



# Living well with dementia









## Are you worried about your memory?

If you're worried because you, or someone you care for, is becoming confused and forgetful, visit your GP. You may have heard about Alzheimer's Disease or other types of dementia, and be concerned. It's important to have a proper assessment to find out whether these symptoms are as a result of dementia or are caused by some other condition which may respond to medical treatment.

#### What is dementia?

Dementia is a condition which is caused by damage to, or disease of, the brain. It is more common in older people, but in some cases dementia can also affect people under 65.

People with dementia have particular problems with short term memory, and their sense of time and place may become impaired. They have difficulties with communication, understanding and judgement. They may become withdrawn, anxious or frustrated, have mood swings or behave in unusual ways. They may not be safe alone. As the condition progresses, people with dementia have increasing difficulty with most every day tasks and will need a lot of help from other people.

However, although dementia is usually a progressive illness, for most people the changes are gradual. There is help and support available to help you to live well with dementia.

If you seek help you can have time to plan for the future, and to find out about services that are available to support both the person with dementia and their carer.





People with memory problems can now get expert help from the Memory Assessment Service provided by Cornwall Partnership NHS Foundation Trust, who also provide comprehensive services to support people after diagnosis.

The service provides an assessment for people with memory problems and who may have dementia. Although there is currently no cure for Alzheimer's Disease or other types of dementia there are treatments and support available to improve a person's quality of life.

Early assessment and diagnosis is crucial in identifying the right treatment and support for people. The service is run by specially trained memory assessment practitioners which include nurses, doctors and occupational therapists.

They use a variety of assessment tools to measure different aspects of cognitive function. The term cognition relates to a person's thinking processes such as remembering, learning, thinking and reasoning. Staff assessing memory can organise brain scans which may help diagnosis and rule out any other causes of memory loss.

Everyone who is diagnosed with a form of dementia will receive a personalised care plan. Links will also be made with other support services, which will include groups offering 'brain training' exercises known as cognitive stimulation therapy. The service will also provide post-diagnosis counselling and support to people who are diagnosed with dementia and their families.

If you are worried about your memory, visit your GP who will have the right information to help you decide whether you would benefit from a specialist memory assessment either in a memory clinic or your own home.

Anyone can refer themselves directly to the service.

## **Keeping healthy**

While it is not possible to prevent all cases of dementia, there are some measures that can help prevent vascular dementia, as well as cardiovascular diseases, such as strokes and heart attacks. Vascular dementia is the second most common form of dementia after Alzheimer's. It is caused by problems in the supply of blood to the brain.

### **Prevention methods**

- Eat a healthy diet
- Maintain a healthy weight
- Get regular exercise
- Drink alcohol in moderation
- Don't smoke
- Make sure your blood pressure is checked and controlled
- If you have diabetes, make sure you keep to the diet and take any medicines.

There is some evidence that rates of dementia are lower in people who remain as mentally and physically active as possible throughout their lives, and have a wide range of different activities and hobbies.



What is good for your heart is also good for your head

### Activities that may reduce the risk of developing dementia

- Reading
- Writing for pleasure
- Learning foreign languages
- Playing musical instruments
- Taking part in adult education courses
- Playing tennis or golf
- Swimming
- Group sports, such as bowling
- Walking

(Source: NHS Choices 2010)



### Depression

Getting help as soon as you think you may have depression may prevent your depression getting worse. The exact causes of depression are not fully known.

It seems more likely to occur if there is depression in the family, but having a relative with depression does not mean you will necessarily become depressed yourself.

Furthermore, there are a number of lifestyle factors or influences in the world around you that may increase the risk of you developing depression.

The good news is that with the right treatment and support, most people make a full recovery from depression.

It is important to seek help from your GP if you think you may be depressed.



# Top tips for memory problems

# Forgetting to do things and / or to remember appointments

This is often very noticeable as the forgotten events may involve other people (for instance, forgetting someone's birthday or anniversary, or an appointment to meet someone), or directly affect yourself (forgetting to put the oven on or forgetting a shopping item).

The use of 'memory prompts' (diaries, calendars and notebooks) can be very useful in coping with these problems.

### **Difficulty remembering names**

Word finding difficulties occur when it becomes difficult to retrieve the word from the brain. If you think more consciously about 'storing' the name it may become easier to recall.

This can be done in a number of ways. First of all, simply rehearsing the names of people you know can be helpful. Write down, perhaps with the help of your spouse or friend, a list of people you know names on one side, who they are, or a distinguishing feature on the other side of the page (for example "Bill - next door neighbour", "Mabel - organiser of bridge club" or "Jim - with the bushy beard").

A second way of trying to remember names is to associate the person whose name you are trying to remember with a visual image that will recall their name. For example, as you go through the list and learn it, try to form a bizarre or vivid image of the person's name and what they do. For example for "Bill the neighbour" you may form a clear image of him talking to you across the fence with a fistful of bills!

### Trying to remember whether or not you have done something!

If the task (or tasks) is something that you do on a regular basis, write them down in large print on a big piece of paper and place in a prominent position. For example, if you are always forgetting to do something or forget to take everything with you when you go out make a check list. For example:

- Are the windows closed?
- Are the fires switched off?
- Is the back door locked?
- Have you got your purse / wallet and keys?

Tape the checklist where it can't be missed, such as next to the front or back door handle so that it can be seen and referred to easily. This sort of list is the same as having a shopping list.



Use clocks, wear a watch, put up a calendar and think about taking a daily newspaper to help you keep track of time.

Use sticky-backed notes to help remind you of things you have to do and important phone numbers by the phone so they are always on hand.





Break up tasks into bite-sized chunks to make them more manageable and try to do one thing at a time - tackling too many things at once can be confusing.

Keep important things such as money, keys or spectacles in the same place, so you always know where to find them.





Arrange to pay regular bills by direct debit or standing order. It can take a while to get into the habit of using these memory aids, so give yourself time and persevere.

Consider keeping a diary in which you can note down appointments, 'to do' lists and anything else you want to remember.





Try to have a routine to give structure to your day and help you remember what you are supposed to be doing.



### What support and services are available?

In Cornwall and the Isles of Scilly, support for people with dementia and their carers is provided by a range of agencies, including the NHS, local authority and voluntary organisations. In most cases, the initial point of contact to access these services is either your GP (for health care services) or your local Adult Care and Support office (for most other care). Some useful support and information services are outlined in the following pages.

### Education, Health and Social Care (Cornwall Council)

Personal Budgets: Following an assessment of your circumstances, you may be entitled to a personal budget from Adult Care and Support if you have eligible social care needs. A personal budget is money from the local authority to enable people who have been assessed as having eligible social care needs to organise and purchase support for themselves, or to have the local authority arrange this on their behalf. Some examples of what people use their budgets for include employing a personal assistant, organising practical help in the home, or taking part in the community.

**Short breaks:** Short breaks are designed to give people who need support, and their carers, a break from their usual routine or caring role. People who are eligible for support from the local authority, or their carers, can ask for a short break. The length and frequency of the breaks will be agreed with a case coordinator or social worker following an assessment.

# Care homes and care homes with nursing

In some circumstances, a person with dementia cannot be cared for in the community. Care homes may offer nursing or personal care, or both. All care homes are required by law to be registered with, and inspected by, the Care Quality Commission (CQC).

The CQC will provide a list of suitable care homes on request, and most registered care homes in Cornwall are also listed in the 'Care Choices Directory' and the 'Right Care Index' which are updated annually and are available from your local Education, Health and Social Care office.

# Contacting Education, Health and Social Care

Telephone **0300 1234 131**. The office is open 8.45am to 5.15pm Monday to Thursdays and 8.45am to 4.45pm on Fridays. If an emergency arises outside office hours, please telephone **01208 251300**.

### **Red Cross services**

Red Cross provide practical and emotional support at emergency incidents such as fire. They also provide a mobility aids loan at a small cost for up to 12 weeks for people living alone.

Red Cross House Lighterage Hill Newham Truro TR1 2XR Telephone: **01872 260173** or **0844 330 8039** 

# Advice on equipment and adaptations

Simple aids and equipment, such as rails, bath seats or raised toilet seats may be provided directly.

### whttp://asksara.dlf.org.uk

Tremorvah Industries has a lifestyle centre where 'smart house' equipment for people with dementia is on display and available to sample.

### 01872 324340

## Advice, information and someone to talk to

### **Alzheimer's Society**

For information and advice on all aspects of dementia including a helpline with a call back service.

- Staff will direct you to all services in your area
- Provide information leaflets
- Help to sort out any problems
- Someone to listen
- Support to liaise with services
- Help to prevent a crisis
- Legal and financial information
- Provide information on memory cafes in your area
- 'Singing for the Brain' activities
- End of life care and decisions
  advice
- Information on dementia friendly communities.

### Helpline opening hours:

- Monday to Wednesday 9am to 8pm
- Thursday and Friday 9am to 5pm
- Saturday and Sunday 10am to 4pm.

t 0300 222 1122 (national)
 t 01872 277963 (local)
 w www.alzheimers.org.uk

The Alzheimer's Society has volunteering opportunities for a number of roles in Cornwall, If you would like to discuss volunteering opportunities, please call **07889 604537** or **01752 608911** or have a look on the website under volunteering opportunities.

Side by Side: This service helps people with dementia to keep doing the things they love with the support of a volunteer. Person centred, one-to-one support makes it easier for people with dementia, who might sometimes feel isolated or find it difficult to leave their homes, remain active and feel part of their local community. By doing things like going for a walk, attending a football match, or joining a local class together, volunteers can support people with dementia to take up hobbies and get out and about. The focus of the service is to build upon the existing skills and strengths of people with dementia; working with them to identify and implement solutions to the barriers they face in getting out and about, supporting and encouraging them to be part of their community.

# Age UK Cornwall and Isles of Scilly

Telephone **01872 266388** for information and advice service offering information on:

- Befriending
- Day care services
- Home care services
- Transport services.

www.ageuk.org.uk/cornwall

### **Cruse Bereavement Care**

Cruse offer support and help to those who are grieving, following the death of someone close. Such an event can affect us emotionally, physically, socially and in many practical areas of our life.

Cruse Bereavement Care in Cornwall offers help and support and is strictly confidential and is given without charge.

### Dementia Support Worker Service

The service provides one to one support to people with dementia and carers, which can be provided face to face, over the telephone or via written communication. Dementia support workers provide information, guidance and practical support to help people understand dementia, cope with day to day living with dementia and prepare for the future. The service also supports people to access other services.

### 01872 277963

### Healthwatch

Healthwatch can provide a local information and signposting service.

t 0800 0381 281 (Cornwall) t 01720 423037 (Isles of Scilly)

### t 01726 76100

# Take steps to get help when you're worried about someone's memory

- 1. Plan a conversation in a familiar, non-threatening environment.
- 2. Explain why talking is important you're worried because you care!
- 3. Use examples to make things clearer. It's important to be careful not to create a sense of 'blame' eg instead of telling someone they could not make a cup of tea, suggest they are finding it difficult.
- 4. Have an open conversation be honest and direct. Ask how they are feeling about their memory?
- 5. Make a positive plan of action together.

### **Primary Care services**

If you have any concerns about Primary Care services (such as a GP or dentist), you should contact the provider of the service direct or NHS England's national call centre on **0300 311 2233**. For concerns about secondary care or community services, you should contact the provider trusts direct.

### **Telephone Befriending Service**

This ring back service aims to improve quality of life for people with dementia, carers, family and friends by supporting them to manage at home for as long as possible. The service aims to provide information and help to access services and support in the community. This may be by providing information, signposting to other organisations or offering telephone befriending support, thereby ensuring individuals are better able to cope. The service is run by dedicated trained volunteers.

### Singing for the Brain

Singing for the Brain is designed to be a fun, stimulating and social activity for people in the early to moderate stages of dementia and their carers. Contact Alzheimer's Society on **01872 277963** or email **cornwall@alzheimers.org.uk** to find out more.

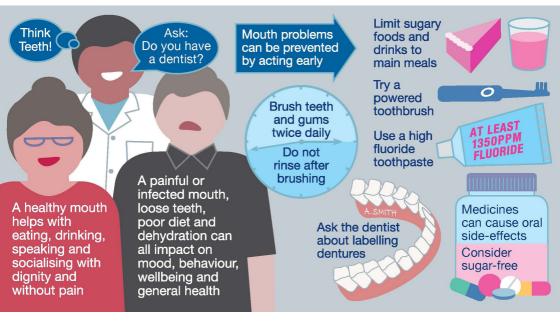
### Volunteering

Volunteering can be a good way to keep active and allows you to meet new friends and try new things. There are also lots of services for people with dementia, and their families or carers, run by volunteers. If you are interested in finding out more about volunteering opportunities with or for people with dementia, contact Volunteer Cornwall on **01872 266988**.



Dublic Health England

ORAL HEALTH is very important in DEMENTIA



## **Oral health**

Good oral health is important for health and wellbeing. Because dementia is a progressive condition (meaning it gets worse over time) it is important to establish a dental care programme at, or soon after, a diagnosis.

The programme should help to improve oral health and reduce the risk of developing poor oral and dental health. Maintaining oral health brings benefits in terms of self-esteem, dignity, social integration and nutrition. Poor oral health can lead to pain and tooth loss, and can negatively affect self-esteem and the ability to eat, laugh and smile.

There may come a time when the person with dementia is unable to say that they are experiencing pain or discomfort in their mouth or teeth. They will need to rely on other people to notice and interpret their behaviour and to arrange a visit to the dentist if necessary.

www.nhs.uk/Livewell/dentalhealth

## Support groups and therapies

### **Memory cafes**

A memory cafe is somewhere where people with dementia and their carers can visit to support each other and share information. The groups usually offer reminiscence-based activities. Health and social care professionals may also be on hand to answer questions and offer advice in an informal setting. There are numerous memory cafes across the county. To find the group closest to you contact Age UK Cornwall and Isles of Scilly on 01872 266388 or Alzheimer's Society on 01872 277963.

### **Books on Prescription**

Reading books can be an effective way of helping people learn more about a subject and understand how others have coped. Living with memory loss or dementia can be a lonely, frustrating, upsetting and confusing time for both the person who experiences the difficulties and the family and friends in their life. Reading a sensitive and insightful book may help you understand the issues that surround memory loss and dementia. The books have been checked by healthcare professionals as being accurate and helpful. There is also advice on books that may stimulate conversations with people with dementia.

There is normally a small charge to reserve books. However, if the request is signed by a health professional, the service is free. If you are not already a member of the library, you will be asked to join, which is free. Library staff will need proof of your name and address.

### t 0800 032 2345 www.cornwall.gov.uk/library



## **Carer support education and information**

### **Creative Spaces**

This is a project run by the Sensory Trust. Activities include social walks, meeting others and exploring the outdoors. It uses outdoor environments and nature-based activities to help people with dementia and their families to increase / maintain physically and socially active lives in their communities.

There are also specific outdoor activity clubs in Cornwall for people living with dementia and their carers/families:

- Potager club: A mix of working in the garden and nature activities.
- St lves club: Mixes nature walks with studio sessions at the Leach Pottery.
- Walking clubs: Available in St. Austell, Bodmin and Bude.

Telephone the Sensory Trust on 01726 222900 or email w.brewin@sensorytrust.org. uk for information on project activities, events, workshops and advice on how they can use nature as a means of supporting and benefiting dementia care at home.

### **Dementia Roadmap**

The Dementia Roadmap is a website that provides information about dementia alongside local information about services, support groups and care pathways to assist people living and working with dementia to access national and local information all in one place. Visit www.dementiaroadmap.info/ cornwall for more information.

### **Care and support services**

This website lets you search by postcode or region for care homes, care homes with nursing, home care and housing with care providers.

### www.carechoices.co.uk

### **Kernow Carers Service**

Carer support workers in Cornwall provide information, support and advice to carers. Your GP surgery will give you the name and contact details of the carers' support worker for your area, or you can telephone the service through Cornwall Rural Community Council.

### 0800 587 8191



### **Shared Lives South West**

Shared Lives South West offers long-term care and support, short breaks and day care for people with a learning disability or mental health needs and for older people, including those with dementia.

Free introductory respite sessions are available; this can be for a long weekend or up to three nights, subject to the Shared Lives matching process.

t 01209 891888 cornwall@sharedlivessw.org.uk



## Cornwall and Isles of Scilly Dementia Roadmap Helping to support people with dementia

The Dementia Roadmap is a website that provides information about dementia alongside local information about services, support groups and care pathways to assist people living and working with dementia to access national and local information all from one place.

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- http://dementiaroadmap.info/cornwall
- f facebook.com/dementiaroadmap
- youtube.com/user/dementiaroadmap
- twitter.com/dementiaroadmap



## **Useful numbers and contacts**

Adult Care and Support Telephone 0300 1234 131

Assistive Technology: Tremorvah Industries - equipment or technology that helps to promote people's independence at home. Telephone **01872 324340** 

Cruse Bereavement Care Telephone 01726 76100

Carers Direct: information, advice and support Telephone 0300 123 1053

Carers education and booklet: Cornwall Council Telephone 0300 1234 100

Kernow Carers: caring and support for those who care. Telephone 0800 587 8191

## **Helplines**

Alzheimer's Society: 01872 277963

Age UK Cornwall and Isles of Scilly: 01872 266388

Memory Assessment and NHS Community Services: Cornwall Partnership NHS Foundation Trust - 01208 251300

Red Cross: 01872 260173 / 0844 330 8039

## **Useful websites**

Age UK Cornwall and Isles of Scilly www.ageuk.org.uk/cornwall

Alzheimer's Society www.alzheimers.org.uk

Carers Direct www.nhs.uk/carersdirect

Cornwall Council www.cornwall.gov.uk/dementia

Cornwall Partnership NHS Foundation Trust www.cornwallft.nhs.uk

For information on medications: http://choiceandmedication.org/cornwall

**Cornwall Rural Community Council** For information on memory cafes and carer support: www.cornwallrcc.org.uk

### Memory Matters South West

For information on carers coaching, training, information: www.memorymatterssw.co.uk





This booklet has been produced in partnership with Cornwall Council.

To order extra copies of this leaflet, please contact NHS Kernow.

kate.mitchell8@nhs.net

**S** 01209 832427



## To get this information in another format call: **01726 627800**