

Caring for someone with dementia

Caring for someone with dementia can seem a daunting prospect.

Providing care and support

Dementia is a disease that can eventually affect a person's ability to understand, to remember, and to connect with the outside world. They will need your support to do some basic activities of daily living.

But all these changes happen slowly, and not everyone will experience the same difficulties.

This section gives advice on:

- Medication and monitoring
- Advice on eating
- Help with personal care
- Incontinence
- Mobility issues

Medication and monitoring

There is no cure for dementia and no medicine that will reverse dementia, but there are medicines that may slow down the progression of the condition.

Medication

There are some medicines that may be used to help in some causes of dementia. Medication is usually used for two reasons:

- as treatment to help with symptoms that affect thinking and memory; and
- as treatment to help with symptoms that affect mood and how someone behaves.

Speak to the individual's GP (with their permission or if you are the Appointee in the Health and Welfare Lasting Power of Attorney) about what medication is best for them. The Alzheimer's Society also has a factsheet on its website (www.alzheimers.org.uk) on its website that includes a list of questions to ask their GP.

All medications can cause side effects and many can react to other underlying conditions. Be aware that common side effects of medications are dizziness, constipation, a dry mouth or nausea etc. - don't be alarmed and think that it is connected to the dementia - talk to the medical professionals.

Therapies that you might hear about:

Regular physical activity

Keeping physically active is proven to be beneficial to all and people with dementia should be supported to remain as physically active as possible.

NHS Choices offers guidance which can be found on their website (www.nhs.uk/conditions/dementia-guide).



Cognitive Stimulation Therapy (CST)

This is a series of meaningful activities over a number of weeks that can involve carers as well as the person with dementia. The aim is to stimulate the brain and CST may help to improve memory, language and problem-solving abilities. CST is usually offered in the earlier stages of dementia and may be provided by a

memory clinic. Find out more on the CST dementia website (www.cstdementia.com).

Reminiscence therapy

Encouraging people to talk about their past may help stimulate their long-term memory. There is some useful information on the SCIE website (www.scie.org.uk).

Whatever treatment or medication is prescribed, the person with dementia will be monitored by their GP, specialist clinics or health and social care professionals. It is important also for you, as a carer, to regularly monitor how they feel, so that you can give an accurate account to the person in charge of their health. This helps them gain a true picture of their well-being; and if necessary, make any medication adjustments. To find out about keeping someone with dementia active and occupied visit the dementia section of SCIE website.



Monitoring

Pain management

We tend to accept pain as we become older as just something that happens with age and something that we have to put up with. Also, one person's experience of pain is different to another's. We all get used to managing pain in our own way. This means that we don't always know when we should tell people about any pains. Sometimes they can be a sign of something more serious.

For someone with dementia, this can be doubly difficult because they might find it harder to explain to people - either because they forget or because they have problems finding the right words. You may notice changes in the individual's behaviour, demeanour, mobility, appetite and general wellbeing. This means the pain might go undetected as you may think that these changes are as a result of the dementia.

Some of the common causes of pain they might experience are:

- constipation,
- a urinary tract infection,
- arthritis, toothache,
- uncomfortable dentures,
- uncomfortable or tight clothing or shoes; or
- other medical conditions.

Underlying causes of pain need to be treated and managed e.g. constipation, where the person requires laxatives. If the person suffers with pain as a result of a chronic condition e.g. arthritis, seek medical advice if you think that the medication is no longer effective. However, be aware that some pain-killers can cause side-effects such as constipation, dizziness and a general feeling of being unwell.

Spotting the signs of infection

While most of us know when we feel unwell, a person with dementia may not. Or they may feel different but not realise that they could be ill. Or they simply may not be able to find the words to express what they're feeling. If they have an infection and it goes undetected this can lead to behavioural changes, typically increased confusion or



restlessness. This could be the first signs that you notice that they are unwell. If you do notice very obviously different behaviour, seek medical advice as soon as possible.

Common types of infections in people with dementia are urinary tract infections and chest infections. Whilst they can be treated, they can be preventable.

Becoming dehydrated is one of the most common causes of urinary tract infections. Ensure the person drinks regularly. Aim for six to eight cups of tea or glasses of juice or water a day.

Check with the health professionals about getting a flu jab – you can find out more about influenza vaccinations on the NHS website (www.nhs.uk/vaccinations).

Infection is a common cause of increased confusion and pain in someone with dementia. If you observe any of the signs or symptoms listed below make sure you seek medical advice.

- having difficulty passing urine or irregular or difficult bowel movements,
- loss of appetite,
- problems sleeping,
- hallucinations,
- problems moving,
- feelings of agitation or restlessness; or
- a raised temperature



Advice on eating

Eating and drinking habits often change as we get older and this can be more noticeable in people with dementia.

Eating and drinking

Over time, a person with dementia can find eating and drinking more difficult. Mealtimes can become a struggle, either because they find the effort too hard, they simply don't recognise that they are hungry and need to eat, or they may think they have already eaten. They may adopt messy eating habits because they have forgotten the table manners that were once automatic. None of this is deliberate. However, it is important that they continue to eat a healthy, balanced diet. It's also important to try and make food attractive so that they will want to eat and enjoy their food.

In some instances, poor appetite or a lack of interest in food can indicate an underlying physical problem, such as constipation or an infection. Do check for this first. Try to help people retain skills for as long as possible by helping with food preparation, making their own drinks and helping set and clear away tables. You may feel that you want to do everything for the person you are caring for, but this often does not help them.

Diet and nutrition

Staying well with dementia requires a healthy diet. To find out more about diet and nutrition, including useful tips on healthy eating, please see our **Living Well with Dementia** booklet.



How you can help

Below are some practical tips that may help you to support a person with dementia to eat or drink:

Try to keep the individual involved in the preparation of food and drink. This is also important for maintaining a sense of self and being in control.

Allow plenty of time for meals.

Try to maintain their routine of timings and where they sit for meals. If they are used to sitting at a table it is best to continue to do so.

Avoid distractions such as TV.

Sit and enjoy meals together - this is more likely to encourage eating and drinking.

Plastic tablecloths are very useful but try and avoid bibs and aprons - use napkins instead.

If they have difficulty grasping cutlery and cups, try using just a spoon and spill-proof cups.

If they have problems cutting certain food, present it in manageable bite-sized pieces.

If they have a small appetite use smaller plates, and don't overface them with large portions. You could also try making snacks and finger food - sandwiches, toasted fingers, Scotch eggs, small sausage rolls, slices of quiche, pieces of fruit, bananas, biscuits.

Sometimes you might find it better to offer smaller meals, but more often.

If the individual does not want to sit down for a meal, or has a short attention span, it may be better to have plates of finger food in the areas that they walk. This will provide them with easy access to food. This technique can also be used with drinks.

If someone has a poor appetite, a glass-fronted fridge - so the food is easily seen - can provide good temptation. Also, leaving small snacks beside their armchair within easy reach is another way to tempt them to eat.

Take care with microwaved food and drink, check the heat - it may be too hot or the heat may not be evenly distributed. If an individual is tired they will be less likely to eat. Also, be aware that some medication can make people drowsy - in this case organise mealtimes before the medication is taken.

Use plain plates and ensure that there is a contrast between the food, the plate and tablecloth. Colour contrast gets more difficult as we get older and this is especially so for people with dementia, who can lose the ability to recognise the difference between colours of a similar hue and will therefore not recognise objects such as food against the background it sits on. For example, mashed potato, cauliflower and white fish on a white plate are difficult combinations for people with dementia to recognise, equally a white bread sandwich on a white plate also may cause problems for some people. Patterns can also be distracting and disturbing to some people, so, make sure the table cloth or table is plain.

Mix colours in a meal (this is good nutrition advice anyway) - if people like mashed potato but have stopped eating it, try a little food colouring, or mash with swede or carrot to create colour. Try brown bread instead of white.

You can buy plastic primary coloured table mats cheaply from most department stores, so if you have white plates, try using one of these which will help with the contrast. Red is a useful colour to try, as it is the colour that people recognise the longest as they age.

Remember also that people's tastes change, and for some people with dementia this can be quite dramatic. They may suddenly like spicy food, when they've hated it before. Or they could get cravings for certain types of food such as fish and chips, which they associate with a happy memory. Indulge in these choices, and don't just stick to old routines if they are not working.

Make sure they drink enough; around 8 cups of tea, water or juice a day is ideal. If they seem reluctant to drink, tempt them with a biscuit each time you make a cup of tea. Not drinking enough can lead to urinary tract infections.

If they get confused about mealtimes, tell them that you're about 'to make dinner' so that they start to think about eating and are prepared for it. Perhaps ask them to set the table.

Make sure 'hot' drinks are not scalding (add cold water) as they may forget to let them 'cool down' before drinking.



Help with Personal Care

This is one of the most difficult areas for people with dementia and their carers.

Personal care

Personal hygiene routines (bathing, showering and strip washing) are private, something all of us have done for ourselves since we were very young. However, handled sensitively and with thoughtfulness, there are ways around the difficulties.

Remember, someone with dementia may not be aware that they are forgetting to wash and care about their appearance. Sometimes just a gentle reminder is all that's needed; miming the action of cleaning teeth, for example, or putting the soap on a sponge or face flannel. If you can encourage someone to continue to manage washing and bathing independently, with a little unobtrusive support, that will be good for their self-esteem and morale.

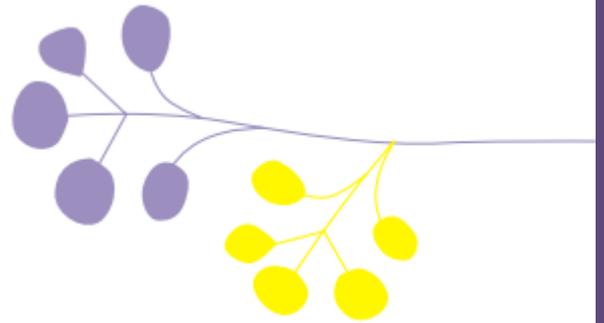
When it is apparent that help is needed, talk to them calmly about their preferences, rather than just taking over and doing things your way. Maybe they like to wash their face first, and then clean their teeth. Maybe they like to start with their feet when in the bath. Do they have a favourite shower gel?

Care of the skin

If the person with dementia does not look after these aspects of their lives, or they refuse support, it can lead to skin sores and infection. If someone has poor mobility and spends much of the time sitting down, particularly if they are incontinent, pressure sores can develop. Essentially, these show as areas of red and damaged skin where the blood supply has been reduced or cut off. If caught early, the sores can be easily treated. Keep a look-out for them when you help the person wash and dress.

Also, a person with dementia may not eat or drink enough, which can cause skin dryness and flakiness. Look for signs of this and ensure you keep the skin thoroughly moisturised. The key is to be vigilant for signs of dryness, soreness, redness and treat before the area becomes infected.

If you are at all concerned about their skin condition, contact their GP or Practice Nurse. For general information about pressure ulcers visit the NHS Choices website (www.nhs.uk/conditions).



Helping with personal care

Below are some practical tips that may help you assist a person with dementia with their personal care:

Remember to help the individual to retain as much control over this aspect of their life as possible.

If someone is reluctant to wash, don't argue. Try persuading them at a time of day when they're at their most alert. Or try reasoning - for example, they will feel fresher, or it would be a good idea as they're going out soon. It helps to stick to their normal routine of when they usually bathed or showered.

On the practical front, check the bathroom is warm and the water temperature not too hot or cold (check with your elbow not your hand), and the floor not slippery. It's a good idea to remove any locks from the inside of the door. Have everything ready that you will need.

Ask the individual if they are ready for bathing and if they decline, leave it for a while and try asking in a different way. If they continue to decline you have to accept this, try leaving it for the next day or consider whether you need some professional support. Your local authority should provide information and guidance.

If they don't want to bath or shower as often as you would, don't panic. It's only recently that showering every day has become the norm. It may be that having a strip wash is closer to what the individual might be used to.

Consider aids such as lever taps, shower-seats, bath seats, grab rails, and non-slip bath and shower mats. The Red Cross website's gift shop provides useful information and independent living products that you might find useful (www.redcross.org.uk). Another useful website is Complete Care Shop (www.completecareshop.co.uk).

If possible let the individual undress themselves by guiding with verbal prompts. If you are undressing a person maintain their dignity by covering them with towels or if strip washing removing

the clothing and redressing, as you wash each part of the person's body. Only uncover the areas that you are washing and leave a towel to cover the rest, a dressing gown may be useful for this.

When assisting stepping into a bath, hold a towel around them until the last minute. Adding bubble bath or playing music to make bath-time more of a pleasure is a good idea.

Where the individual is still able to bathe themselves, if they want you to stay in the bathroom, or you feel it's necessary for their safety, put a chair beside the bath so you're not standing over them.

Chatting as you're helping them wash will help you both relax and make the activity less intrusive.

Let them do as much as they can for themselves so they still feel in control. For example, you could guide their hand to the areas that need washing. Or hold out the towel when it's time to get dry. This will also remind them what they need to do next.

Keep their flannel visible next to the sink - and use ones that are the same so the person with dementia recognises it as theirs.

Where the individual is reluctant to wash their genital area or their bottom, using non-perfumed baby wipes may be acceptable to them and will maintain hygiene. There are also some good products available from Tena. Visit their website for more information (www.tenadirect.co.uk).

Hair washing may be a problem. Many people do not like water on their face. You can use a no-rinse shampoo or a dry shampoo, which can be purchased from the Complete Care Shop.





Advice about incontinence

Incontinence is embarrassing, whether you are the person with dementia or their carer.

Incontinence

Problems or accidents around going to the toilet are difficult issues to think about or deal with. This is true whether you are the person with dementia or their carer. For the former, it is a very obvious sign that they are losing control; they can feel humiliated and try to cover it up. For their carers, it can be embarrassing, and unpleasant, to have to deal with such a private matter. The best way to approach it is to think about in practical, matter-of-fact terms (although tactful) and deal with it in a similarly pragmatic way. A dose of humour never goes amiss, either.

There are two types of incontinence:

- Urinary incontinence - when someone loses control of their bladder
- Faecal incontinence - when someone loses control of their bowels

The former is far more common than the latter. While neither is inevitable with dementia, it is not uncommon. The first thing to check is whether there is a medical cause such as constipation, prostate problems with men, or urinary tract infection. These can be treatable, so check with their GP.

In other instances, the cause can be the person not realising or recognising the signs that they need to go to the toilet, not knowing where the toilet is, not being able to explain that they need to go to the toilet, finding it too difficult to undress, or poor muscle control. If an accident happens, try not to get angry or upset. Remember, it is not the person's fault.

If the accidents are becoming more frequent, ask for an assessment by a continence nurse or advisor (through their GP). They will be able to advise about incontinence pads, pants and protective bedding. If you're prescribed them, you won't have to pay for them - so don't go buying your own supplies.

Helping with incontinence issues

Here are some practical tips that can help prevent or assist with the problem:

1

The person with dementia may be struggling to find the toilet. This could be that they do not know which door is the toilet door, or the route to the toilet is cluttered. Putting a sign on the toilet door, a picture as well as the name, or leaving it open may help. Leave a light on at night with the door open. Use night lights on the route to the toilet. If the toilet is a long way away, consider having a commode or a urine bottle for a man. These are readily available online.

2

If you have an en-suite, it may be worth considering moving the bed (or get someone to do this for you) so the bed is facing the toilet door and the person can see the toilet.

3

Try and establish a regular routine of going to the toilet (typically every two to three hours), and remind them 'it's time to go'. You may wish to ask someone in the night if they want to go to the toilet, but keep interaction to a minimum so that you and they are not too disturbed, and don't force people to go if they don't want to.

4

Watch for signs of the person becoming restless or fidgety. This could indicate they are feeling uncomfortable and need to go to the toilet.

5

Use clothing that's easy to undo - elasticised waistbands or Velcro fastenings. Make sure the toilet is warm, comfy and well-lit.

6

A useful aid for someone with infrequent incontinence is a washable, absorbent pad for the bed, chair or car seat. Visit the Allanda website (www.allaboutincontinence.co.uk).

7

Make sure bedding has protective, waterproof sheets (this saves a lot of cleaning) and that any faecal matter is washed off before you put this in the washing machine (if not, you could end up with bacteria and germs spreading onto other clothing and causing health problems). If the person has mobility problems, there are a number of aids such as raised toilet seats and grab-rails available. The person you care for may be eligible for assessment by an Occupational Therapist, via your local authority or their GP.

8

A coloured toilet seat and lid that contrasts with the rest of the toilet and bathroom, can make it easier for someone to find and correctly use the toilet.

9

People with dementia may need to use incontinence pads as their dementia progresses. They will need to be changed regularly. If the need for pads is increasing then contact their GP or Practice Nurse who can refer them to an Incontinence Advisor.

10

Remember, you should wear protective gloves, put soiled pads into an appropriate container or sealed bag and make sure that you are scrupulously hygienic - you don't want to catch an infection or become ill due to poor hygiene.



Mobility issues

It's important to support someone with dementia to remain active.

Positive risk taking

It is a natural carer's reaction to want to keep the person you are caring for safe – and this sometimes means that your actions contribute towards the person losing their skills and becoming really dependent.

Try to help the person to retain their skills and independence for as long as possible. Try not to stop them from doing something they want to do because you don't feel it's safe. Sometimes your anxieties about the person can make them anxious as well – with inevitable results.



Out and about

Even though a person has dementia and may be less mobile and steady than they used to be, it's important that they remain as active as possible. Physical exercise is important both for general health and well-being and for mental stimulation. It also gives the person a feeling of independence and a sense of achievement.

If you're concerned about their mobility, you can request a mobility assessment through their GP. There are many lightweight walking aids available, from wheeled zimmer frames to three wheeled 'walkers'. Some of these are available free from your local health services.

Don't feel you always have to be with them if they want to go out. There are some clever pieces of technology such as GPS devices that mean if they are out for longer than usual, you will always know where they are.



Moving and assisting

As a carer you will increasingly be helping the person for whom you care move around the house and do specific tasks such as get in and out of the bath. If you don't assist somebody correctly, it can put a strain on your back. It is important, both for your own health and their safety, that you use the correct techniques to support the person.

You could ask the district nurse to show you how to lift and move a person safely. Ask your GP or Practice Manager how to contact them. You might find your local carers' centre also has courses or information.

Don't forget there are practical aids or home adaptations that could help you, such as grab-rails, shower-seats, walk-in baths and portable aids that help someone stand up from the bed. You may get these free from your local health services team or be offered financial help.

You may be eligible for a carer's assessment from your local authority. This will look at what aids and support could help you carry out your caring tasks.

Visit the [NHS Choices website \(www.nhs.uk\)](http://www.nhs.uk) for more information.



Driving

Many people in the early stages of dementia can continue to drive safely. However, they must tell both the Driver and Vehicle Licensing Authority (DVLA) and their insurance company that the person has been diagnosed. The DVLA will send a questionnaire to check the person's competence and may also ask them to take a driving assessment. They will also ask for reports from the person's doctor. They will then decide whether or not to renew their driving licence, usually for a year at a time. Be aware, the insurance may not provide cover for you if you don't let them know about the changed circumstances.

You can have a look at the [Who you must tell](#) section of our [Diagnosed with dementia?](#) booklet for more information.

If everyone feels the person is safe to continue driving, make some sensible 'rules'. For example, suggest the person sticks to routes they know well and avoids busy roads, driving at night or in bad weather, and never drives when they're tired.

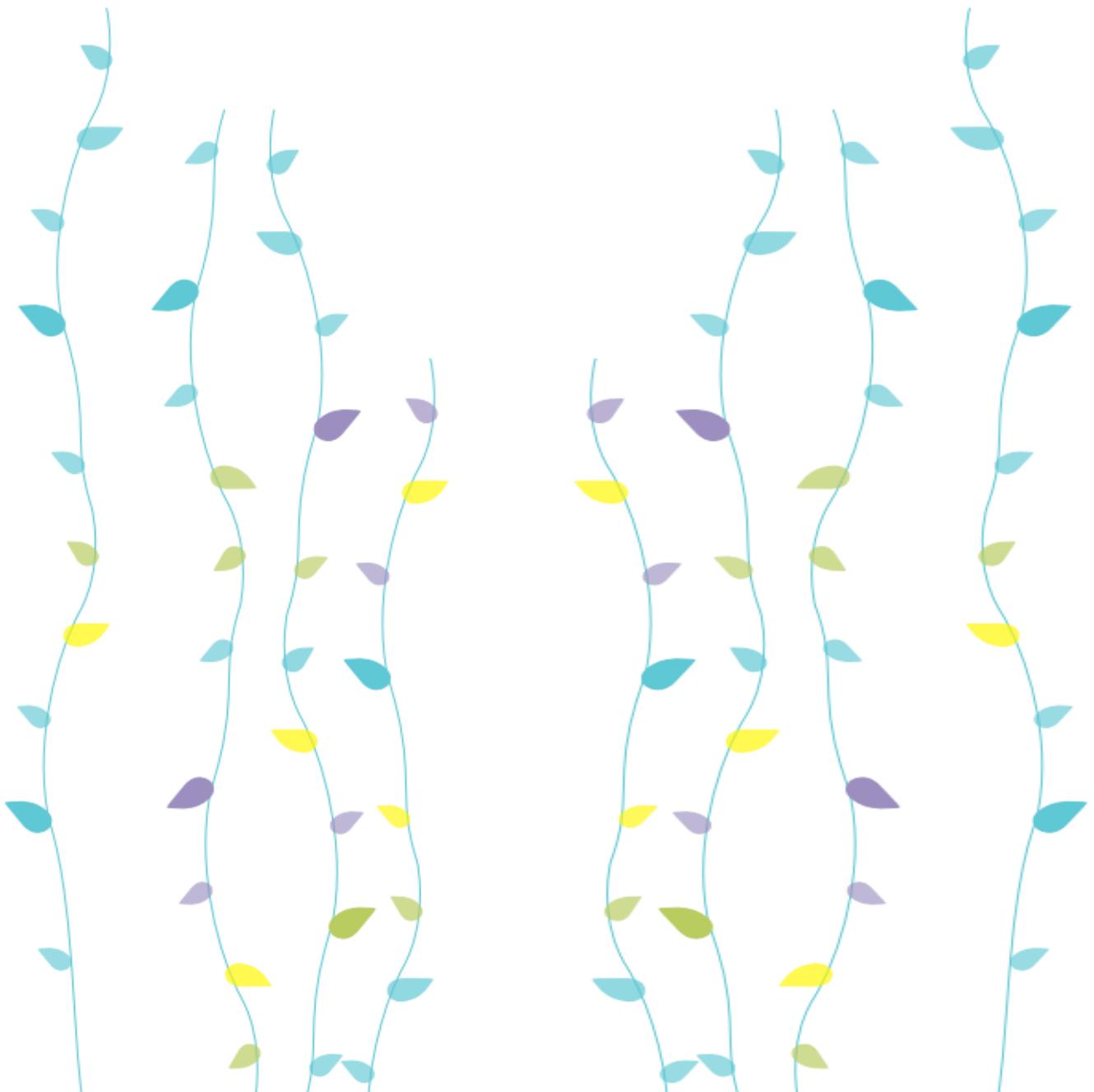
Don't just take the keys

If you feel they are no longer safe to drive, talk about it with them, rather than just take away their car keys. They may well resist the idea, as they may not realise how unsafe they are becoming. Emphasise the need for quick reactions when driving, and being able to predict what other drivers might do - and that even you can find this difficult at times.

Point out the benefits of not driving - the cost savings for a start! - the convenience of using taxis (which they can now afford as they're no longer running a car), or the fun and pleasure of taking trains.

If the person is still resistant, they may respond better to someone in authority explaining that they should give up - the doctor, for example. As a final resort, you should contact the DVLA direct, who will ask for reports from their doctor.

Don't worry that you are going to end up as a permanent taxi-driver. Contact a local, reliable taxi firm and set up an account for regular trips, such as to day centres, clubs, the hairdresser or the shops. You'll probably also find that friends and family are very willing to help share giving lifts. See if you can work out a routine that fits in with theirs.



Support organisations

For more information or advice, please call Dementia Care on 0191 217 1323 and ask to speak to one of our Dementia Guides. They offer free face-to-face support for people with dementia and their families in Newcastle upon Tyne, Hexham and the surrounding areas.

A variety of support groups will exist in your local area. To find out who they are and how to contact them, it may also be useful to contact some of the national organisations listed here:

Age UK
www.ageuk.org.uk
or call 0800 169 2081

Alzheimer's Society
www.alzheimers.org.uk
or call 0845 300 0336

The Lewy Body Society
www.lewybody.org
or call 0131 473 2385

Carers UK
www.carersuk.org
or call 0808 808 7777

The Princess Royal Trust
www.carers.org
or call 0844 800 4361

Concerns regarding financial or other abuse of a vulnerable person

If you have any concerns regarding financial or other abuse of a vulnerable person, you should contact the Office of the Public Guardian:

PO Box 16185
Birmingham
B2 2WH
Tel: 0300 456 0300 or
Email: customerservices@publicguardian.gsi.gov.uk

Opening hours:
Monday, Tuesday, Thursday and Friday - 9 am to 5 pm
Wednesday - 10 am to 5 pm

