

## MAINTAIN GENERAL FITNESS AND HEALTH

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The general state of health of the person with dementia will affect their overall condition. If good general health is maintained it will help to preserve existing physical and mental abilities for as long as possible as well as encouraging independence and sustaining morale.

### **Keeping a check on the condition of someone with dementia**

As the main carer you are the best person to monitor any changes in the condition of the person you care for. They will still catch the common colds, coughs and minor complaints that make everyone uncomfortable. However, they are also more prone to certain ailments, such as chest infections, and are more likely to fall. People who are unable to move easily and who spend much time in one position may develop pressure sores or hypothermia in cold weather (a serious drop in body temperature, which can lead to death). All these things need to be carefully looked for, as the person may not be able to explain to you what is wrong and may experience needless discomfort. Sometimes you may be able to give a remedy yourself, but do remember that even everyday drugs such as aspirin may worsen their symptoms unless given in small doses. A check with your doctor is advisable if the symptoms persist, or if you are unsure what to do.

A district nurse, social worker, or GP who makes regular home visits can also look out for any changes and reassess the person's needs. They can refer the person with dementia to specialists or services for particular problems, such as incontinence. A GP can prescribe medicines that may give relief from problems such as sleeplessness and walking at night, depression and delusions, although care needs to be taken when prescribing drugs as they can increase the confusion.

### **Diet**

As the disease progresses there may be problems with the practical side of eating, and tastes for food may alter. If someone is experiencing difficulty with eating or swallowing their food this may lead to problems with getting a balanced diet. Your GP can refer you to a speech therapist who can give advice on these sorts of problems.

It is most important to try to include all the ingredients of a balanced diet, especially as the symptoms of dementia can be worsened by an inadequate diet. Try to provide something they like to eat from each of these food groups every day:

- Meat, fish, eggs, pulses (dried peas, beans, etc.).
- Fruit and vegetables.
- Cereals and bread.
- Dairy produce, milk, cheese, etc.

Make sure they drink enough liquid to prevent them becoming dehydrated or constipated. If constipation

becomes a problem an increase in high fibre foods, such as wholemeal bread, cereals and fruit and vegetables, will help. For more dietary advice ask your GP or health visitor.

### **Physical activity**

Physical activity can be pleasurable as well as helping to preserve existing abilities. The kind of exercise depends on the person's condition and what they are used to, but the best kind of activity is usually something they like doing such as walking, dancing, gardening, swimming or playing bowls – at least until these things become impractical. As the disease progresses, a gently stroll in familiar streets or a park may be more suitable.

### **KEEP CHANNELS OF COMMUNICATION OPEN**

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*'He can't get the words ... He knows what he wants to say and he expects me to know. He gets angry and very frustrated. The only consolation is that five minutes later he's forgotten and gone on to something else. His frustration doesn't last – it lasts more with us.'*

As the person's dementia progresses there will be increasing problems of communication between them and others. There will be difficulties for them in expressing themselves and for carers in explaining things and making themselves understood. This will affect daily activities and the expression of thoughts and feelings.

Talking becomes a problem for the person with dementia. They may use the wrong words, forget words completely, endlessly repeat words or phrases and lose the thread of the conversation. This can be distressing for both them and the carer.

There are several things that can be done to help maintain open channels of communication. At a practical level it is extremely important to check that the person's senses are not additionally impaired by, for example, a hearing aid that does not work properly, dentures that are too loose, or glasses that are no longer the correct prescription.

In conversation you should remember to speak clearly, simply and slowly and to talk about only one topic at a time. Allow extra time for the person to reply. You may need to repeat things several times, find a simpler way of saying something, or guess the sense of what they are saying. If the person is confused, remind them of basic information gently, perhaps by using a picture or object. Try not to contradict or embarrass the person by correcting them bluntly.

Of course, speech is not the only or the most important way of communicating. Body language – the way we look at a person, how close we move towards them, how we touch them – can be more important than words alone. In the later stages of dementia, looking and touching may be the main ways of expressing affection and care for the person, and their body language also gives you clues about what they mean and how they are feeling.

**This woman's mother no longer recognises her, but they still communicate:**

*'I spend an hour sitting with her with my arm round her cuddling her and I tell her that she's the loveliest mother I've ever had, and she just keeps rubbing my hand and face and saying "I like you".'*

## USE MEMORY AIDS

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In the early stages of dementia memory aids may be useful. These are things that may help to jog the



*'Their world stands still. He doesn't know what 3.30 or Tuesday mean, so what's the point in telling him?'*

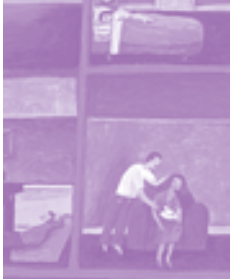
*'Supposing he remembers? There he is sitting in a wheelchair, can't walk half a yard, and there am I trying to bring his memory back.'*

memory, clear confusion and disorientation, and keep things as normal as possible.

Here are some things carers have found useful:

- Frequently remind the person with dementia of the time, day and where they are.
- Keep a clock with a large clear dial on view.
- Keep a calendar that can be changed by the day, month and year.
- Label the doors of rooms, such as the bedroom and lavatory, with words, pictures and colours.
- Keep photos of familiar people and the family on view.
- Leave the personal possessions of the person with dementia where they can easily find them.
- Keep furniture in the same place.
- Keep checklists of things to do that day, or lists of expected visitors, which can be ticked off.
- Set things out in the order in which they have to be done.
- Leave out only the things required, for example, one day's drug supply.
- Leave a simple, clear note with an address if you are going out.
- Don't forget textures, tastes and smells can also evoke memories.

Eventually, however, as the disease progresses, even these aids may become less useful as these comments from carers show.



## DEALING WITH COMMON PROBLEMS

**P**eople with dementia may not be able to carry out everyday tasks on their own.

For example, they may lose their ability to cook or wash themselves, and may not recognise the need to go to the toilet. This chapter highlights common problems and suggests practical solutions on how to deal with them.



## DRESSING

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People with dementia sometimes don't remember which clothes should be put on, in which order, nor how to put them on. They may end up wearing several skirts and no underwear, or with things on back-to-front or done up incorrectly. They can have difficulty doing up buckles, laces, bras and so on. They may not recognise the need to change their clothes, for example, when they are dirty or if they are going to bed. They may choose to wear inappropriate clothing – for example, going out in the daytime in their nightwear.

### Possible solutions

Try laying out clothes in the order they have to be put on. Avoid clothes with complicated openings and fastenings. Replace buttons with zips and Velcro (but show them how to use them), buckles and belts with elastic, lace-up shoes with slip-ons and men's 'Y'-front pants with boxer shorts. Choose women's bras with a front opening.

You may need more persuasive tactics to overcome the last two problems. They may resent interference. Don't argue, try to encourage instead. Set out the clean clothes saying, 'These are the clothes you chose to put on', or 'That dress really suits you'. You may have to become tolerant of their preferences. One carer's father frequently wore four pairs of trousers at one time, another's mother went to the day centre in her dressing gown. But ask yourself if these sort of things really matter – for whom is 'problem' behaviour a problem?

## WASHING AND BATHING

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Forgetting to wash and no longer recognising the need may be problems for people with dementia. They may have forgotten what to do, or be unable to wash certain parts of their body because of physical impairment. Some will be unable to climb in or out of the bath safely or manipulate taps. They may be embarrassed by helpers seeing parts of their body usually kept private, and may refuse to wash at all. These problems are increased if they are incontinent and need to wash frequently.

### Possible solutions

Try to establish and maintain a routine for washing. You will need much tact. You cannot tell them to wash but perhaps you can emphasise the more pleasant aspects, the comfort of warm water, perfumed soaps and so on. You may have to tell them step by step what to do, wash with them, or clean your own teeth to demonstrate. You may have to help or supervise them because of physical difficulty and risk of accident or injury. There will be difficulties for the carer too if the person they care for is large or heavy and needs to be lifted. You may be able to get a bath attendant or aids, such as rails and a bath seat, which may alleviate some problems (see *Practical help* on p.46).

Incontinence can be a real problem, especially if embarrassment leads to concealment. It can also be a problem for the carer who may be just as uncomfortable. Try to be matter-of-fact: 'You know and

I know that you're wet, and you'll get sore if you don't wash'. Telling them off or showing that you are upset won't help.

## GOING TO THE TOILET

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People with dementia may forget to go, leading to incontinence and constipation. They may forget where the toilet is, even in their own home. There may be problems undoing their clothing in time. At night they may lose their way in the dark or mistake some other object, such as a waste-bin, for the lavatory.

### Possible solutions

At regular intervals either remind them or take them. Label the door, or paint it brightly. Make sure clothing can be easily removed. (Try some of the possible solutions from *Dressing* on p.66.) Take them before they go to bed. Leave a lamp with a low wattage bulb on, use night-light plugs or stick luminous tape on the wall as a guide. A pot by the side of the bed may help – this used to be common practice for most people when lavatories were outdoors.

The RADAR National Key Scheme offers independent access to disabled people to locked public toilets around the country. The key is free of charge (though in some cases VAT will be charged) and can be obtained from RADAR on [www.radar.org.uk](http://www.radar.org.uk) (see *Useful organisations* on p.91).

## COOKING

The problems are most severe if the person with dementia lives alone. The ability to cook even simple meals may be lost. Just buying food and keeping it fresh may be beyond their capacity. They may eat food that has gone bad or, in some cases, even pet food. The gas cooker may be switched on and left unlit, pots may be left to burn. Poor physical co-ordination can lead to burns and scalds or cuts from utensils. The combination of these problems leads to malnutrition in many people with dementia who live alone.



For those living with others, the problems are diminished if the carer cooks for them – the problem then may be for the carer who is unused to buying or cooking food.

### Possible solutions

There are a few safety devices that can be fitted to cookers to prevent some of these problems (see *Practical help* on p.46). Invest in an electric kettle that switches itself off. Remove sharp knives and other potentially dangerous utensils. You may need to visit daily to help or supervise – or arrange for someone else to be there. Try to get the meals-on-wheels service to call (see *Practical help* on p.46), but check to see that the person knows how to open the container. You may need to put the food out on a plate for them if they don't understand what the carton is for.

Most libraries stock books about cooking on a range of themes – 'for beginners', 'for small households', 'for those on a budget' and so on.

## EATING

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Many people with dementia forget whether or not they have eaten. Some don't want to eat and claim they have just done so; others want to start on the next meal as soon as they have finished the previous one. They may develop strong dislikes of certain foods and cravings for others. Some don't know how to eat. They may forget how to use cutlery and generally be very messy. They may play with their food, not realising it is to go in their mouth. They may be confused by different foods on one plate. Others have physical problems; they can't chew properly and have difficulty swallowing, which could lead to choking. Some forget to drink and may become dehydrated.

### Possible solutions

Have regular times for eating, and eat with the person with dementia. If they often want to start another meal soon after the last one, keep some washing up in the sink to show the remains of the last meal. If they will eat only certain foods you may have to ask your GP about diet and vitamin supplements.

Don't worry about table manners – spoons are easier than knives and forks, and fingers came first of all! Use plastic tablecloths and place mats so mess can be cleaned up easily.

You may have to remind them how to eat by talking them through each stage, or show them by eating something yourself. Sometimes spoon-feeding may be

necessary. Try to keep food simple. Cut it up or keep it to one texture – soft, thick foods are best. A mixture of liquid and solid may lead them to swallow instead of chewing and could result in choking. Check that dentures fit and are left clean. If the person is experiencing problems with eating or swallowing you can ask your GP for a referral to a speech therapist.

You may find it helpful to provide ‘finger foods’, which are intended to be eaten without cutlery and can help people with dementia to be independent in eating.

Make sure that the person has several drinks a day (at least eight cups/1500 ml), and more in hot weather. It is important to make sure the drinks are not too hot – they may have lost their judgement and hurt themselves. You may need to use a spill-proof cup like the ones sold for children.

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## GOING OUT ALONE AND SHOPPING

The most worrying problem for many carers is the safety of the person they care for (see also *Wandering* on p.74). Traffic presents a threat on even the quietest roads and crowded, busy streets or shopping centres can confuse and alarm. A person with dementia may not recognise even familiar places, and become lost and frightened. Other people are not always helpful and may interpret confused behaviour as drunkenness.

If a person with dementia is shopping alone there are additional problems of remembering what they went out to buy and of handling money.

### Possible solutions

Many carers are rightly reluctant to prevent the person with dementia going out alone as it is often the last thing they can do on their own. Encourage the person to walk in the park or other area safe from traffic and crowds. If this is not possible you may have to accompany them – perhaps take them part of the way to a point where they cannot go wrong, or meet them on the return journey. One carer relied on a well-trained and trusted dog to help her husband cross the road and bring him home.

Persuade them to carry identification – a bracelet or card explaining that they might become confused and showing where you can be contacted. Or sew a nametape into a pocket.

If they are shopping give them a clear note and only the amount of money they will need. They will be able to buy only one or two straightforward items. If they need clothes you will have to go with them. Do not be embarrassed to explain the problem to shop assistants who are usually most helpful once they understand.

### DRIVING

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People with dementia are able to continue driving in the early stages of the disease. However, the DVLA should be told that the person has a diagnosis of dementia so that regular checks on their ability to drive can be made. It is important to remember that it is a criminal offence not to inform the DVLA of a medical condition, such as dementia, which may affect a licence holder's ability to drive.

### Possible solutions

Once you feel that someone should stop driving, broach the subject with them gently. Some may be pleased to be rid of the responsibility driving brings. Others, who resent their loss of independence, may find giving up driving particularly hard. If gentle persuasion doesn't dissuade them from driving, you will have to take firmer action. In the first instance, offer to do the driving (if you can), or suggest using public transport. If need be, hide the car keys or immobilise the car (go to a garage for advice about the easiest way to do this). You can also talk with your GP if you are worried about the fitness to drive of the person you care for. Remember, many insurance companies require a medical certificate of fitness before insuring older drivers.

## ALCOHOL AND CIGARETTES

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If the person is in the habit of drinking alcohol in moderation, there is no reason why it should be stopped. Having a drink may be one of their remaining pleasures, and something you can enjoy together. You should take care, however, that alcohol is not left out where they can help themselves. If they are on medication, remember to check with the GP or pharmacist that the drugs mix safely with alcohol.

The use of cigarettes represents a greater danger. People with dementia may not be safe with matches, and they may smoke in bed, leave lighted cigarettes on the edge of armchairs, or throw them away in waste-paper baskets.

### Possible solutions

Give them a cigarette lighter that cuts off when their finger is removed from the ignition button. If they really need to smoke, it should be only under strict supervision. It is far better to dissuade them from smoking. If persuasion fails, choose a moment when they are otherwise occupied to remove their cigarettes. It may be reassuring to know that many people with dementia forget to smoke so don't miss the habit once it is broken.

## WANDERING

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'Wandering' is a common and difficult problem to deal with. People with dementia may appear to others to be walking aimlessly or anxiously around the home, or wander around the neighbourhood having slipped secretly out of the house. In fact most people with dementia are walking about with a purpose but find it difficult to express what it is. They may walk long distances to old haunts and get lost. You will be worried about their safety and their own bewilderment or fear.

### Possible solutions

If you can work out a reason for the 'wandering' you may find a solution. Sometimes it results from general restlessness and boredom and is a sign that the person needs more stimulation or physical activity. They may be searching for things they think are lost. Keeping personal possessions on view may help here (see also *Losing things and accusations of theft* on p.78). Often they feel insecure and may need both the emotional reassurance that you care and the concrete reassurance

of things being kept in the same places and routines maintained. 'Wandering' frequently starts after a visit to a strange place – for example, after a holiday – or after a change of habit – such as starting at a day centre, in which case it may help if you go with them a few times until the change becomes familiar. Moving home can be very distressing for people with dementia and should be avoided if at all possible.

If you can find no apparent reason for the 'wandering', then you have to prevent them finding their way to places where they will be at risk. You may have to lock some rooms at home and will need to install unfamiliar or difficult locks on street doors. Put the locks on the bottom of the door where they are less likely to find them.

An identity bracelet worn by the person with dementia, giving details of how you can be contacted, is an additional safety measure. If they do still manage to leave the house or walk away from you while you are out, contact the local police who are often able to provide help.

## NIGHT DISTURBANCE

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Many people with dementia are restless at night and disturb the whole household by wandering and making a noise. This can be one of the most wearing problems for carers.

### Possible solutions

Again, if you can find a reason, you might be able to alleviate the problem. Some of the more obvious reasons may be that the person:

- Is looking for the toilet.
- Sleeps too much in the daytime.
- Goes to bed too early.
- Needs less sleep.
- Is not comfortable.
- Wakes up and is confused or frightened.
- Thinks it is daytime.

Make sure they have been to the toilet before going to bed (see also *Going to the toilet* on p.68 and *Incontinence* on p.78). Try to discourage long sleeps during the day, perhaps by increasing physical activity. Try to make them as comfortable as possible. A bedside lamp with a low-wattage bulb left on may help if the person wakes up frightened. Sometimes talking gently to the person will reassure them too and send them back to sleep. If they think it's daytime or they think they need to get up for some reason you might have to play along with them as arguing could lead to upset. One carer spoke of her husband who regularly woke at night wanting to go to the shops. She always said, 'All right then, let's go,' walked him round the room and back to bed by which time he'd forgotten where he was going.

If nothing seems to work and the disruption to your own sleep makes you unable to cope, you will have to ask your GP about medication.

## REPETITIVE QUESTIONING AND ACTIONS

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This can be extremely irritating for carers! Usually the person with dementia is unaware of what they're doing, although their behaviour may reflect underlying anxiety or insecurity.

### Possible solutions

There is no point getting angry or saying, 'I've just told you 10 times'. Try to distract them by talking about something else or giving them a different activity. Sometimes writing down the answer helps. Reassuring them of your concern may reduce insecurity. You may also have to develop your skills at turning a deaf ear.

Sometimes it will help to give the person the things they ask for rather than explaining/arguing that perhaps you may have made them a cup of tea five minutes ago. The time spent explaining/arguing can cause more distress or frustration for both parties.

## CLINGING

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Some people with dementia become reluctant to let their carer out of their sight and follow them from room to room. This can be very distressing for you, as it means you're allowed no privacy, often even to go to the lavatory.

They probably behave like this because they're feeling insecure, and the caregiver represents security. When they see you leave the room, they forget that you will come back, and get frightened.





### **Possible solutions**

While you're gone, give them some simple task to do or use the clock to point out when you'll return. Reassure them that you'll be back when the task is finished or when the clock reads a certain time.

If this happens to you, it is important that you use sitters or find some other way of getting a break.

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## **LOSING THINGS AND ACCUSATIONS OF THEFT**

Many people with dementia really do forget where they have put things; others deliberately hide things and then forget. In either case they may accuse you or someone else of stealing the missing items.

### **Possible solutions**

Try not to take their accusations too seriously. Don't deny the charge and get into an argument – it won't be possible to reason with them and they will become more upset. Try to find out if they have a regular hiding place, such as under the mattress or in an old shoe. Keep replacements of essential items, such as keys or glasses. Put away or lock up valuables, money or dangerous things. Get into the habit of checking rubbish bins before emptying them. Make sure that other people who help care for the person are aware of the problem.

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## **INCONTINENCE**

Many people with dementia may be incontinent occasionally and wet the bed. Regular bladder incontinence and bowel incontinence is less usual. But

even the occasional accident can be difficult to deal with. It is embarrassing and degrading for them and distasteful for the carer who has to clean up.

However, incontinence is a condition that can be greatly improved by medical treatment, so ask your GP or health visitor for help.

If incontinence becomes frequent or develops suddenly always check with your GP, as there could be a medical reason.

There could be several reasons for occasional incontinence:

- They forget to go to the toilet.
- They can't get to the toilet in time.
- They can't undo their clothing easily.
- They can't find their way at night.
- They have an attack of diarrhoea.

### **Possible solutions**

- Take the person to the toilet regularly.
- If the toilet is upstairs or some distance from where they spend most of their time try to get a commode (see *Practical help* on p.46).
- Clothing can be adapted by using Velcro instead of buttons or zips. Men's 'Y'-front pants can be replaced by boxer shorts. Your district nurse can tell you about the special clothing that is available. If you're not already in touch with your district nurse ask your GP to put you in touch.