

Where do I go from here?

**A local guide for people with dementia
and their Carers living in East Kent**

Produced by:



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FOREWORD

If you or someone you know suspects they have a form of dementia, or has just received a diagnosis, you may be asking yourself:

'Where do I go from here?'

In this booklet we hope that you will find some answers to your questions. This booklet gives information about dementia and local services, with the aim to inform you about dementia, how to manage it, and where to find support.

Most importantly, we hope that by reading this booklet you will have the information and tools to maintain a good quality of life.

This booklet replaces the 2019 edition of 'Where do I go from here'.

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EXPLAINING DEMENTIA

What is Dementia?

Dementia is a term used to describe conditions that affect the brain cells and other mental abilities. Symptoms include loss of memory, mood changes and problems with reasoning and communication.

There are lots of different types of dementia, including:

- Alzheimer's Disease
- Vascular Dementia
- Mixed Dementia
- Dementia with Lewy Bodies
- Fronto-Temporal Dementia

All the dementias are progressive conditions, which means symptoms and difficulties will gradually get worse over time.

Dementia affects each person differently, the difficulties and progression a person experiences will vary. However, you may experience difficulties such as:

- Remembering names and remembering the day or date
- Forgetting things you have been told
- Keeping track of conversation, finding the right words in conversation, or forgetting what you were about to say
- Concentrating when watching TV or reading
- Misplacing things around the house
- Planning the day and making decisions
- Finding your way around unfamiliar places
- Learning how to use new appliances and gadgets

These difficulties can make you feel anxious, frustrated and confused. It is a good idea to talk to someone such as a close friend or relative.

Who can get Dementia?

Anyone can get dementia.

The highest risk factor for developing dementia is age. Dementia mainly affects people over the age of 65. The chance of getting a dementia increases as age increases.

Dementia can also affect those under the age of 65, although this is less common. This is known as young-onset dementia. It is thought that most young-onset (e.g., Huntington's disease) and other rare types of dementia have a strong genetic link.

For dementia occurring in the over 65's the genetics are less clear. There are genes that have been identified as a cause of some types of dementia, however these only account for a small portion of cases.

The vast majority of cases of dementia are not directly genetically inherited and many people who do have risk genes for dementia will never actually go on to develop dementia.

Overall, with most dementias there is only a very slightly increased risk of getting a dementia if a close relative has a dementia.

Scientific research is currently ongoing in the genetics of dementia.

Other risk factors can include:

Health:

- Cardiovascular disease
- High blood cholesterol
- Being overweight and physically unfit
- Type 2 diabetes
- Depression
- Hearing loss
- Traumatic brain injuries

Lifestyle:

- Social isolation
- Inactivity
- Poor diet
- Too much alcohol
- Smoking

Other **environmental** factors may also play a part. An **active healthy lifestyle** can help both **reduce the risk** of dementia and help **slow its progression**.

Types of Dementia

There are over 100 different types of dementia. In this section the most common types of dementia are explained.

Alzheimer's disease

Alzheimer's disease is the most common type of dementia. Currently it is reported that over 850,000 in the UK have Alzheimer's disease. This figure is expected to rise to over 1.5 million people in the UK by 2040.

What is Alzheimer's disease?

In Alzheimer's disease, groups of proteins called '**plaques**' and '**tangles**' develop in **brain cells**. These plaques and tangles cause disruption in the communication between cells, and ultimately cause brain cells to die.

There is also disruption of two **brain chemicals** present in the brain. Acetylcholine

activates muscles and is involved in memory and learning, this chemical is reduced in Alzheimer's disease. Glutamate is also involved in learning and memory, this chemical is over produced in the brain, which also has a toxic effect and causes brain cells to die.

The death of brain cells can have a 'knock on effect' to other cells, this will eventually lead to tissue loss and overall reduction in the size of the brain (atrophy).

Several genes have been identified as risk factors for Alzheimer's disease. The most commonly referred to gene is called **ApoE4**. The ApoE4 gene has been identified as one of the higher risk genes and increases the likelihood to develop Alzheimer's disease at a younger age. However, up to a quarter of the population carry this gene and most do not go on to develop Alzheimer's disease.

Common symptoms

No two people will experience Alzheimer's disease in the same way, but there are some common symptoms. These include:

Difficulties with short term memory

You may forget what you have just said or done. You may also become confused about people's names, places, the date and time. This confusion can be incredibly frustrating, leading to mood swings.

Difficulties with communication

You may find you have increased difficulty in interpreting both spoken and written language and understanding the meaning of words. You may also have difficulty finding the right words to respond, when speaking and writing.

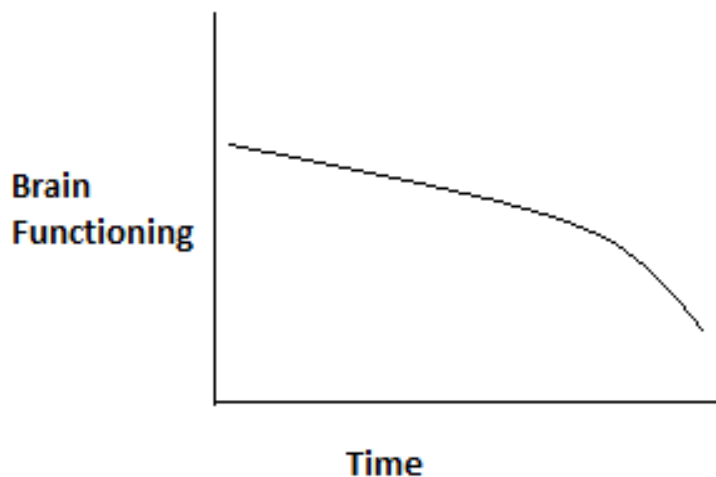
Difficulties in functioning in everyday life

You may have difficulty carrying out everyday activities such as counting change to pay for items in a shop. You may no longer feel confident in doing previously enjoyed activities,

due to difficulties with concentration. You may also have difficulty learning new skills.

How does it progress?

The progression of Alzheimer's disease is gradual, meaning that as time passes you steadily lose more brain functions. The likely pattern is shown in the illustration below:



In the early stages, people may remember memories from their adulthood and childhood in great detail, but as the illness progresses this long-term memory also slowly deteriorates.

Vascular Dementia

This is the second most common type of dementia.

What is Vascular Dementia?

Vascular dementia is primarily caused by **poor blood circulation in the brain**. If blood vessels in the brain burst or become blocked, oxygen and nutrients cannot reach the brain cells. This leads to the eventual death of brain cells.

Vascular dementia can be caused by a single stroke or more commonly caused by a series of '**mini strokes**' in the brain. Mini strokes happen when the small blood vessels in the brain become blocked or burst, resulting in small areas of damage in the brain. Mini strokes can be referred to as '**Silent strokes**' as they are often small enough that you don't notice them.

Small vessel disease is another common cause of vascular dementia, this is where small blood vessels become narrow and clogged, reducing blood flow to parts of the brain, this damage can build over time lead to cognitive impairment and progress to vascular dementia.

Common symptoms

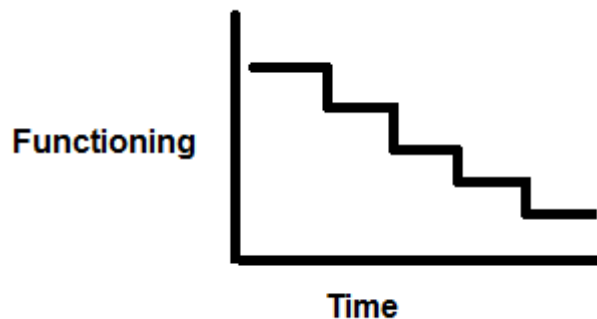
The symptoms of vascular dementia vary widely from person to person. This is because the loss of abilities depends on the area of the brain affected by poor blood circulation.

However, people with vascular dementia may experience:

- Problems concentrating and communicating
- Periods of sudden confusion
- Memory problems (although this may not be the first symptom)
- Symptoms of stroke, such as physical weakness or paralysis
- Depression accompanying the dementia

How does it progress?

Vascular dementia is often described as having a stepped progression. This means that people may deteriorate suddenly, and then stay on that level for a while, until they deteriorate suddenly again. This is shown in the illustration below:



This sudden deterioration happens when a mini stroke happens. It is possible that after the mini stroke, some functioning that was initially lost returns. However, as time goes on the person's functioning will decline.

Mixed Dementia

Mixed dementia is when one type of dementia occurs simultaneously with any other type of dementia.

The most common type of mixed dementia diagnosed is when Alzheimer's disease and vascular dementia are present at the same time.

Common symptoms

The symptoms of mixed dementia are dependent on the types of dementia present, and the areas of the brain affected. Generally, symptoms can be more pronounced, though one type of dementia may present more prominently than the other.

How does it progress?

Often mixed dementia progresses at a quicker rate as the brain is affected by more than one type of dementia and the person may have damage in more than one area of the brain.

Dementia with Lewy Bodies

Dementia with Lewy Bodies accounts for roughly 10% of dementia cases.

What is Dementia with Lewy Bodies?

Lewy Bodies are **protein deposits** found **around nerve cells**. It is not yet fully understood how they cause damage to the brain, but we do know they interrupt normal brain functioning.

Lewy Bodies also disrupt important chemicals in the brain that allow brain cells to communicate with each other.

Lewy Bodies are also found in the brains of people who suffer with Parkinson's disease. Many individuals diagnosed with Parkinson's disease go on to develop a dementia similar to Dementia with Lewy Bodies.

Common Symptoms

No two people will experience Dementia with Lewy Bodies in the same way, but there are some common symptoms. These include:

- Difficulties with attention, alertness, confusion and spatial orientation
- Difficulties with executive functioning – meaning difficulty planning ahead, making decisions, correcting errors and responding to new situations
- Symptoms similar to Parkinson’s disease such problems with movement including increased falls slowness and muscle stiffness
- Detailed visual hallucinations & delusions
- Problems with speech and swallowing
- Changes in sleeping pattern, such as sleeping during the day but being restless during the night

How does it progress?

Symptoms of Dementia with Lewy-bodies can vary significantly from day to day. Overall progression is gradual, meaning that as time passes you steadily lose more brain functions.

Frontotemporal Dementia

Frontotemporal dementia is also known as **Pick's Disease**, it is one of the rarer types of dementia.

There are several types and classifications of frontotemporal dementia depending on a person's presenting symptoms, the three most commonly referred to types are the Behavioral Variant, Semantic Dementia and Progressive Non-Fluent Aphasia.

What is Frontotemporal Dementia?

Fronto-temporal dementia **affects the front parts of the brain** known as the frontal lobe and the temporal lobe. These parts of the brain are responsible for our behaviour, emotional responses and language skills.

Fronto-temporal dementia tends to affect people at a slightly younger age, and is a frequent cause of young-onset dementia.

Several genes have been identified as a cause of frontotemporal dementia, however genetic

inheritance only accounts for around 30% of all cases.

Common Symptoms

Each person who has fronto-temporal dementia will experience the illness differently, although there are common symptoms. These include:

Personality, mental ability and behavioural changes

- A loss of inhibitions, seeming insensitive or rude and displaying inappropriate behavior
- Loss of insight and your ability to empathise
- You may lose interest, motivation and become aggressive or easily distracted
- You may engage in repetitive behaviors, routines or hoarding
- Difficulty with planning, organization, poor judgement and rigid thinking
- Change in food preference such as sudden liking of sweet foods or compulsive eating, drinking or smoking
- May become socially isolated, subdued or withdrawn

Language difficulties

- Forgetting meaning of words, difficulty finding the right words or getting words in the wrong order.
- Repeating phrases or what others have said.
- Slow, hesitant and reduced speech.

Physical difficulties

- Slow stiff movements
- Difficulty swallowing
- Loss of bowel or bladder control

Additionally, up to 20% of people with frontotemporal dementia develop neuromuscular problems such as; Motor neurone disease (MND/ALS), corticobasal degeneration, progressive supranuclear palsy or parkinsonism.

How does it progress?

The rate of progression in those with frontotemporal dementia varies greatly, ranging from two to ten years.

Mild Cognitive Impairment

What is it?

Mild cognitive impairment is not dementia.

Mild cognitive impairment is a condition where cognitive abilities such as memory and thinking are impaired.

It is often recognised as the stage between normal ageing and dementia. This is because the cognitive decline is not as severe as someone with dementia, and it does not significantly impact day to day living. However, the decline is more than just normal aging.

Mild cognitive impairment can be temporary or because of other factors such as medications, low vitamin levels, thyroid problems, or depression.

Common symptoms

Symptoms are often similar but milder and fewer in number than dementia symptoms.

If you have mild cognitive impairment, you may:

- Forget recent events or repeat questions
- Have difficulty with planning and problem solving
- Are easily distracted
- Take longer to find the right word
- Have trouble judging distances

How does it progress?

Mild cognitive impairment may resolve completely, stay the same or get worse. In some cases the cause of mild cognitive impairment can be early Alzheimer's disease or another dementia. Although this does not always lead to dementia, it is estimated that 10-15% of people with mild cognitive impairment will go on to develop dementia.

Keeping mentally and physically active, being socially stimulated and leading a healthy lifestyle can help starve off mild cognitive impairment and dementia. Many of the tips and advice in living well can benefit those with mild cognitive impairment live well too.

Delirium

What is delirium?

Delirium is not dementia.

Delirium is a sudden change in mental state, which includes increased confusion & disorientation. Delirium is often confused with dementia, the primary differences being that delirium has a much more sudden onset (1-2days) and is reversible.

While delirium is not unique to people with dementia it is unfortunately quite common. Up to 50% of people with dementia in hospital also have delirium.

Symptoms:

Hyperactive symptoms include:

- Disorientation
- Paranoia
- Visual and auditory hallucinations
- Agitation, restlessness or aggression
- Difficulty speaking and following conversations

- Vivid dreams that continue on awakening
- Increased appetite

Hypoactive symptoms include:

- Poor concentration
- Less aware & less responsive
- Reduced mobility
- Reduced appetite

Symptoms can flick between both hyperactive and hypoactive symptoms and can also vary in intensity throughout the day.

Risk factors for delirium:

- Having dementia
- Being dehydrated or constipated
- Infections
- Having surgery
- Sight and hearing difficulties
- Unfamiliar or distressing environments
- Being in pain
- Being at end of life

It is important to recognise the signs and symptoms of delirium as it can be fatal at its most extreme. Often addressing the cause can relieve symptoms of delirium. Contact your GP if you suspect delirium.

DIAGNOSIS

Is diagnosis important?

Diagnosis is important to consider if you think you may have a dementia. It is your own decision whether you would like to know if you have a dementia, and some people may not want a diagnosis. However, there are several very important benefits to having a diagnosis:

- There may be another physical cause for your symptoms, such as depression. Your GP will be able to rule these causes out
- Having a diagnosis will mean you may be prescribed some medication, e.g. there is medication available for Alzheimer's disease which can slow down the progression of dementia.
- A diagnosis may help you prepare and plan for the future, and access support from social services, voluntary agencies and support groups.

If you are concerned that you may have a dementia, always visit your GP. If you are concerned about someone else, you may want to accompany them to appointments.

How is dementia diagnosed?

Dementia is usually diagnosed by a psychiatrist but this may be a geriatrician or a neurologist and in some cases it may be your GP who makes the diagnosis.

Jack's story is quite typical:

Jack went to see his GP, because he had been worried for several months about loss of short term memory. His doctor asked about the development of the problem and took blood to test for medical conditions which might be causing the memory problems. The doctor found that Jack was low in mood, but not depressed. When his blood tests proved normal and Jack lost two points on a simple memory test the doctor suspected a dementia. She asked Jack if he would like to be referred to a Memory Clinic. At the Memory Clinic dementia was confirmed and the doctor, psychologist and nurse were able to tell Jack what type of dementia he had.

Diagnosing dementia is not always straightforward, and your doctor will carry out a number of tests. These will include blood tests, brain scans, tests and questionnaires to check your thinking skills and ability to carry out everyday tasks. These tests allow your doctor to rule out any other physical causes for your symptoms, and inform them of which type of dementia you have.

What happens after a diagnosis?

If you receive a diagnosis of dementia, it is very likely that you will experience a range of different emotions. You may need a great deal of reassurance and support. Initial feelings of shock and disbelief are often combined with sadness, anxiety and frustration.

You may be feeling:

Angry “Why is this happening to me?” to
“What did I do to deserve this?”

- Worried** "How will I cope?"
"Will my family be ok?"
- Fearful** "I'm scared for my future"
"I'm scared I will embarrass myself"
- Sad** "Things get on top of me."
"There doesn't seem much point in making an effort."
- Guilty** "I feel bad for asking for help."
"I don't want to be a burden."
- Alone** "No one seems to understand."
"Sometimes I feel like I am tackling this on my own."
- Frustrated** "I just can't do the things that I used to."
"Sometimes I feel like screaming."

You may also experience feelings of loss, as things you had planned for the future may no longer seem possible or may be more difficult.

However, many people also feel relieved to discover that there is a medical explanation for

the changes in thoughts, feelings and behaviour that had started to affect their daily lives.

“I have an illness, I wasn’t having a breakdown.”

“I thought well, best foot forward, I can cope with this.”

Dementia should not prevent you from continuing to have a **fulfilling life** and is certainly not a reason to stop doing things you enjoy. It is important to stay as independent as possible, and continue enjoying hobbies and activities. You are certainly not alone and you may find it helpful to meet with other people who are living with dementia.

Thinking about your future may seem daunting and make you feel anxious, but it is important you plan ahead when you have a diagnosis.

There are many agencies that can provide you with further information, advice and support. Some of these details can be found in this booklet in **‘Help and Support Available’** on **page 53.**

LIVING WELL WITH DEMENTIA

It is important to remember that you are still able to have a good quality of life with dementia. This section aims to provide information and tips for your wellbeing and important issues to consider for your future. There are a range of organisations that can offer more information and advice on issues discussed in this section. **For their contact details, please view the section named 'Information, advice and emotional support' on page 54.**

Treatments for dementia

Most types of dementia cannot be cured, although there is continued research into developing drugs, vaccines and other treatments.

A number of drugs have been developed that can temporarily alleviate some of the symptoms of certain types of dementia.

There are 4 types of medication available primarily for Alzheimer's disease. These are Aricept (Donepezil), Reminyl (Galantamine), Exelon (Rivastigmine) and Ebixa (Memantine).

The major brain chemical responsible for forming memories is called acetylcholine or ACh. People with Alzheimer's disease have low levels of ACh. The first three medications prevent the breakdown of ACh in the brain. This enhances attention and memory.

Ebixa (Memantine) works by blocking a chemical called glutamate. Glutamate is released in the brain when brain cells are damaged by Alzheimer's disease. Glutamate causes further damage to brain cells, and Ebixa blocks this.

These medications are not suitable for everyone, and may not work for everyone. Some people also experience side effects from taking these drugs. Your consultant will decide whether they are suitable for you.

Complementary Therapies

Whilst there are no scientific or medical evidence for some complimentary therapies, aromatherapy, massage and reflexology may help you to feel more relaxed.

Do discuss with your doctor before taking any complimentary medicines.

Reducing Risk Factors

Exercise, good diet and regular health checks are important. Ensuring that your blood pressure and cholesterol are not too high is particularly important if you have vascular dementia.

Tips for making the most of your memory

People with dementia most commonly experience difficulties with memories of recent events. This can be very frustrating and distressing to both the person with dementia and those around them. Below are some tips to help manage memory problems:

General Tips:

- When completing tasks, be as relaxed as possible and take your time
- Break tasks down into manageable 'chunks', writing down what you need to do and taking it one step at a time
- Try to keep a daily routine, as you will benefit from a regular schedule as the illness progresses.
- Accept that you may need more time and help to do things you once found straightforward

Strategies for remembering:

- Keep a **diary** to write down appointments and things you have to do
- Avoid the distraction of T.V. or radio when trying to take in important information
- Put up a **notice-board** in the kitchen and use it to write 'to-do' lists and reminders
- Invest in a **clock** which shows the day and date, or a digital watch which has similar functions
- Find a place where you can keep important things such as keys, glasses, etc
- Put a list of **useful phone numbers** by the telephone
- Keep a **notepad** and pen by your telephone to take down messages
- Ask your GP or pharmacist for a **Nomad tray** for your medication
- When you are going somewhere, try to use the **same route** each time
- Always carry the **telephone number** of a close relative or friend when you go out

Managing your feelings

Talking Helps

If you can, talk to your friends and family about your worries. Don't bottle things up.

George has difficulty keeping up with conversation at a social gathering. He explains this to his grand-daughter and they find a quiet spot to talk together away from the noise and laughter of a family crowd.

There are also a number of organisations you can contact to talk to someone about your feelings and worries. **For their contact details, please view the section 'Information, advice and emotional support' on page 54.**

Get Support

Local support groups can be a great source of help. This is because you can meet other people who are also living with dementia and realise that you are not alone. If you are looking after someone with dementia, you may find it helpful to talk to others in a similar situation.

Stay as active as you can

Maintain your interests, see your friends and carry on with life. Don't be hard on yourself if you have to do things slightly differently.

Telling other people about your diagnosis

Telling people that you have dementia may seem daunting, but most people find that it is best to be open about your illness. Family and friends will be able to help you best if they know something about your illness, and the way it affects you.

Elsie gets anxious when she finds bills and bank statements in her post box. When she mentions this to an old family friend he offers to spend some time helping Elsie to sort out an easy method of getting bills paid.

Your interpretation of the difficulties you face can affect how you feel. Taking a more positive approach will be more helpful, e.g. learning new ways of coping with your memory problems, accepting help from others and developing a fighting spirit.

Healthy living

Visiting your GP

Keep in regular contact with your GP who can offer you:

- Advice and support on a range of health issues, including mental health
- Regular physical health checks
- A referral onto other professionals and services e.g. nurses, speech therapists and Social Services
- Medication
- It is vital that you visit your GP if you suspect an infection. People with dementia can become more confused if they have an infection.

Food and Nutrition

A balanced diet is vital for good health. Eat plenty of foods such as:

- Fresh fruit, dried fruit and vegetables
- Wholemeal bread, pasta and rice
- Protein such as meat, fish, eggs, nuts and soya
- Dairy products
- Pulses such as beans and lentils

Eating foods that are high in fibre, such as fruits, vegetables, salads, wholegrain bread and cereal will help prevent constipation. In vascular dementia, a healthy diet plays a part in preventing further strokes.

If your GP or nurse has recommended you avoid certain foods, make a note of these somewhere in your kitchen so that you don't forget!

Shopping

Some local stores will deliver to your home. If you have access to the internet you can place

an order with several major supermarkets which do home deliveries. One of the larger supermarkets offers a telephone ordering service. There are also various meal delivery services available.

Drinking

It is recommended to drink between 1.5-2 litres of fluid each day. Make sure you drink plenty of liquids to help prevent dehydration.

Signs of dehydration may include dry mouth, dark coloured urine, poor wound healing, headaches and confusion. Dehydration can lead to constipation and urinary tract infections.

You can also test for dehydration at home with the 'pinch test' - gently pinch the skin on the back of your hand, the slower the return to normal the more likely you are dehydrated!

If you find it difficult to drink enough fluid throughout the day, try adding foods to your diet with a higher water content such as melon, pineapple, cucumber, tomato's, jelly etc.

Drinking alcohol should be done in moderation.

Smoking

If you are still smoking you may be advised to cut down or stop in order to reduce the risk to your health.

Exercise

Keeping active is vital to good health. Exercise of any kind is good. Try to maintain activities you have been used to doing. If you need to gradually change the pace do so.

There are various groups locally or even online videos for gentle exercises you can do from your chair at home, see **pages 65 & 66** for example resources to get you started.

Socialisation

Social isolation has been identified as a risk factor for dementia.

Being socially active is thought to increase blood flow in the brain, help to reduce stress, help starve off dementia and slow the rate of progression.

There are coffee mornings as well as support and activities groups available locally for people

with dementia as well as freephone support lines. See Sections: **Information, advice & emotional support (pages 54-60)** and **Activities and support in the community, (pages 60-67)**

Mental stimulation

Just like our bodies need exercise so do our minds. Mental stimulation can act as a protective factor against dementia and help slow the rate of progression. Existing and new hobbies are encouraged as well as engaging in various puzzles, games, reading and brain training tasks. There are many freely available puzzles and workbooks online and many dementia friendly brain training apps. see **pages 60-67 (Activities and support in the community section)** for community based and at home activities and ideas.

For more information on nutrition, hydration or healthy living tips you can check the NHS website information listed on **page 58.**

Driving and transport

If you have a diagnosis of dementia, it does not necessarily mean you cannot drive. However, it is important you are able to drive safely, for both legal and practical reasons.

If you have been given a diagnosis of dementia you must, by law, inform both the **DVLA** and your **insurance company**. If you do not you are breaking the law and can be fined up to £1,000.

If you are unsure of your ability to drive, you may want to take a driving assessment. This is not a driving test, but an overall assessment of your driving performance. You can request an assessment at your local Driving Assessment fee for the assessment

The DVLA may also request that you take a driving assessment if you have a diagnosis of dementia and wish to continue driving. In this case, there is no fee for the assessment.

If you continue driving:

- Keep to familiar routes
- Avoid busy areas
- Drive during daylight and when the weather is good
- Keep your journeys short and for longer journeys, try using trains or buses
- Drive with a companion
- Avoid driving when you are stressed or upset

Giving up driving:

Giving up driving is a difficult decision to make, especially if you are used to being independent. Some people may still be reluctant to give up driving even if they are not safe. The person who is giving up driving will need support. This is because they may feel unhappy about losing some of their independence or may not understand why they are no longer able to drive.

Alternatives to driving:

- Create a **taxi account** with a local taxi company
- Use **public transport** - Travel Line are a national service which will provide travel information for any area
- If you are of state pension age, or over, or are 'eligible disabled', you may be entitled to **free off-peak travel on local buses** in any area in England which offers free off-peak bus travel. 'Off-peak' is any time after 9.30 am Monday to Friday and all day at weekends
- If you are unable to manage on a bus, there may be a **Volunteer Transport Scheme** that you can access in your area. Volunteer drivers can take you where you need to go e.g. shops, hairdressers, doctors etc. There is a mileage charge – ask for the current rate. (See **page 76**)
- If you have mobility problems you can obtain a **Blue Badge** to display in any car from Kent County Council, which will allow you to park in disabled parking bays. For eligibility requirements check the gov.uk website. (See **page 75**)

Safety, security, and environmental considerations in the home

When a person has dementia, it is important to balance independence safety. There are some simple things you can do to reduce the risk of accidents in the home. It's important to remember there is no such thing as a risk-free environment, and some minor accidents may be inevitable.

Accidents are more likely to happen when people are stressed and confused. If you are feeling stressed, breathe deeply, slow down or take a break, and ask for help if you need it.

Avoiding accidents such as falls:

- Get plenty of natural light and keep the home well lit. You may find it useful to leave on a light in the hall and bathrooms at night
- Try to have things within easy reach so you don't have to use steps or climb on chairs to get them
- Make sure the floor coverings are well fitted and that you do not have electric cables where they may cause you to trip

- Avoid stripes, multi-coloured and patterned furniture or flooring (these can be confusing, distracting or trigger visual hallucinations)
- Remove Black or dark coloured matts & rugs, and reduce shadows, these can be distressing and look like black holes.
- Handrails and grab rails may help if you are unsteady on your feet
- Always store medicines somewhere safe, and lock away poisonous substances as the person with dementia may no longer recognize what they are.

Other environmental considerations

❖ Use contrasting colours

- Having walls and flooring in contrasting colours can help with depth perception
- Have different colour furniture to flooring so it stands out (using coloured throw would be a low cost adaptation)
- Use different coloured crockery to tables or tablecloths can help define the edges of plates
- You can install brightly coloured handrails, toilet roll holders and toilet seats so they are easily identifiable

- Avoid having too many reflective or shiny surfaces as these can be disorientating
- It may be useful to have signs and labels for things like cupboards or on the bathroom door, having picture signs can make things more easily identifiable
- You can use brightly coloured tape around things like light switches to make sure they stand out.

You can contact your local council for an assessment or occupational therapy referral through your GP they can help find practical solutions to everyday problems and helpful equipment or home adaptations.

Alternatively, there are various falls prevention services, home improvement services and retailers where you can purchase various support aids (See **page 79**)

Fire safety

- If you discover a fire in your home, leave the house and dial 999 from a neighbour's house. Do not try and tackle the fire yourself
- Make sure that all your appliances are in good working order, especially cookers and heaters
- Avoid cooking with lots of fats or oils, and don't put metal in your microwave
- Ensure you have a smoke alarm fitted and test your alarms regularly. The Kent Fire and Rescue services can do a free Home Safety Check

Security

- Get a chain fitted to your front door and always ask to see identification before opening your door to a stranger
- Make a note on your calendar if you are expecting tradesmen and put the company name to check identification

Planning for the future

If you or a person you know has a diagnosis of dementia, you may be worried about your future. There are certain financial and legal matters you need to consider whilst you are still able to.

*The section '**Help and Support available**' provides further information (**Page 53**).*

This is me

This plan allows for personal information to be entered on a form for the person with dementia and is designed to help nursing staff understand the needs of the person, should they be admitted to an acute hospital ward. The form goes with them into hospital for the duration of their stay.

Keeping track of your finances

Organise your bills so you can distinguish between paid and unpaid bills. Setting up direct

debits for household bills may save time and worry.

Using a cash book to note down what money you have received and spent will help you to keep a track of your money. If you worry about remembering your pin number, some banks may be able to give you a signature card.

Benefits

People with a dementia are entitled to certain benefits and allowances. Some of these are means tested, others are not. *It is important you are receiving all the benefits you are entitled to, so do check to see if you are in receipt of the correct benefits.*

Council Tax Reduction

If you have a diagnosis of dementia and are in receipt of certain benefits, you may be entitled to *Council Tax reduction*. This is based on the fact that anyone with these conditions cannot make full use of the facilities that the Council Tax pays for.

There can be no more than two people living in the house to get a discounted Council Tax. If a person has been diagnosed with dementia the claim form must be signed by a Registered Medical Practitioner.

Power of Attorney

Power of Attorney is an important legal document that allows someone you appoint to make decisions on your behalf. If you have dementia, it is important to get this document in place before you are no longer able to make your own decisions.

There are different types of Power of Attorney. Power of Attorney covers decisions about your financial affairs or your health and care. A solicitor can provide advice based on your individual needs. If you do not already have a solicitor, do make enquiries with more than one solicitor as the prices charged for these documents vary.

You can also find information online at:

<https://www.gov.uk/power-of-attorney>

Appointeeship

If the person with dementia is no longer able to manage their income from benefits, an appointee can do this on their behalf. For more information about Appointeeship, or to request the form to become someone's appointee, contact the Department of Work and Pensions.

Wills

A will is the only way to ensure your money, property, possessions or investments go to the people and causes you care about. If you do not have a will yet, or wish to make changes to your will, you should seek legal advice from a solicitor.

There are several free will writing services available. (may request charitable donations)

See **page 72.**

HELP AND SUPPORT AVAILABLE

In this section you can find **contact details for organisations that can support you.** These contact details have been divided into six sections, so you can easily find the support you are looking for.

These sections are:

Information, Advice and Emotional Support Page 54

Activities and Support in the Community Page 60

Health and Social Care Page 68

Finances, Benefits and Legal Matters Page 72

Transport and Driving Page 75

Safety and Security in the Home Page 78

If you can't find what you are looking for please contact us (see page 54 for contact details)

Information, Advice and Emotional Support

Carers' Support – East Kent

Provides information, support and signposting to services to Carers by phone, email, online, text and in person.

- Information – find out about services available to Carers, benefits and rights.
- Support – a listening ear, drop-ins, support groups, social activities and training workshops.
- Carer's Needs Assessment – to identify and access the support you need as a Carer.
- Kent Carer's Emergency Card – peace of mind when you are away from the person you look after.
- Carers' Hospital Service – a team supporting Carers at QEQM, William Harvey and Kent & Canterbury Hospitals.
- Services for Young Adult Carers (16-24 years)

80 Middle Street, Deal, Kent CT14 6HL

Tel: 0300 302 0061

Text: 07545 916 214

Email: support@carersek.org.uk

Web: www.carersek.org.uk

24 Hour Kent Dementia Helpline

Provides practical and emotional support to people with dementia, their main Carer and other relatives and supporters, 24 hours a day.

Tel: 0800 500 3014

Alzheimer's Society (National)

Offering a range of support services, online and in person support groups, memory walks, dementia cafes as well as a variety of useful information, factsheets and advice on their website.

Tel: 0330 330 804 (general enquiries)

Dementia Support line: 03331 503456

National helpline: 03002 221122

Email: helpline@alzheimers.org.uk

Web: www.alzheimers.org.uk

Talking Point online discussion forum

It's a place to ask for advice, share information, join in discussions and feel supported. Talking point is available 24 hours a day, every day of the year.

Web: www.alzheimers.org.uk/talkingpoint

Together in dementia everyday – Tide

Tel: 01512372669

Web: www.tide.uk.net

Email: Carers@tide.uk.net

Care Navigator Services & Social prescribing

Care Navigators work with older adults to provide information and advice to help you understand community services and help resolve any problems or issues.

- Connect well

Covering: Ashford, Canterbury, Dover, Deal, Folkstone and Thanet.

Tel: 0300 302 0178

Email: Connectwell@sekgroup.org.uk

Web:

<https://www.connectwelleastkent.org.uk/>

- Imago

Medway

Tel: 0300 0222965

Email: KMCCG.Carenac-Medway@nhs.net

Web: www.imago.community/

- Involve

Maidstone

Tel: 0300 810 005

Email: Office@involvekent.org.uk

www.involvekent.org.uk/

Admiral Nursing & Dementia UK

Admiral Nurses are mental health nurses specialising in dementia care. They provide support to Carers of people with dementia as well as the person with dementia.

The Dementia UK website hosts lots of information on dementia, films and other resources

Tel: 0800 888 6678

Email: helpline@dementiauk.org

Web: www.dementiauk.org

Young Dementia network

Hosted by Dementia UK, the young dementia network is tailored to those with young onset dementia. Lots of information, advice, webinars and resources on their website

Email: youngdementianetwork@dementiauk.org

Web: www.youngdementianetwork.org

Eventbrite

This website hosts lots of free (some paid) events, courses and seminars, so if you want to keep up to date on what's going on or expand your knowledge on dementia or up to date advice as a carer you'll find something here.

Web:

<https://www.eventbrite.co.uk/d/online/dementia/>

The Silver line

Free confidential helpline providing information, friendship and support to older people, open 24 hours a day

Tel: 0800 4 70 80 90

The Samaritans

Provide 24/7 confidential emotional support to those experiencing despair, distress or suicidal feelings. Self-help app available to download.

Tel: 116123

Web: www.samaritans.org

Email: jo@samaritans.org

The Dementia Dictionary

As dementia progresses, communication can become difficult. This online resource aimed at those who care for people with dementia, you can post a query about a particular behaviour and the dementia translators will reply with their definition of what the person is really trying to say.

Web: www.dementiadictionary.com

NHS resources

For tips and advice on nutrition and hydration

Web: www.NHS.uk/live-well/eat-well Help and advice on stopping smoking

Web: www.NHS.uk/better-health/quit-smoking

Help to care app

Designed to help identify a problem and find information and advice.

Available to download on Appstore or google play

Tel: 03000 422 357

Email: innovationdeliveryteam@kent.gov.uk

Web: www.innovationdeliveryteam.co.uk

Next steps

Helpful guide taking you through the memory assessment process, looking after your wellbeing, available support and what to do after diagnosis.

Web: <https://www.nextsteps.org.uk/>

Activities and Support in the Community

Crossroads Care Kent

Offering carers short breaks, respite, coffee mornings, crisis service, dementia outreach and carer wellbeing services.

- **Carers Short Breaks - home based respite**
Free, regular (usually weekly), home based replacement care for family Carers, caring for people of all ages, with any condition or illness, including end of life and dementia.
- **Carers pre-bookable health appointment service**
- Carers can pre book a replacement care service to enable them to attend their own health or treatment appointments; i.e. GP appointments; outpatients' clinics; treatment sessions eg. chemotherapy/physio.
- **Volcare – carers respite**
- Supports Carers in the community by offering flexible home based respite care to suit the individual's needs. Respite is on an occasional basis and can be for a whole day, a weekend or a week to 10 days. The service is fully funded by Social Services and is free at the point of delivery. Whitstable, Thanet, Herne Bay and Canterbury

Tel: 03450 956701

Email: Enquiries@crossroadskent.org

Website: www.crossroadskent.org/

UK Network of Dementia Voices (Deep)

Nationwide independent organisation linking together 80+ Dementia groups across the UK.

Web: www.dementiavoices.org.uk

Local support groups consist of people with dementia and professionals meeting once a month, discussing topical issues, working to raise awareness of dementia, combating stigma, improving services and taking part in various projects.

Local groups:

Margate	The New Seaside	Tel: 01843 267 071
Canterbury	East Kent Forget Me Nots	Tel: 01304 216 625 Elizabeth.feild@kmpt.nhs.uk
Dover, Deal & Shepway	SUNshiners	Tel: 01304 216 626 Email: dawnpeerbhoy@nhs.net y.kusel@nhs.net
Ashford	Ashford Phoenix - rising above dementia	kmpt.pheonixgroup@nhs.net
Swale	Pathfinders	Tel: 01795 438 446 Email: kmpt.pheonixgroup@nhs.net

Age Concern/Age UK Centres

Age Concern Centres offer social opportunities to those over 50. They have a range of activities, services and social events as well as buddy boxes, activity workbooks, handy man services, foot services to name a few. Contact your local centre to find out what they offer.

Ashford	01233 668765
Canterbury	01227 462368
Deal	01304 372608
Dover	01304 207268
Faversham & Sittingbourne	01795 532766
Folkestone	01303 279621
Herne Bay & Whitstable	01227 749570
Hythe & Lyminge	01303 269602
Riverside Centre Dover	01304 207268
Sandwich	01304 614237
Thanet	01843 223881

Web: www.ageuk.org.uk

The Age UK website has over 60 free activity packs you can download! Web:

www.ageuk.org.uk/sheffield/our-services/dementia-advice-sheffield/corona-virus-resources/resources-for-activities/

Dementia Day Care (Age Concern/UK)

These centres offer specialist day care in a secure environment for those with dementia. There are suitability criteria and charges for this service, so call your nearest provider to find out more:

Canterbury	Collins Unit	Tel: 01227 462368
Herne bay Age UK	Hazel Neville Centre	Tel: 01227 749570
Sandwich Age Concern	Sunflower Centre	Tel: 01304 614237
Faversham & Sittingbourn e Age UK		Tel: 01795 532766
Riverside Day Centre	Dover	Tel: 01304 207268

Cogs Clubs

Based on Cognitive stimulation therapy and aimed at those with mild-moderate dementia, cogs clubs run once or twice a week providing a day of stimulation and fun activities as well as respite for carers. Costs vary in each location (£15-£24).

Birchington, Broadstairs & Cliftonville	01843 294 919
Canterbury	01227 462 368
Deal	01304 372 608
Dover	0345 095 6701

Faversham	01795 532 766
Folkstone	01303 279 031
Herne Bay	01227 749 570
Lyminge	01303 269 602
Ramsgate	01843 867 818 or 01843 586 320
Sandwich	01304 614 237
Whitstable	01227 749 570

Volunteer Centres

Volunteer Centres offer a range of services that offer help and support to the community. Their services include befriending, gardening/DIY and transport services. Contact your local Volunteer Centre to find out the services they offer, as this varies across areas.

Volunteer Centre	Tel no
Ashford and Tenterden	01233 665535
Canterbury and Herne Bay	01227 743700
Kent Coast Volunteering Dover, Thanet, Folkstone & Hythe	01843 609337
Shepway Volunteer Centre	01303 259007
Swale Volunteer Centre	01795 473828 or 07735 553829
Whitstable – Red Zebra	01227 262313

Bright shadow

Can provide training sessions. Offer 1-2-1 sessions in your own home. Zest community groups located at Canterbury, Dover, Whitstable and Hythe. The bright shadow website has some free activity videos and activity sheets, and other activity packs for purchase.

Tel: 01227467272

Email: info@brightshadow.org.uk

Email: zest@brightshadow.org.uk

Website: www.brightshadow.org.uk

Sing for your life – Silver Song Club

Regular interactive singing and music sessions for older people. Clubs are held in: Ashford, Folkestone, Tenterden, Deal, Margate, Herne Bay and Whitstable

Tel: 01303 298242

Email: info@singforyourlife.org.uk

Website: www.singforyourlife.org

East Kent Independent Dementia Support

Offer a range of support groups in the Canterbury, Whitstable, and Thanet areas, including informal get-togethers, memory clubs, lunches and outings. These are for Carers and people with dementia.

Tel: 01227 730000

Email: enquiries@ekids.org.uk

Website: www.ekids.org.uk

Alzheimer's and dementia support services

Based in Dartford and Gravesend. Website provides lots of information and includes some online video activities including sing-alongs and armchair yoga.

Web: www.alz-dem.org/activity-videos/

Care visions healthy aging

This website includes some short videos including music, quizzes, reminiscence, and gentle exercises

Web:

<https://carevisionshealthyageing.com/dementia/support-videos/>

Dementia adventure

Aimed at those with mild-moderate dementia with reasonable mobility. Offers supported short holidays for people with dementia and their family member/carer on an individual or group holiday basis. Cost varies depending on package.

They also run information and support sessions.

Tel: 01245237548

Email: info@dementiaadventure.co.uk

Web: www.dementiaadventure.co.uk

Playlist for life

Music has been shown to have many psychological benefits and is often one aspect that is retained well into the later stages of dementia. This website helps you to make a playlist of old favorites.

Web: www.playlistforlife.org.uk

Interactive Me

Interactive Me is an Occupational Therapy service which supports Carers of people with memory impairment by building digital memory boxes for their loved ones. Interactive Me, Southwood Road, Ramsgate, CT11 0AJ

Tel: 01227 678061

Website: www.interactiveme.org.uk

Health and Social Care

NHS Community Mental Health Service for Older Adults (CMHSOP)

Community mental health services are for older people with mental health needs, which are complicated by age, and for people, of all ages, who have needs relating to dementia.

There are different community mental health services in Kent and Medway, depending on where you live. If appropriate, your GP will refer you to the most suitable community mental health service for you.

Tel: 0800 783 9111

Website: www.kmpt.nhs.uk/services/

Ashford Community Mental Health Team for Older People

Eureka Business Park, Eureka Place, Trinity Road,
Ashford TN25 4BY

Tel: 01233 658125

Canterbury Community Mental Health Team for Older People

Gregory House, St. Martin's, Canterbury, Kent,
CT1 1TD

Tel: 01227 812054 or 0122 812083

East Kent Hospitals University NHS Foundation Trust Dementia Team

The dementia team cover hospitals across East Kent. The service offers support and guidance during a patients time in hospital.

Trustwide	
Joy McCue <i>Dementia specialist Lead Nurse</i>	Tel: 07771814076
Jade Garlick <i>Senior specialist in Dementia care</i>	Tel: 07929849625
Queen Elizabeth Queen Mother Hospital (QEQM)	
Karen Scrivener <i>Dementia Specialist Nurse</i>	Tel: 07964438094
Gemma McNutt <i>Dementia Nursing Associate</i>	Tel:07500120994
Kent and Canterbury Hospital (KCH)	
Amy Harris <i>Dementia specialist practitioner</i>	Tel: 07964436911
William Harvey Hospital & Kent and Canterbury Hospital (KCH)	
Ann McGovern <i>Dementia Associate Practitioner</i>	Tel: 07973947060
Maria Kertesz <i>Dementia Trainee Nursing associate</i>	Tel: 07771833669

Web: <https://www.ekhuft.nhs.uk/>

Community Mental Health Team for Older People Dover/Deal

Coleman House, Brookfield Avenue, Dover, Kent, CT16 2AH

Tel: 01304 216678

Shepway Community Mental Health Team for Older People

Folkestone Health Centre, 15-25 Dover Road, Folkestone, Kent, CT20 1JY

Tel: 01303 228838

Swale & Faversham Community Mental Health Team and Day Services for Older Adults (CMHSOP)

Chris Ellis Centre, Sittingbourne Memorial Hospital, Bell Road, Sittingbourne ME10 4DT

Tel: 01795 852660

Thanet Community Mental Health Team for Older People

Thanet Mental Health Unit, 164 Ramsgate Road, Margate, Kent CT9 4BF

Tel 01843 267071

Patient Advice and Liaison Service (PALS) / Patient Experience Team

The PALS service at East Kent Hospitals University NHS foundation Trust aims to help patients and Carers with their questions and problems concerning health and related services.

PALS, First Floor, Trust Offices, Kent and Canterbury Hospital, Ethelbert Road, Canterbury CT1 3NG

Email: ekh-tr.PALS@NHS.net

Web: www.ekhuft.nhs.uk/patients-and-visitors/information-for-patients/pals/

Tel: 01227 783145

Kent Social Services

Can offer advice, guidance, help in the home, respite and a range of services related to social care.

Tel: 03000 416161

(out of hours 03000 419191)

Website: www.kent.gov.uk

Finances, Benefits and Legal Matters

Disability Living Allowance helpline

- Born before 8/4/1948:

Telephone: 0800 731 0122

Textphone: 0800 731 0317

- Born after 8/4/1948:

Telephone: 0800 121 4600

Textphone: 0800 121 4523

Attendance Allowance helpline

Telephone: 0800 731 0122

Textphone: 0800 731 0317

Personal Independence Payment helpline

Telephone: 0800 121 4435

Textphone: 0800 121 4493

Web: www.gov.uk/disability-benefits-helpline

Carer's Allowance

Telephone: 0800 731 0297

Textphone: 0800 731 0317

Web: www.gov.uk/carers-allowance

The Pension Service

This service can provide advice on pensions and pension related entitlements, as well as work out pension entitlements. They can do this by phone, e-mail, face-to-face or by post.

Tel: 0800 731 0469

Textphone: 0800 731 0464

www.gov.uk/contact-pension-service

Citizens Rights for Older People (CROP)

Help people over the age of 50 to maximise their benefits, by providing assistance with completing forms, advocacy. Also offer assistance with financial matters, consumer disputes and complaints.

Tel: 01622 851200

Email: lenham@cropkent.org.uk

Website: www.cropkent.org.uk

Citizens Advice

Help people resolve legal, money and other problems by providing free, independent and confidential advice. Their advice helps people resolve their problems with debt, benefits, employment, housing, discrimination, and many more issues. Call your nearest centre for support.

National Advice Line: 08082787846

Web: www.citizensadvice.org.uk

Will Aid

Will Aid is a partnership set up with 9 UK charities. During November you can have a professionally drawn up basic will.

Web: www.willaid.org.uk

Free wills Month

In partnership with UK charities and applicable for the over 55's. The free wills campaign usually runs during March and October each year

Web: www.freewillsmonth.org.uk

Transport and Driving

DVLA – Medical Enquiries

Call the number below to let the DVLA know that you or your loved one has a dementia. You may be required to complete CG1 form which can be found on the DVLA website listed below.

Tel: 0300 790 6806

Website: www.gov.uk/driving-medical-conditions

Driving Assessment Centre – South East Driveability

Driving assessment and driving advice centre. Based in Maidstone, with satellite centres in Herne Bay and Hailsham.

Tel: 0300 0134 886

Website: www.kentcht.nhs.uk

Blue Badge

A blue badge allows severely disabled people and those with mobility problems to park closer to amenities.

The Blue Badge Service, Kent County Council, Invicta House, County Hall, Maidstone. ME14 1XX

Tel: 0300 041 6262

Website: www.kent.gov.uk

Transport Services

Volunteer Centres may also run transport schemes to enable you to go to hospital appointments, visit relatives, go shopping or other social events. There is a charge for petrol per mile, and you will need to book in advance. You will find Volunteer centre details below.

Centre	Transport Number and Website
Ashford and Tenterden Volunteer Centre	Tel: 01233 633219 Web: https://ashfordvc.org.uk/services
Canterbury and Herne Bay Volunteer Centre	Tel: 01227 743700 Web: https://chbvc.org/
Kent Coast Volunteering	Dover & Thanet Tel: 01304 380513 Folkstone & Hythe Tel: 01303 253339 Web: www.kcv.org.uk/need-a-driver/
Swale Community & Voluntary services	Tel: 01795 426647 or 0300 365 0045 www.swalecvs.org.uk
Red zebra (Whitstable)	Tel: 01227 271111 Web: www.redzebra.org.uk/volunteer-car-scheme/

Thanet Community Transport Association (TCTA)

Offering Dial a ride – a door to door service to appointments or shopping trips. Personal shopper service. Short breaks. Plus, if you become a member and sign up for the newsletter there are many prearranged trips available, from afternoon teas, theatre shows, shopping trips, and pub lunches, book in advance.

Covering; Thanet, Herne Bay, Canterbury, Dover and Deal.

Tel: 01843 602030

Web: www.transportinthanet.co.uk

Travel Line

Point to point journey planner

Tel: 01142 211282

Website: traveline.info

Safety and Security in the Home

Canterbury Lifeline

Offer a lifeline pendant as well as a range of assistive technology to allow safety and peace of mind in the home.

Tel: 01227 862000

Web:

<https://www.canterbury.gov.uk/lifeline>

Lifeline24

UK wide personal alarms, particularly helpful to those at risk of falls.

Tel: 0800 999 0400

Email: Info@lifeline24.co.uk

Website: <https://www.lifeline24.co.uk/>

Kent Fire and Rescue Service

Offer a safe and well home visit service to check over safety in the home and address any concerns.

Tel: 0800 923 7000

Email: home@kent.fire-uk.org

Web: www.kent.fire-uk.org/your-safety/home-safety

KCC Living made easy – AskSARA

Impartial advice about equipment to help daily living easier. Choose a topic, answer some questions and receive impartial advice about equipment to help make daily living easier.

Website:

<https://kent.livingmadeeasy.org.uk>

Peabody (formerly Family Mosaic / In-Touch)

Offer a home improvement service and housing advice. They can assist with home adaptations such as grab rails and bathroom adaptations. Also providing a handyman service and can help make your home more secure.

Tel: 0800 028 3172

Web: www.peabody.org.uk

If you are caring for someone living with Dementia and would like information or support please contact:



80 Middle Street, Deal, Kent, CT14 6HL

Tel: 0300 302 0061

E-mail: support@carersek.org.uk

Web: www.carersek.org.uk