

What is Dementia?

Dementia is a serious progressive illness which affects the brain. People of any age can develop dementia, although it is more common in older people. It will slowly affect your life more and more and can affect the way you think, your memory and your actions.

There are a number of different types of dementia and you can ask your GP which type you have. This may be a well-known type of dementia such as **Alzheimer's** or **Vascular (multi-infarct) dementia** or a less well-known type.

Alzheimer's disease damages individual brain cells one by one, so the brain cannot work as well as it used to.

Vascular (multi-infarct) dementia means you have problems with the blood supply to brain cells. In vascular dementia, tiny strokes (infarcts) damage small areas of the brain. Each time you have a little stroke, there will probably be a change in how well you are managing. The strokes may make you feel unwell and more confused for a short time, or you may not notice them at all.

There is more detailed information available about each type of dementia. Once yours has been identified you can find out more from a number of sources including your GP, CPN, Carers Café or other support networks.

For more information, or to talk things over with someone who understands, you can telephone or call into the [Romsey Carers Café](#) where you will be able to access information on the various forms of dementia and other neurological conditions such as Parkinson's.

Collated and produced by Carers Café Romsey 02 08 02 Revised 04 08 04



Living with Dementia

Have you been informed that you have a type of dementia?

Has one of your relatives been diagnosed with dementia?

This booklet may help you and your family and friends

This booklet may help you and your family and friends if you been informed that you have a type of dementia or if one of your relatives has been diagnosed with dementia

It includes suggestions to help you cope with everyday living and will give you some ideas on

- Who** you can talk to
- What** you can do to help yourself
- When** you should take action
- Where** you can turn for help
- Why** you should include family and friends in your plans
- How** to understand more about dementia
- How** to cope with the effects it could have on your life
- How** to start planning for your future
- How** to maintain some control over your future



want. A simple will through a solicitor costs about £50, or less if you are on a low income.

If you are fairly well off, it might be to your advantage to set up a trust. This might be worthwhile if you own your home or have savings of more than £10,000. A trust can take over your money and property and administer it for your benefit. Trusts can be worded so that the money in them does not count as part of your capital for assessing some benefits. A solicitor can help you with Trusts.

Other Information



There is a lot of **information about dementia** and other related conditions available. Ask your GP or consultant, your CPN or social worker, call the Carers Active Listening Line or your local Carers Forum, Drop in to the Carers Café when someone will be pleased to help you find the information you are seeking.

Medical research into the causes and possible treatments of the different kinds of dementia is one of the most well-funded areas of research world-wide, but the causes are not yet known and there is no cure. Media reports of 'breakthroughs' are often exaggerated, so don't let them raise your hopes.

Some **new treatments** for Alzheimer's disease, that are being tested, look as if they may delay the development of the illness for a few months in some people. Unfortunately they are not a cure and some of the drugs under trial have unfortunate side-effects. Information on current research, and on what to consider before taking part in research, is available and you should discuss these with your GP or Consultant.

For vascular dementia, **medication** to lower blood pressure may help reduce the risk of having small strokes.

Romsey Carers Cafe
is open on the first and third Friday of each month
from 11am to 1.30pm

Woodley Village Hall
School Road
Romsey
Telephone 01794 515126
or Email: support@romseycarers.org.uk

Power of Attorney

You can choose who will look after your financial affairs if you become unable to do so. Ask a solicitor to draw up a Power of Attorney, which authorises someone you trust to deal with your money affairs and will give you and your family peace of mind. If you are on a low income, a Power of Attorney may be available free, or much cheaper than usual, otherwise, it will cost about £50

Whoever you appoint as your attorney need not take over your affairs while you are still capable of doing it yourself, but they must be appointed in advance. It is important to do this early, to make sure that no-one can claim later on that you weren't well enough to grant a power of attorney.

You can choose what you would like your attorney to be able to do for you. For example, you might want them to be able to run your bank account, complete your tax returns, sign documents or buy and sell property for you. It helps if you can talk to your family about who you choose as your attorney so that they are aware of your wishes. You can choose more than one person to be joint attorneys for you if you like, or you can choose a solicitor (but he or she will charge fees).

You can change your mind at any time and take away the Power of Attorney by writing to the person or people you chose as your attorney and telling them that they no longer have the authority to act for you. You should also write to your bank/building society to tell them.

Make a will

Like everyone, you should make a will to make sure that your possessions go to the right people when you die. It is important to draw up your will now, while you are clear about what you

How are you feeling?

If you have recently been informed, possibly by your GP or Consultant, that you have a type of dementia, you may feel shaken, upset, worried, alone, angry, depressed or frightened.

You will probably need time to start getting used to the idea and may also want to know more about your condition.

Your GP or Consultant may have tried to explain more when you were first told your diagnosis, but you were probably unable to take it in at the time.

It is difficult for anyone to take in immediately the information that they have a serious condition or to understand what it means.



Finding out what is wrong can, however, be a positive step and will allow you to access the right support.

Don't be afraid to make another appointment to ask your GP to explain more about it.

Don't be frightened to take someone with you, take notes or tape record what the GP says as this will help you to understand and remember later,

You might find it difficult to believe you have dementia, although you may already have noticed that something was not quite right. Perhaps your memory was not as good as it used to be, or possibly you were not managing to do things as well as you once could.

It may be helpful to talk to someone about how you feel. Some people find it easier to talk things over with someone close such as partner or close friend or relative or with others, in complete confidence, with someone they don't know such as an independent volunteer or befriender, community psychiatric nurse or social worker.

Who can assist you?

You may contact the **Carers Forum** by telephone at any time for help and support, or call in to the **Carers Club** on the first and third Friday of any month, from 11am to 1.30pm, to have a chat in confidence, obtain more information, or just feel comfortable having a coffee and/or snack in pleasant surroundings and meeting others who understand how you may be feeling. It is run by Carers and is a useful resource for your family and friends to find out how they can best support you and how to find assistance to do this.

You can do a lot to help yourself and your family both now and in the future. One of the first things is to identify all those people and services that can help you. These could include:

- **Members of your family** - for everyday support and communication
- **Friends/neighbours** - for social activities, friendship and for practical support
- **Your General Practitioner (GP)**
- **Consultant in Old Age Psychiatry** - for specialist help and treatment
- **Citizen's Advice Bureau (CAB)** - for financial advice and information
- **Department of Work and Pensions (DWP)** for benefits
- **Romsey Carers Cafe** - for information/social interactivity
- **RAIN and RADISH** - for information and support at home
- **Other local support groups** - for support
- **Other activity facilities** - for support with activities
- **Local transport groups (Good Neighbours, STVVTs)** - for help with transport



advantageous to have someone with you at these discussions - a relative, friend or possibly someone from your union or an advocate.

Benefits

You may be entitled to benefits to help you cope with the extra costs of having dementia or, if you are of working age, benefits may help to compensate you if you can no longer work. You can find out what benefits you and your family would be entitled to, if you have to stop work, from your local Benefits Agency at Andover, or CAB Romsey. Your social worker, community psychiatric nurse, or **Romsey Carers Café** can also help.

Some of the benefits you may be entitled to include Attendance Allowance, Disability Living Allowance, Income Support, Invalidation Benefit, Council Tax Discount/Benefit, Housing Benefit, Community Grant, Carers Allowance.

Financial Arrangements

Dementia will affect your ability to look after your financial affairs and it is important to deal with this now so that you can arrange everything the way you want it. Make sure that all your important papers are in order, such as your mortgage, rent, rates, insurance, tax details, utility bills, pension, bank and building society statements. If possible go through them with someone you trust.



Paying bills

You can save yourself the trouble of remembering to pay bills by setting up direct debits and standing orders for all your regular bills such as gas, electricity, rent and so on, or you could ask your bank manager to organise paying any bills for you from your account using a general mandate - note, the bank may charge a fee.

write down your wishes in a 'Living Will'. They are not legally binding on doctors but they do help people to know your wishes. If you want to make a Living Will, you should talk to your GP, your solicitor and to your family and friends.

Living arrangements

Discuss with your family or friends what you would like to happen if you become unable to live in your own home. Perhaps there is someone who you would like to help take care of you, but moving in with someone is not always the best answer for either of you.

You might not wish your family or friends to be involved and might prefer to be cared for in a residential or nursing home if it should become necessary. You may get help with the cost of a Home if your social worker has assessed you as needing to live there. You can also speak to your local CAB or Solicitor about this.

You may like to talk about the different possibilities with someone who is not involved such as your GP, social worker, CPN or someone at the **Romsey Carers Café**. Make sure your wishes are known and write them down if you can. No one knows the future, and circumstances may change so that what you decide may no longer be possible, but it will help if your wishes are clear.

Work

If you are still working, your employer cannot legally sack you for having dementia. However, in time, you will be less able to do your job and eventually you will need to give up work. You should discuss with your employer what arrangements they may have for shorter hours, a simpler job or early retirement. If you have an occupational pension, it would be useful to find out how much you will get if you retire early. It would be

- **Community Psychiatric Nurse (CPN)** - for ongoing support and advice (refer by GP)
- **Memory Assessment Services** - for support and treatment if referred by GP
- **Occupational Therapist** - for advice/help with aids and adaptations (referred by GP)
- **Social Worker** - contact the local Social Services Office in Church Street, Romsey
- **Home Care Services** - access privately or through social services
- **Sitting Services** - access privately or through social services
- **Day Centre and groups** - for activities and respite
- **Other respite care services** - The Western Hospital or residential /nursing homes
- **Intermediate Care Centre** - e.g. Romsey Hospital
- **Meals on Wheels** - contact through Social Services
- **Test Valley Borough Council** - for help with housing, housing benefits, transport

What can you do to help yourself?

It is important to remember that any changes are going to be gradual.

You will have time to adjust your lifestyle and to seek the right support and assistance when you need it.

You can help yourself to manage in many small ways and there are some positive things you can do including:

Decide where to keep important things

- Have one place to keep documents, notes and diaries
- Make sure someone else knows where you keep them
- Have one place to keep money, keys & glasses
- Put them in the same place every time.



Write things down

- Make lists of what you need to do and keep them in one place
- Keep a diary and get into the habit of checking it regularly
- Make notes of where things are.
- A weekly calendar up on the wall could be useful.

Keep to a routine

- You may find it easier to keep to a regular way of doing things.
- You may find it easier to keep to a particular time to do things
- Take your medication regularly and keep it in the same place at all times.
- Always keep your keys in the same place so you do not lose them.

Take care of yourself.

- Drink and eat properly
- Do some regular exercise
- Make sure you take any medicines you are prescribed.
- Continue to enjoy a drink if you wish but be sensible about it.
- Make sure you have someone to talk to about your feelings and about the dementia
- If you are worried or feel depressed ask your GP for help.

The changes will be usually be slow and you may stay the same for months or years. Every person with dementia is different and it is not possible to predict when changes will occur. Although it may become difficult to continue some of your usual activities, you will be able to enjoy other things such as gardening, art or listening to music.

Driving

Dementia will affect your ability to drive. If you been diagnosed with dementia your insurance will probably no longer cover you, so you will have to give up driving. You should check this with your insurance company and write to DVLC, Swansea SA99 1BN to tell them your diagnosis.

Many people find that giving up driving is one of the hardest things to face. Your car may be an important part of your independence, and you may find it hard to think about life without it. However there are steps you can take to make the loss of your car less stressful.

- Work out how much your car costs, including the cost of the car, tax, insurance, maintenance and petrol. It will be a surprisingly high figure, which you can spend on buses, trains and taxis.
- Your local council, TVBC, has a scheme for tokens that give cheap travel on public transport.
- Ask family and friends if they can offer lifts, most people will be happy to help.

Medical Care

You may have ideas about what health care you would like to have in the future. Some people have strong views about whether they would want to take part in research, or what they would want doctors to do if they become terminally ill. You can

When should you plan for the Future ?

It is important that you think about the future and start to organise your personal affairs. If you set things in order now, everyone will know what you want. You should start to make your plans soon. If you wait too long, your right to make your own arrangements may be questioned.

How will Dementia affect you?

You will need to come to terms with the gradual changes in your life. These anticipated changes may be hard for you to accept at present, but if you take the opportunity to plan, you can think about how you will manage.

You may have trouble finding words, finishing sentences, following directions, remembering names or recent events.

You may sometimes get irritable and frustrated or feel confused.

You and your friends and family may notice changes in your personality and behaviour. They will understand if you have told them what is happening to you, or if someone such as your GP or a volunteer has discussed the effects of dementia with them.

Problems with memory and thinking processes are likely to increase in time. Reading and writing will slowly become more difficult, and it will become harder to take in new information or make decisions.

You may begin to find everyday activities difficult. You could begin to have a problem with remembering appointments, shopping needs, coping with money or cooking. Eventually, you may need help with basic activities such as drinking, eating, washing or dressing .

Keep up your social life.

- See your relatives and friends
- Keep going out and socialising.
- Explain to friends that you still need to see them, even if it is sometimes difficult
- Join a support group and meet others who understand what you may be feeling

Try to be positive.

- Try to concentrate on the things you can do instead of things that are too difficult.
- Tell people that you have a memory problem and ask them to repeat or explain things.
- Don't be afraid to ask for help and to accept it.
- Plan and organise your affairs so you feel in control
- Try to keep a sense of humour and share it with others

What support is available to help you?

Personal Support

You don't need to face living with dementia on your own.

Friends, family, your local support group, volunteers, others who have dementia and professionals will all be able to give you support.

Everyone reacts differently to being told they have any condition.

Some people want to talk about it, others keep it to themselves. However talking about your condition, and sharing how you feel, will help, although you may find it difficult at first and worry about how other people will react.



If you are unsure who to talk to, try speaking to someone you aren't close to such as your GP, CPN or someone from the Romsey Carers Club. They will know about dementia, can help you think things through and will provide information.

Some people have found great support from meeting and talking to other people with dementia, and their carers, and you can do this at the **Carers Café**, or ask for information about other support available.

Ask for help, even though you may find it hard to accept help at first. Asking for help does not mean you are giving up, it means you are facing your difficulties realistically and with help you can be independent for as long as possible.

You may not want to accept help from outside your family, but they will probably find it easier to support you if they are not on their own.



Practical Support

As your dementia develops you may find it more difficult to deal with everyday activities such as shopping, cooking or remembering appointments. You should try to continue to do normal things, with help if necessary:

Ask your family and friends to help you to do things rather than just do them for you.

- Ask for help in ensuring your physical surroundings are safe and accessible
- Ask someone to help you to keep appointments by checking that you have them in your diary, or reminding you of dates and times.
- Perhaps you could go shopping at the same time as someone else who can help you to find the items on your list?

- Find out what community transport there is to assist you e.g. Dial-a-Ride, Good Neighbours
- Use the tokens from the District Council to help with the cost of transport
- Consider having meals on wheels, Roast Out or frozen dinners delivered
- Ask your chemist about help with remembering to take your medication. There are packs that sort your medication into the times and days when you should be taking them which could help you to remember

Professional Support

Ask your GP to refer you to a Consultant in old age psychiatry or a Community Psychiatric Nurse (CPN). They are specialists in helping you with the practical and emotional difficulties that you may face and can come and visit you regularly to see how you are getting on and to help you get more help when you need it. You may also benefit from the local memory clinic.

You will be able to access more help as your dementia develops.

Contact your local social services to find out what help they can offer you. A social worker will visit to assess your needs and, if you have one, to assess to your carer's needs. You will receive a written copy of the social worker's assessment and if you do not think it's right, you can ask them to change it.

They should direct you towards, services to meet your needs including: home care, cleaning service, sitting service, day centre, equipment to help and keep you safe in the house, respite breaks to give you and/or your carer a real break from every day living.