

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to help...

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and advice, please  
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DEMENTIA

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dementia care eases the  
tensions associated with  
living with dementia.



DAY CARE

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company, entertainment and  
outings are part of our  
daily schedule.



RESIDENTIAL

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warm, calming and homely  
environment that enhances  
capabilities whilst supporting  
declining abilities.



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