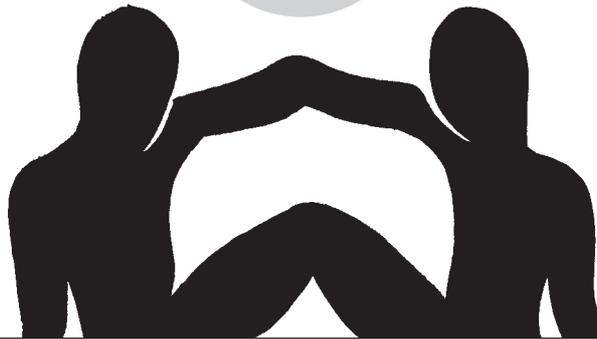


I N F O R M A T I O N



for younger people
with *dementia*

in Oxfordshire

S E C O N D E D I T I O N





Information for younger people with dementia in Oxfordshire

'I started noticing things not being quite right even as much as five years before my husband Tony received the diagnosis of Alzheimer's disease. Little isolated incidents began to occur, which to start with I put down to the normal failing memory of people in their fifties.

He was starting to have difficulty with finding the way, particularly in the dark, on the half hour drive home from work. He seemed to be losing interest in financial matters. Though I had taken the main responsibility for domestic finances since the beginning of our marriage, he had always wished to be consulted and involved, and knowledge of finance was an important part of his job. When our Financial Advisor visited, he seemed to have difficulty absorbing the information.

I talked to my daughter, who was a nurse, and found that she had also noticed that something was not quite right, though Tony was still very reluctant to admit to having any concerns.

The really difficult phase started about a year before the diagnosis was finally made. One night, I woke at about 4 a.m., worrying, and connecting the previously possibly unconnected incidents. I decided to write it all down in a letter to our doctor, which I never sent, but which made me realise that there was a process happening which could have serious implications. I saw that he must have been having quite a struggle to keep things together at work where he was still holding down an executive position.

I started to ask him more about how things were going, and he gradually shared some difficulties he had been having at work. He had made a couple of small mistakes which were quite unlike him, and which his manager had brought to his attention. Though everybody was being very understanding, he was feeling the stress.

I started to collect all the information I could about the likely diagnoses, what treatments were possible, and the financial and legal implications. I felt such an urgent need to acquire information that I even began to get a bit ahead of myself. Thoughts and plans for the future started flooding in.

With some encouragement from me, he decided to go to the doctor, and I went along too. This started a long phase of tests, scans and psychological testing. Then we received the diagnosis from a psycho-geriatrician together with the psychologist. When we got home, Tony started asking me all the questions that I had been asking for the previous nine months.

Three months later, things were becoming more and more stressful at work. We decided to return to our GP. It was when he wrote out the medical certificate with the words, 'Alzheimer's disease', that the whole thing really sank in emotionally, and I became very distressed myself. This was when it really hit us, and we came home and wept together.

We had to pick ourselves up, re-focus and re-balance. As advised, we began to plan a move back to Oxfordshire, where we had lived for most of our lives, and where we still had long term friends, family members, and many acquaintances that knew Tony well from his sporting achievements. We began to realise the many blessings we have, particularly in our close and confiding relationship, and with our wonderful family and friends.'

Sally Bradbury

The Clive Project information resource was originally published in 2000, in response to requests from younger people with dementia, their families and friends. It provides clear and comprehensive signposting to sources of help and information on a wide range of relevant issues. Dementia affects many aspects of life.

Although The Clive Project is the only service specifically for younger people with dementia in Oxfordshire, there are other organisations offering general help. We have identified these sources for you. We have tried hard to ensure the accuracy of the contact details to enable you to find out more. If you find any errors, or feel there are useful items that have been omitted, please let us know. We would welcome any other comments and contributions you may have. The resource is available in print and on The Clive Project website: www.thecliveproject.org.uk

January 2003

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About dementia

Introduction

'My wife probably started noticing that things were not right sooner than I did. I started with feeling uncomfortable about driving home from work in the dark. I felt unhappy when a colleague at work was competing aggressively, and when my sympathetic and supportive managing director had to point out a couple of minor errors that I had made.

Eventually I decided to go to my GP. Then started a long and frightening period of testing. Sometimes I had to take time off work every week to go off to appointments. It was hard to explain to everybody what was going on when I didn't know myself. It was very distressing indeed. When my doctor wrote Alzheimer's disease on that certificate was when everything seemed to stop and go stone cold. No leaving parties, just a whole lot of sadness and loss.

But I have a wonderful family and friends, and we decided to move back to Oxfordshire to be close to them all, so that we could continue as we always have, living every day to the full.

There was a particularly helpful social worker who found out about The Clive Project for us before we moved. I don't know how she knew, maybe she looked it up on the internet.

I have been on the memory medication for two years now, and I think it has really helped to slow things down. I am sure that the day will come when they have a real breakthrough with all the research that's going on, and I'll get a cure.'

Tony Bradbury

Early onset dementia refers to a progressive degeneration of the brain before the age of 65. The use of 65 years of age is arbitrary and is widely employed by the medical profession as a cut off point between 'younger' and 'older' people. Although dementia occurs more often in older people, the symptoms are similar, irrespective of age. Everyone's experience of dementia is unique though and life history, family circumstances and personality affect the way people cope. For a younger person who may have a young family, financial and work responsibilities, dementia is a devastating shock. Early onset dementia is likely to generate a multitude of needs requiring specialist responses.

This section gives a brief introduction to the most common forms of dementia.

● What is dementia?

Dementia is a general term for a range of disorders resulting in physical changes occurring in the brain. The progressive deterioration in the brain may affect memory, personality, behaviour, concentration, reasoning, learning, and understanding. The symptoms and rate of decline vary from person to person, and some symptoms are more likely to occur with certain types of dementia.

● Different forms of dementia

There are many different illnesses resulting in dementia. They are defined by the type of symptoms, and the rate of progression. Diagnosis is difficult, and can often only be confirmed by examining a sample of brain tissue after a biopsy. Researchers are beginning to discover what

changes in the brain cause the illnesses, but as yet no-one knows what triggers the changes in the brain. It is generally agreed that Alzheimer's disease is the most common form of early and later onset dementia. Quite a number of younger people are also affected by vascular dementia, diffuse Lewy body disease and frontal lobe dementia.

Alzheimer's disease

In the early stages, a person with Alzheimer's disease is likely to have problems with remembering recent events, and may seem more anxious or confused. They may find it hard to make decisions or seem depressed. The symptoms of Alzheimer's disease and the rate of progression vary from individual to individual. As the illness progresses changes become more marked and the person's need for help with day-to-day living increases.

Vascular dementia

Multi-infarct dementia (MID) is the most common vascular dementia. It results from the cumulative effects of small strokes occurring at intervals in the brain. Memory, speech, language and learning are affected. MID progresses in a jerky step-like way with deterioration after a stroke and then stabilising until the next stroke. There may be more insight during the early stages than with Alzheimer's and some abilities may be preserved for longer.

Diffuse Lewy body disease

Dementia caused by Diffuse Lewy body disease is often mild in the early stages with degrees of dementia varying from day to day. Symptoms may include movement disorders, mild tremor and acute confusion. Depression, delusions and hallucinations are quite common.

Frontal lobe degeneration (including Pick's disease)

Frontal lobe dementias cause changes in personality. Behaviour may become erratic, and speech and language are often affected. Obsessive or aggressive behaviour may develop. An awareness of time and an ability to recognise people and places is often retained until quite late in the illness.

Alcohol-related dementia

Excessive use of alcohol can cause brain damage. A person drinking heavily over a long period of time combined with poor nutrition and vitamin deficiency may experience memory loss. Replacing the missing vitamins can improve the memory problem but most people affected do not fully recover.

Dementia related to Down's syndrome

People with certain kinds of learning disabilities may be more likely to develop dementia in addition to their existing disability. This may occur at an earlier age than for the rest of the population. Information and advice is limited at present though it is an active area of development. Professionals already involved with the person's support are likely to be able to offer advice and support. If symptoms of dementia are present, having a clear diagnosis may help in getting the most appropriate support.

Other dementias

Other dementias occurring in younger people include:

- Dementia related to Huntington's disease
- HIV-related dementia
- Prion disease (including Creutzfeldt-Jakob disease)
- Multiple sclerosis related cognitive impairment

● Symptoms of early onset dementia

The symptoms of dementia are similar whatever the person's age. Dementia affects the brain in many ways and may cause:

- Memory loss
- Personality changes
- Behavioural changes
- Mood changes
- Disorientation in time, day and place
- Difficulties in recognition, understanding and comprehension
- Difficulties in communication and co-ordination
- Inability to concentrate
- Inappropriate interaction with other people

● Potentially treatable conditions

Early diagnosis is important as some conditions causing dementia may be treatable. The list below is not comprehensive:

- Chronic sub-dural haematoma
- Cerebral tumour
- Normal pressure hydrocephalus
- Alcohol related memory impairment
- Vitamin deficiency
- Anoxic disorder
- Flammatory and infective disorders

One in ten of all early onset dementias can be treated if diagnosed early enough. Such treatment usually prevents the dementia getting worse, rather than curing it.

● Incidence in the UK and in Oxfordshire

One in ten people over the age of 65 have dementia, and the risk rises rapidly with age, to a quarter of people over 85. Research indicates that there are around 19,000 people under 65 with dementia from a primary cause in the United Kingdom. Based on these national figures, it is estimated that there are approximately 190 younger people with dementia as the primary diagnosis in Oxfordshire. The majority of people are between 50 and 65 years of age.

Excellent current information on any form of dementia, including early onset, symptoms, research and treatment is available from the *Alzheimer's Society* and from **CANDID** (Counselling and Diagnosis in Dementia).



Alzheimer's Society
Gordon House
10 Greencoat Place
London
SW1P 1PH
Helpline 0845 300 0336
e-mail: info@alzheimers
www.alzheimers.org.uk

CANDID
Box 16
National Hospital for Neurology
and Neurosurgery
Queen Square
London WC1N 3BG
0207 837 3611
e-mail: candid@dementia.ion.ucl.ac.uk
www.candid.ion.ucl.ac.uk

● Organisations offering information and support to people with dementia associated with other conditions



HEADWAY/National Head Injuries Association
4 King Edward Court
King Edward Street
Nottingham NG1 1EW
Helpline: 0800 8002244

Huntington's Disease Association
108 Battersea High Street
London SW11 3HP
020 7223 7000
e-mail: info@hda.org.uk
www.hda.org.uk

MS National Centre,
372 Edgware Road
London NW2 6ND
020 8438 0700
e-mail: info@mssociety.org.uk
www.mssociety.org.uk
Helpline Freephone—for people with MS, their families, friends and carers:
0808 800 8000
MS Telephone Counselling Service,
London: 020 8422 2144 (24-hours)

Pick's Disease Support Group
8 Brooksby Close
Oadby
Leicester LE2 5AB
0116 2711414
e-mail: carol@pdsg.org.uk
www.pdsg.org.uk

Parkinson's Disease Society
215 Vauxhall Bridge Road
London SW1 1EJ
020 7931 8080
Freephone helpline: 0808 800 0303
www.parkinsons.org.uk

Stroke Association
Stroke House
Whitecross Street
London EC1Y 8JJ
020 7566 0300
Information Service line: 0845 3033100
e-mail: stroke@stroke.org.uk
www.stroke.org.uk

YAPPRS (Young, alert Parkinson patients and relatives) is a special interest group for young people
Contact via Parkinson's Disease Society
Freephone helpline as above
www.youngonset-parkinsons.org.uk

How to get a diagnosis

Early diagnosis of dementia is important for many reasons. Some causes of dementia are treatable if diagnosed early. There are many conditions causing symptoms similar to dementia which improve with treatment. These conditions include infections, constipation, depression, stress and the side effects of drugs. Finally, if a progressive dementia is diagnosed early then it enables the person's current difficulties to be understood in the context of their illness. It also allows time to be able to plan the future for themselves and their family, and offers access to new medication which may delay the progression of the disease.

● NHS Direct

NHS Direct is a free health information service detailing health services, self-help groups, medical conditions, diseases and treatments, hospital waiting times. You can also phone for urgent advice from a nurse if you or your family are ill. Contact NHS Direct if you wish to comment or complain about your health service, or, currently too, about your GP.

 *NHS Direct: Freephone 0845 4647*

● General Practitioner

Consulting the General Practitioner (GP) is the first step in diagnosis. The GP acts as 'gate-keeper' to hospital and community-based health services. Most GPs have little experience of early onset dementia and symptoms can be confused with other disorders. Be persistent if problems continue. Return to the GP and/or seek advice elsewhere. Meanwhile keep a diary of changes occurring so that the GP has an accurate history of symptoms.

The GP should take a thorough history of the person's problems and any family history, conduct a physical examination and carry out any tests that might exclude conditions with symptoms similar to dementia. Questions are asked to give an indication of mental ability. It is valuable for the GP to talk to someone who knows the person well to understand the changes occurring. If the GP suspects early onset dementia then referral on to a specialist consultant is the next stage in diagnosis. If there are any difficulties in getting a referral, request one. It is possible at this stage, or at any other time, to request access to medical records.

For lists of general practitioners, and to gain access to one in areas with a shortage, contact:

 *Thames Valley Primary Care Agency: 0118 9822720/8*

● Referral

Medical consultants

In Oxfordshire a specialist referral is usually made to a consultant neurologist at the Radcliffe Infirmary, Oxford. Other possible referral routes might be to a psychiatrist, a psycho-geriatrician, to a research project called *OPTIMA*, at the Radcliffe Infirmary, or to a local memory clinic. The

presenting symptoms determine which specialist the GP chooses for assessment and diagnosis. Some of the medical specialists encountered are listed below:

- **Neurologist:** specialises in disorders of the brain and nerve pathways
- **Psychiatrist:** specialises in assessing and treating mental health problems
- **Psychologist:** specialises in the study of human behaviour including memory, learning ability and other mental functions
- **Physician:** specialises in physical illness and disabilities
- **Old age psychiatrist:** specialises in diagnosing and treating mental health problems, including dementia, in older people
- **Gerontologist:** specialises in assessing and treating illness in older people

OPTIMA—Oxford Project to Investigate Memory and Ageing

The GP may refer to **OPTIMA**. This Oxford-based research project was set up in 1988 to study Alzheimer's disease and other forms of dementia. They have developed more accurate methods of diagnosis using special scans of the brain. Using these improved diagnostic techniques, the project hopes to be able to detect Alzheimer's disease before the symptoms appear, provide new insights into its progression and identify key events that trigger the disease. In the future, **OPTIMA** may be able to devise ways of preventing the disease from developing. **OPTIMA's** participants and their families are supported and counselled throughout the course of the disease. An **OPTIMA** nurse is always on-call to offer support, both to **OPTIMA** participants and to anyone who has a problem relating to dementia.



OPTIMA

*Radcliffe Hospitals NHS Trust
Woodstock Road
Oxford OX2 6HE
01865 224356*

Memory clinics in Oxfordshire

These clinics offer early identification of memory problems and any related disorders through a comprehensive assessment. Support and advice are offered to the person with dementia, their family and friends. There is an opportunity to consider the use of new medication which would then be monitored by the clinic. Referral to these local clinics is through your GP. Home visits may be an option if mobility problems make it difficult to attend.

● **Assessment**

Assessment usually includes a detailed history together with an examination of physical and mental state. Someone who knows the person well will also be consulted. The assessment may take several hours or several visits or may require attendance at a day hospital for observation. Blood samples may be taken to test for some treatable causes of dementia. Other investigations may include:

- **CAT scan:** looks at the structure of the brain and detects evidence of stroke, tumours, changes in the flow of fluid around the brain and blood clots which may put pressure on the brain, as well as detecting the shrinkage or wasting that occurs with dementia
- **MRI scan:** this scans the structure of the brain and is useful in detecting evidence of strokes and vascular changes that can be difficult to see on a CAT scan
- **EEG:** shows any perturbation in the electrical activity of the brain
- **SPECT scan:** examines the pattern of blood supply to the brain which is often altered in dementia
- **NEURO-PSYCHOLOGICAL ASSESSMENT:** involves tests of memory, reasoning and co-ordination

These are possible investigative techniques only and they will not all be used in one assessment. It will usually be the specialist consultant who has overseen the assessment who will give the diagnosis in a follow-up appointment. It is useful to take a companion with you to the follow-up appointment, and to ensure that there will be an opportunity to discuss the diagnosis and its implications with the consultant at a later date. The consultant will notify the referring GP. The consultant and the GP are both potential sources of information about dementia.

After diagnosis

Someone to talk to

People experience many difficult emotions following diagnosis: helplessness, relief, shock, anger, guilt, shame, disbelief to name just a few. Family and friends can be supportive but often share in the emotional response to the diagnosis. Consider finding some objective, expert advice.

CANDID—Counselling and Diagnosis in Dementia

CANDID provides information, advice and education on dementia for younger people, their families and professionals. Telephone advice is offered by a nurse counsellor supported by a consultant neurologist. Currently this service operates on Friday mornings.

 **CANDID:** 0207 813 7333

● Local Counselling Services

Your GP may be able to refer you to a psychological counsellor within the health practice. He or she may be able to help in coming to terms with difficult emotions and thoughts during and after diagnosis. Counselling offers the opportunity to explore personal challenges and distresses in confidence. It is useful even where the counsellor does not have specific expertise in dementia. At its best it can help you to feel in control, and gives you an opportunity to unburden thoughts and feelings safely. *The British Association for Counselling* produces a directory of registered counsellors including contacts in Oxfordshire.

 **The British Association of Counselling**
 1 Regent Place
 Rugby
 Warwickshire CV21 2PJ
 01788 578328
www.counselling.co.uk

In addition there are organisations in Oxfordshire providing counselling.

i **The Listening Centre**
c/o Cuddesdon Corner Family Centre
61–63 Cuddesdon Way
Blackbird Leys
Oxford OX4 5JH
01865 407807

Isis Centre
Little Clarendon Street
Oxford OX1 2HS
01865 556648

Samaritans
123 Iffley Road
Oxford
01865 722122
National 0345 909090

Wantage Counselling Service
6 Newbury Street
Wantage
Oxon OX12 8BS
01235 769744

Local branches of the **Alzheimer's Society** can offer someone to talk to. Many of the members have had personal experience of caring for someone with dementia and can listen, support and visit on a local basis.

i **Abingdon and Vale Branch**
143 Upper Road
Kennington
Oxford OX1 5LR
01865 739868

Banbury and District Branch
Wardington House
Wardington
Banbury OX17 1SD
01295 757124

Oxfordshire Branch
28 Crown Road
Wheatley OX33 1UL
01865 876508
Advice line 01865 556469

Alzheimer's Society Oxfordshire Branch Carers Support Service

A Carers Support worker offers services to people living in Oxfordshire, apart from Banbury and the Vale of White Horse. These services include telephone support and information. Home visits can be made and counselling can be offered to help resolve particular problems. Support groups offer opportunities to meet other people experiencing similar challenges.

i **Carers Support Worker: 07796 441203**

Alzheimer's Society Gay and Lesbian contact

Specialist support is available for carers in gay and lesbian relationships where the partner has dementia.

i **Gay and Lesbian support worker: 01865 847471**

Support to children

For children affected by a parent's dementia, specialist support and counselling is available from the education authority, Social and Health Care, the Carers Centres and voluntary organisations. Experienced teams provide family visits, assessments of children in need, and support.

**Oxfordshire County Council Social and Health Care Directorate
Children and Families Teams**

These teams assess children 'in need'. This includes children who have a parent with a disability, and who are either acting as carers, or whose own needs are compromised in some way.

 **Customer Services:** 01865 375515

**Oxfordshire County Council Education Department
Education Social Work Service**

Support is offered to maintain children's education.

 **Abingdon:** 01235 555542
Banbury: 01295 272525
Oxford City: 01865 718787
Wallingford: 01491 833293
Witney: 01993 776703

Carers Centres

Carers Centres offer individual support visits to children affected by caring for a parent, or by living with a parent with disabilities. This includes mental health problems and physical or learning disabilities. The centres in the North and South of the county also have specialist workers for children. Clubs meet monthly or bi-monthly and outings are arranged. The workers also take children on activities weekends to give them a complete break from stresses at home, in the company of others with similar needs and experience.

 **North and West Oxfordshire:** 01295 264545 or 08457 125546
Oxford: 01865 205192
South and Vale: 01235 510212

SeeSaw

This is a rapid, flexible grief support service for the young in Oxfordshire. The service also helps children come to terms with someone they love having a terminal illness. Through practical support and understanding, **SeeSaw** helps reduce the distress of children and enables families to work together through the difficult times which follow terminal illness and bereavement. They have an education and training programme about childhood bereavement for professionals working with children, and have developed literature and resources to help children, their carers and professionals understand grief.

 **SeeSaw**
Bush House
2 Merewood Avenue
Headington
Oxford OX3 8EF
01865 744768

Research and treatment

● Types of Research

Medical research

There are two basic areas of medical research into dementia:

- scientific research to advance our understanding of dementia, its causes, effects, diagnosis and prevention
- research into the treatment and management of dementia involving, for example, the testing of drugs and therapies.

The willing participation of people with dementia in all forms of research is vital to the continuation and success of every research project. The *Alzheimer's Society* can give advice about participation in these projects.

Drugs testing

Pharmaceutical companies are actively researching drugs to control dementia. After laboratory development, randomised controlled trials are conducted to find the most useful dosage. Consenting participants are divided into two groups with one receiving the experimental drug while the other receives a placebo or another tried and tested drug. During the trials, all participants are assessed at regular intervals to check whether those taking the new drug have benefited.

Genetic research and counselling

Genetic research has identified defective genes playing a role in the development of some forms of dementia. It is now possible to predict whether a person is likely to develop one of a few forms of rare inherited dementias. There are tests available for Huntington's disease and for gene defects on chromosome 21 and 14 leading to very rare forms of Alzheimer's disease. Your GP can refer you to a regional genetic counsellor free from the NHS. The counsellor will offer guidance before the tests and will follow up after the results. The service is based at:

 ***The Department of Medical Genetics***
The Churchill Hospital NHS Trust
Old Road
Headington
Oxford OX3 7LJ
01865 741841

Non-medical research

In addition there are non-medical research projects in centres of excellence throughout the country looking at how to achieve the best quality of life for people with dementia. In Oxfordshire, non-medical research resulted in the formation of *The Clive Project*. The study identified the needs of people with early onset dementia and their carers within the county. A range of flexible and appropriate services is being developed as a direct result of this research.

The *Alzheimer's Society* funds research and has information on other research projects.

 *Alzheimer's Society Helpline: 0845 300 0336*
www.alzheimers.org.uk

● Treatment

Current treatment takes the form of alleviating the symptoms or, with drugs, slowing down the progression of the disease or the symptoms rather than curing the dementia. Any drugs taken, for example to relieve depression or calm agitation, should be reviewed regularly to ensure that they are still required and are not exacerbating the symptoms. In the case of vascular dementia, drugs may be given to maintain blood flow or correct an irregular heartbeat. This may slow down the effects of the dementia.

Drugs for dementia

Aricept, *Exelon* and *Reminyl* are now used in the UK. The drugs are anticholinesterases and they work by stopping the breakdown of acetylcholine. Acetylcholine helps brain cells communicate and this neurotransmitter is reduced in Alzheimer's disease and other dementias by a chemical called acetylcholinesterase. Deposits in and around the cells and plaques and tangles also reduce the efficiency of the neurotransmitters.

More recently a new drug called *Ebixa* has been developed and launched in the UK. *Ebixa* is available privately through consultants. It acts in a different way to the other three drugs, and may be helpful for people in the later stages of the disease. It is thought to slow down the progress of the disease, whereas the other three drugs slow down the progression of symptoms, rather than the disease itself.

The Memory Clinics prescribe these drugs for Oxfordshire people following a referral from your GP. The Memory Clinic will assess and monitor whether the drugs are beneficial. Contact the Alzheimer's Society for more information on drugs.

 *Alzheimer's Society Helpline: 0845 300 0336*

Non-drug treatment

It is important to maintain good physical and mental health through exercise and nutrition. Keeping the brain and body gently stimulated is also beneficial for all round health, and will encourage independence and a sense of well-being. Make sure that you eat a healthy diet, and try to find an exercise program that you enjoy. There are many natural therapies such as massage, aromatherapy and reflexology which increase well being. Check the Yellow Pages, Green Pages and the local press for practitioners in the local area. The *Institute for Complementary Medicine* offers written information about natural therapies, and a list of local practitioners.

 *Institute for Complementary Medicine*
 15 Tavern Quay
 London SE16 1TX
 0207 237 5165

SPECAL—Specialised Early Care for Alzheimer’s

SPECAL offers an innovative approach to the treatment of Alzheimer’s disease. The *SPECAL* programme is designed to support specialised care throughout the dementia care journey. The aim is to design and develop around-the-clock care plans which can be delivered in the person’s home, or any other place they spend time, by anyone trained in the approach. Previously well-established skills and patterns are used as the basis for all care. Use of these skills is adapted as the disease progresses. *SPECAL* promotes lifelong well-being for the person with dementia by offering specialised help to the carer as early as possible. To find out more, contact the *SPECAL* Advice and Information Service:



Little Orchard

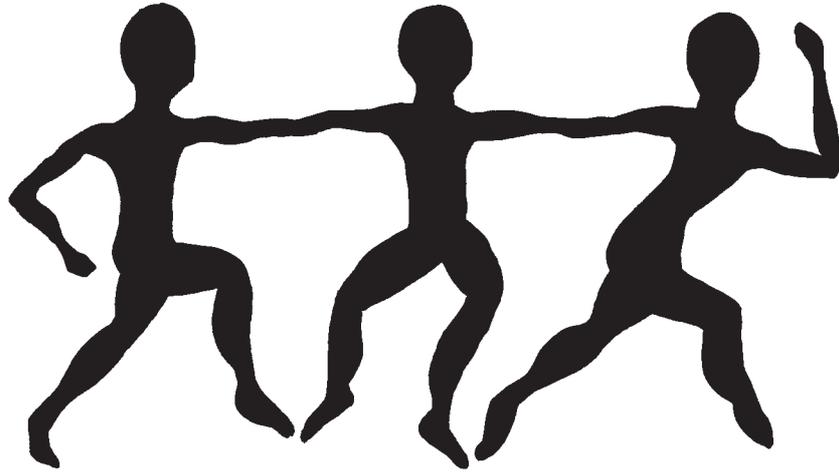
Broadwell

Moreton-in-Marsh

GL56 OUA

01451 870981

e-mail: penny@specal.u-net.com



Where to get help

Introduction

‘Once a diagnosis had been made through OPTIMA, my main sources of help came from the support workers from The Clive Project, the Carers Support and Development worker from the Alzheimer’s Society, The Clive Project Exchange meetings and getting together with other carers to share our problems.

Our community psychiatric nurse has been invaluable. He has steered me in the direction of the benefits that are available, to local Carers Group meetings, and given me reassurance that respite care breaks will be available when necessary.

I have found the local Benefits Agency helpful, when they have taken time to assist with filling in all those dreaded forms.

Our own GP has been wonderful.

It has been especially important to know that friends, family and neighbours are always there with help, support and comfort.’

VB

Family, friends and neighbours

Supporting a person with dementia can be stressful and demanding. To achieve the best quality of life for the younger person and for everyone else involved with the person, a network of support and care needs to be developed. If possible, make a conscious decision to share the responsibility for supporting the person with dementia with other members of the family, friends or neighbours.

Each member of the family experiences different feelings arising from early onset dementia. Past relationships between the family and the person with dementia influence the ability of all concerned to cope. Sometimes the strong feelings generated can cause a volatile mixture of emotions for people, particularly partners, children and parents. There are many losses along the dementia journey. Everyone grieves for these losses at their own pace, and the different timings of these experiences can be a source of pain and struggle. Find someone to talk to. This does not need to be a professional but could be someone who really listens, gives undisturbed time and is trusted. People who have a spiritual belief and faith community may find that very supportive. Meeting others experiencing similar challenges can be an opportunity for mutual support. Relationships, roles and behaviour will shift and change as the dementia progresses. Often the ability to adapt to these changes plays an important role in how everyone copes with dementia.

People assume a supporting role for a mixture of reasons—love, duty, through choice or lack of an alternative. Whatever the reason for caring, every ‘carer’ needs to have access to help and support themselves. Social isolation, stress and poor physical health will reduce the quality of life for the person caring and the person being cared for. Obtaining good information at the right time, taking a break, having someone to whom you can offload, sharing the care responsibility and linking with other carers for mutual support all contribute to living well with dementia.

Understanding why a person with dementia finds it increasingly difficult to look after themselves is a key to how family and friends cope. It may be useful to read about other people's personal experience of dementia. Personal accounts, as well as information written for different age groups, can be found through the *Alzheimer's Society* and on the internet. Children and teenagers in particular may find it difficult to accept that their father or mother has dementia. Social and Health Care, the community psychiatric nurse and Carers' Centre outreach workers also offer support to the family.

Consider keeping trusted neighbours and friends in touch with what is happening for the person with dementia. This helps them understand the person's behaviour. They may cast a kindly eye on the person to keep them safe. Remember how vulnerable people with dementia can be to financial, physical and emotional abuse. With this in mind, it may be useful to inform the local police and relevant businesses (shops, pubs) close to home.

Introduction to professional help

At some point you may need help in addition to that available from friends and family. Timely support eases life for all those affected by dementia and significantly improves the quality of life. The health and well-being of Oxfordshire residents is the formal responsibility of Oxfordshire Healthcare Trusts, Primary Care Trusts, Oxfordshire Social and Health Care Directorate (formerly known as Social Services), and voluntary organisations.

The Oxfordshire Mental Healthcare NHS Trust and the Oxford Radcliffe Hospitals NHS Trust are the most relevant health trusts for early onset dementia. Working in partnership with these Trusts is Oxfordshire County Council's Social and Health Care Directorate (Social and Health Care). Their role is to help Oxfordshire residents who experience any serious disability by assessing the needs of the person, and purchasing or providing services to meet them. Support within local communities is offered through statutory and voluntary partnerships. Such co-operation is contributing to the development of specific services for people with early onset dementia in Oxfordshire. However the right kind of help is not always available when required and often creative adaptations of current services have to be made.

Statutory organisations

The GP, and sometimes the consultant, can link you to community health services, and Social and Health Care. They may be also be aware of services offered by voluntary organisations and carer support groups. However because early onset dementia is relatively rare, it is not possible to rely on a single source to get you the broad range of support that you may need. Below we have listed the help that should be available through the GP. You can request a community care assessment, advice and information from Social and Health Care. Although they work primarily with the most vulnerable people in the community, it is worth making contact early to 'flag up' potential need. They can assist with advice and signposting to other sources of help in the early stages. You may need to be firm and insistent when further help is required.

● Community health services

- **Community psychiatric nurses (CPN's):** part of Oxfordshire Mental Healthcare NHS Trust's Community Mental Health teams. They have the expertise and experience to support people of any age with dementia. Counselling and anxiety management skills may also be offered.
- **District nurses:** provide nursing care at home. They are qualified nurses who have had extra training in nursing people at home.
- **Health visitors:** provide general health advice at home and in the community. They are qualified nurses based at health centres, and can support people with a caring role as well as requesting additional services.
- **Occupational therapists (OT's):** assess ability of the person with dementia to perform everyday tasks and try to equip the person to lead as normal a life as possible. Helpful equipment, environmental adaptations, suggesting different ways of doing things, and referral to other agencies are all part of this service.
- **Physiotherapists:** treat injury, disease or disability through massage and exercise at home or in the health centre.
- **Speech and language therapists:** they provide advice on problems with swallowing, and can provide assistance if someone is having particular problems with speech and language. In Oxfordshire currently there is no speech therapy available for people with dementia. If you feel that you or someone you know could benefit from such advice, your Community Health Council may be able to help. See the Campaigning section of this resource.

● Specialist mental health (NHS) provision

Oxfordshire Mental Healthcare (NHS) Trust provides services for older adults (aged 65 or more) with mental health needs, such as depression or dementia. People with early onset dementia are supported through the Trust's older adult services. These service teams have the most experience with dementia and so are usually the best placed to provide support and advice to the younger person.

The Trust is divided into three geographical localities, to match the Primary Care Trusts (PCTs): North locality covers North East PCT and North Oxon PCT (Banbury, Chipping Norton, Bicester and Kidlington.) City locality covers Oxford City PCT. South locality covers South East PCT and South West PCT (Abingdon, Didcot, Witney, Wantage, Faringdon and Thame. From April 2003 also Wallingford and Henley.) There is a clinical service manager who is responsible for services for older adults in each locality.



City: 01865 223800

North: 01295 229296

South: 01865 223309

Teams comprising of psychiatrists, nurses, psychologists and occupational therapists provide services. These teams link to specific GP practices and work with Social and Health Care, and voluntary organisations such as The Clive Project. The service is run on three levels:

- **Community mental health teams (CMHTs):** These consist of community psychiatric nurses with input from other professions mentioned above.

- **Day Hospitals:** These cover the county and provide weekday places. Trained nurses and occupational therapists staff them. Their main roles are assessment of needs, treatment and rehabilitation. This is different from day care provided by voluntary organisations.
- **In-Patient Stays:** There are wards in Banbury, Witney and Oxford. A small number of people with dementia need this type of 24-hour specialist care.

Referrals

One referral, usually through your GP, gains access to any of these services. One or two of the team members usually assess what is needed by a home visit. The GP is kept informed since they co-ordinate all health care for people living in the community.

Continuing care

After referral to a mental health team, the person and carer are involved in regular reviews to look at changing needs. Changes in care are made after consultation with the person and their carer. This may follow a formal structure called the **Care Programme Approach (CPA)** which keeps all parties involved and informed of how care is progressing.

Specialist services

There are two specialist services in Oxford. The **Oxford Teaching Nursing Home** provides longer-term care for people with severe mental health needs. Some 'health service' places for Oxfordshire Mental Healthcare Trust are available. Windrush Ward at the **Fulbrook Centre**, Oxford looks after people with dementia whose behaviour is challenging. The unit also provides a respite service for families. Contact the clinical service managers for more information on these services.

● Oxfordshire County Council, Social and Health Care Directorate

The **Social and Health Care Directorate** is the new name for Oxfordshire County Council Social Services Department. The name change reflects the Government's wish to ensure a seamless health and social care service. The core role of Social and Health Care is to work with vulnerable Oxfordshire residents in need of social and health care in the community. They try to set up services that support and protect people, and enable them to get the most out of their lives.

The first points of contact are the assessment teams based in Banbury, Oxford and Abingdon. They will offer information and an assessment if required. If longer-term help is needed then a care manager will work with you. The care manager is likely to be part of the specialist team for older people. This team supports people under 65 with dementia because they work closely with older adults teams in the Mental Healthcare Trust. The Mental Healthcare Trust older adults teams have the medical expertise in dementia. For general information on services provided by Social and Health Care in Oxfordshire contact:

 **Customer Services:** 01865 375515

The duty officers in the **Adult Assessment teams** are available at:

 **Oxfordshire Social and Health Care Directorate/North**
Calthorpe House
Calthorpe Street
Banbury OX16 9AL
01295 756432

 **Oxfordshire Social and Health Care Directorate/City**
134b Cowley Road
Oxford OX4 1JH
01865 815434

 **Oxfordshire Social and Health Care Directorate/South**
The Charter
Broad Street
Abingdon OX14 3LT
01235 549220

Specialist services are being developed by **The Clive Project** with the support of Social and Health Care senior staff. In the meantime, the care manager will plan and provide support from a range of more general services adapted to meet the person's needs. Care managers offer emotional support as well as practical help and assistance.

The care manager, after discussion, will try to ease difficult areas of life. Services include personal care, day centres, short term breaks, alternative housing, benefits advice, housework, personal alarms, meals, laundry and specialist assessments by occupational therapists and the sensory impairment teams.

The assessment is free though there may be a charge for services. Currently if you have savings of £18,000 or more, all or most of the cost will be chargeable. Anyone receiving income support makes a flat weekly payment which rises if disability living allowance is also received. There is also a waiver scheme available.

People caring for others are entitled to an assessment of needs in their own right. This identifies support to help them continue in their caring role. Social and Health Care provide information and practical support through the **Relief to Carers Scheme, Adult Placement Scheme** and other services. General advice and support is available from the Carers Centres.

For information about all Oxfordshire County Council services contact their website at:

 www.oxfordshire.gov.uk

Voluntary organisations

● Local—information and advice

There are local organisations offering information and advice on dementia, caring and related issues. Beyond that there are general information sources relevant to early onset dementia. A selection is listed below:

Age Concern

Age Concern has an information and advice service signposting people to a range of relevant factsheets. Trained staff and volunteers also visit people at home to help with forms, including benefit applications.

i *Age Concern/Oxfordshire*
St Edmunds House
39 West St Helen's Street
Abingdon OX15 5BW
01235 849400
www.ageconcern.org.uk

Alzheimer's Society Branches

The *Abingdon and Vale Branch* offers information and advice as well as running a club for people with dementia on weekdays. The Tuesday Club supports people in the early stages of the illness. Current and former carers have regular group meetings.

i *Alzheimer's Society, Abingdon and Vale Branch*
143 Upper Road
Kennington
Oxford OX1 5LR
01865 739868

The *Banbury and District Branch* covers the area extending from the outskirts of Bicester to Chipping Norton and includes Banbury and the adjoining villages. Practical help for people with dementia and their carers is offered through the Relief to Care service and The Clive Project. Advice, information and support covering all aspects of dementia are provided.

i *Alzheimer's Society, Banbury and District Branch*
Wardington House, Wardington
Banbury OX17 1SD
01295 757124
e-mail: tony_tarrant@hotmail.com

The *Oxfordshire Branch* provides information and advice on caring for people with dementia. They can link you with local contacts in most areas of Oxfordshire. Short-term respite care can be arranged through Crossroads to meet an acute need while Social and Health Care complete their assessment. Oxfordshire Branch initiatives include *Vale House*, which is the Botley Alzheimer's Home for people in the later stages of dementia, *The Clive Project* for younger people with dementia, *SPECAL* and *Abingdon Alzheimer's Club*.

A Carers Support worker offers services to people living in the Oxfordshire branch area. Services include telephone support and information. Home visits can be made and counselling may be offered to help resolve particular problems. Support groups offer opportunities to meet other people experiencing similar challenges.

i **Alzheimer's Society, Oxfordshire Branch**
 28 Crown Road
 Wheatley
 Oxford OX33 1UL
 01865 876508
 Advice Line: 01865 556469
 Carers Support worker: 07747 844517

Alzheimer's Society Carers Contacts

A UK network of **Carers Contacts** offer telephone support and advice. Trained volunteers provide a listening and understanding ear to carers. The **Carers Contacts** know the issues facing younger people and their families, often through their own personal experience. They mainly provide emotional support and are also able to offer basic advice on all aspects of dementia and information about regional services. They can contact specialists within the Alzheimer's Society with more complex queries.

i **Carers Contact—Oxfordshire: 01235 200360**

Carers Centres

There are three **Carers Centres** in Oxfordshire providing advice, information and support to anyone looking after a friend or relative, who because of age, illness or disabilities cannot look after themselves. This is a free, confidential service. Carers may contact the Centres by phone, drop in or arrange for an outreach worker to make a home visit.

i **North and West Oxfordshire Carers Centre**
 27 Horse Fair
 Banbury OX16 0AE
 Carers Line: 0845 7125546

Oxford Carers Centre
 174a Cowley Road
 Oxford OX4 1UE
 01865 205192

South and Vale Carers Centre
 5 Lydalls Road
 Didcot OX11 7HX
 01235 510212

Carers Support Groups

Across the county groups of current and former carers meet. Personal experience, advice and support is offered within the groups. **The Clive Project Exchange** is specifically targeted at the family and friends of younger people with dementia. Contacts for **local carers support groups** are available from the Carers Centres. Amongst these are well-established groups:

 **Abingdon Alzheimer's Club:** 01235 205407
Henley Carers Support Group: 01491 412111
Ridgeway Carers Group, Didcot: 01235 810574
Thame Carers Support Group: 01844 260729
The Clive Project Exchange: 01993 776295

Citizens Advice Bureaux (CAB)

Local CABs offer confidential information and advice on legal issues, personal finance, welfare rights, housing and many other topics. In Oxfordshire there are specialist consultants for welfare rights, housing and money advice available through the local CABs. All offer a drop-in service and some offer appointments and outreach visits. More rural areas are covered by one day and outreach CAB services—call your nearest CAB and ask for the most local service. Contact telephone numbers are available in the Yellow Pages.

The Clive Project Exchange

Information, advice, discussion and support are available to the family and friends of people with early onset dementia through *The Clive Project Exchange*. This information resource is part of the Exchange, together with a flexible programme of topic presentations and socials. Participants are encouraged to influence The Clive Project's services.

 **The Clive Project**
 7 Mount Pleasant, Crawley Road
 Witney OX28 1JE
 01993 776295
www.thecliveproject.org.uk

Mental Health Matters

A database with information and advice on all aspects of mental health is available to users of services, carers and professionals.

 **Mental Health Matters**
 19 Paradise Street
 Oxford OX1 1LD
 01865 728981

Oxfordshire County Council Information Service

Oxfordshire County Council's own website provides information on benefits, charities and over 2600 community groups.

 www.oxfordshire.gov.uk

Oxfordshire Council for Voluntary Action (OCVA)

OCVA publishes a directory of voluntary and statutory services in Oxfordshire. Your local library should have a copy.

 **OCVA:** 01865 251946
www.ocva.org.uk

● Local—help at home

Private and voluntary care organisations offer support to people living at home. Charges are made for these services. If you need help to pay for services, contact the Social and Health Care team for your area. They assess whether you are eligible for help with these costs. The Social and Health Care team have lists of accredited organisations.

i *Social and Health Care/North: 01295 756432*
Social and Health Care/City: 01865 815434
Social and Health Care/South: 01235 549220

● Specialist—help at home

The Clive Project One-to-One Support Service

We support younger people with dementia in Oxfordshire in pursuing activities of their choice. Throughout the county, trained support workers partner people who, on referral, are experiencing mild to moderate symptoms of dementia. The sessions are usually between two and four hours duration, weekly or more frequently, with highly flexible, individually tailored content. The support worker provides consistent contact with the individual, their family and friends throughout the changes resulting from the dementia. Emotional, practical and health promoting support is offered. A regular break from care for the family is provided as well as access to other services within The Clive Project, and signposting to further support and information when needed.

i *The Clive Project*
7 Mount Pleasant
Crawley Road
Witney OX28 1JE
01993 776295
www.thecliveproject.org.uk

Continence Advice

Continence problems are a source of anxiety which can be eased with guidance and by maintaining routines. District nurses can advise on how to deal with incontinence and so ensure comfort and dignity for the person with dementia. The **Continence Advisory Service** holds clinics at Health Centres throughout Oxfordshire and they also produce helpful information leaflets. Support and advice is offered by telephone, and by referral to a local clinic.

i *Continence Advisory Service (Oxfordshire)*
Witney Community Hospital
Welch Way
Witney OX8 7JJ
01993 209434

The **Continence Foundation** provides advice, information and publications on continence.

i *Continence Foundation Helpline: 0171 831 9831*

Community Laundry

Available in some areas of Oxfordshire, this service helps people cope with incontinence. Contact Social and Health Care for more information.

 **Customer Services:** 01865 375515

Equipment and Adaptations

Adapting living space or using specialist equipment can ease the practical side of life. Ask for a specialist assessment from an Occupational Therapist or Sensory Impairment worker from Social and Health Care. They discuss your needs, provide free equipment or just advise. **Dialability**, part of the Centre for Enablement at the Nuffield Orthopaedic Centre in Oxford, is a *Disabled Living Centre* displaying a wide choice of products to encourage well-informed purchasing or borrowing. **The Disabled Living Foundation**, a national organisation, also offers advice by telephone, letter and publications. The Oxfordshire branch of the **Red Cross** loans equipment such as wheelchairs and commodes for a short term.

 **Dialability (Oxfordshire)**
Oxford Centre for Enablement
Windmill Road
Headington, Oxford OX3 7LD
01865 791818

British Red Cross Society Medical Loan Service
01235 552664

Disabled Living Foundation
380–384 Harrow Road
London W9 2HU
0870 603 9177

Anchor Staying Put Agencies

Social and Health Care, in partnership with local District Councils and **Anchor**, promote two schemes to enable disabled people to live in their own homes as independently as possible. Aimed at home owners, the **Small Repairs Scheme** carries out plumbing, joinery and electrical jobs and small adaptations around the home in return for a fixed fee. The **Staying Put** scheme tackles bigger jobs, major works and adaptations backed by technical support. Contact your local **Anchor Staying Put/Small Repairs Scheme** at:

 **Cherwell District Council**
Bodicote House
Bodicote
Banbury OX15 4AA
01295 221660

Vale of White Horse District Council
102 Ock Street
Abingdon
Oxfordshire OX14 5DH
01235 521983

South Oxfordshire District Council
PO Box 30 Council Office
Crowmarsh
Wallingford OX10 8ED
01491 823350

West Oxfordshire District Council
Harvest House
28a High Street
Witney OX8 6HG
01993 709524/709788

Oxford City Council
30a Castle Street
Oxford OX1 1LJ
01865 791232

Gardening and home maintenance

Private companies offer these skills as well as local volunteer bureaux. *Citizens Advice Bureaux*, your local *Rotary*, *Lions* or *Round Table* may also have a list of helpers offering services at reasonable rates. A free gardening scheme is available to disabled people living in Oxford City Council property. Contact OCC for more information on this scheme:

 *Oxford City Council: 01865 252369*

Housework

Social and Health Care provide help with housework on an exceptional basis, and where it is part of a larger care plan. Some of the Social and Health Care accredited agencies provide a housework service which you can purchase privately.

Personal hygiene

This can be a source of stress for all those involved with dementia. The *Alzheimer's Society* advises on how to encourage personal hygiene without raising anxiety and avoiding conflict. Social and Health Care are also able to advise and if you are experiencing problems, ask for a community care assessment for help with personal care or an occupational therapy assessment for equipment that might be useful.

Shopping

Again try your local volunteer bureaux which can be found through the Carers Centres. Social and Health Care use a supermarket chain, the Co-op, to provide a delivery service and can help with ordering too. Many supermarkets are starting to offer delivery services on the internet.

● National—information and advice

Alzheimer's Society

Contact the national office for information and advice and helpful publications. The *Alzheimer's Society* promotes specialist support and good practice for younger people with dementia. The information officer for younger people with dementia is able to offer specialist advice and information on a wide range of issues.

Alzheimer's Society—Alzheimer's Helpline

Support and advice on all forms of dementia is offered by the Helpline. It is staffed by trained advisers and includes specialists in welfare benefits, medical and scientific issues. Calls are charged at local rates.

 *Alzheimer's Helpline: 0845 300 0336*

Alzheimer's Society—Younger Persons Network

The network matches younger people with dementia, their carers, families and friends with people in similar circumstances. The joining form requests an outline of individual circumstances and offers a choice of aspects in common, for example, the same relationship with the person with dementia, the same diagnosis or possibly the same age range. Choose the method of continuing contact too—by letter, telephone, email or other means. The Alzheimer's Society Helpline have more information on the Younger Persons Network.

DASS (UK) Learning Network

Launched in 2002 by the Mental Health Foundation, this is a person-centred website covering the early stages of dementia. It serves as an information gateway, an interactive forum for discussion and an exchange of ideas and research.



Mental Health Foundation

7th Floor

83 Victoria Street

London SW1H 0HW

020 7802 0300

www.mhilli.org/dass

e-mail: DASSLEARNNet@mhf.org.uk



Getting a break

Introduction

'For the first year after we received the diagnosis I did not consider there was any need for me to have a break. I suppose that in some way I was reluctant to admit that I needed help.

Fortunately we were then introduced to The Clive Project and initially started with one afternoon a week which was increased to two sessions a bit later. I do not know how I would have coped during the last few years without the breaks as I now realise that it is essential to have some time on your own. The support workers have become friends and I am now able to carry on with various sporting activities. This year my wife has received respite care for longer periods, and these longer breaks have been wonderful. She also attends a day centre once a week. It is always difficult as a carer to try to balance the role with having some time on your own. All I know is that any breaks for a carer are essential and enable you to charge up your batteries and face all the various problems that have to be faced by carers.'

VKB

Dementia can be demanding and frustrating for all closely involved. With that in mind this section gives details of breaks both for the younger person with dementia and for the person who supports them. Services offer breaks from one hour to several hour sessions, and from day care to overnight and sometimes longer depending on what is needed. Apart from The Clive Project which offers specialist, flexible provision for younger people with dementia, the services cater for a wider range of people and needs. They may be able to be adapted to suit the younger person on an individual basis.

● Short breaks

Abingdon Alzheimer's Club

This Club offers activities and social contact for people with dementia each weekday. The **Tuesday Club** is especially for those in the early stages of dementia. Younger people with dementia have enjoyed attending this club, though it is predominantly for elderly people.



Abingdon Alzheimer's Club
Abingdon Hospital
Marcham Road
Abingdon OX14 1AG
01235 205407

Adult Placement Scheme

Adults, including people with early onset dementia, can take a long or short break away from home. Selected carers offer day care, short stays or long term placements in their own homes. They are thoroughly assessed and approved by Social and Health Care and their work is monitored by the scheme. The cost depends on personal financial circumstances. Access to the scheme is through Social and Health Care.



Social and Health Care, Adult Placement Team: 01235 519378 ext. 307

Bridewell Organic Gardens

Based in a walled garden in West Oxfordshire countryside, *Bridewell Organic Gardens* offers people living with health problems, primarily mental illness, a chance to engage in satisfying and rewarding work creating beautiful gardens. There is a charge to attend which increases if one-to-one support is necessary. If you need help with the charge approach your GP, community psychiatric nurse or Social and Health Care.

i *Bridewell Organic Gardens*
The Walled Garden, Wilcote Road
Near North Leigh OX7 3EB
Garden: 01993 868313 Administration: 01993 868445
www.bridewellorganicgardens.org.uk

Carers Centres—Time for Carers

Up to 24 hours per year free care at home can be offered if you are unable to leave a 'cared for' person alone. Contact your local Carers Centre for more information:

i <i>North and West Oxfordshire Carers Centre</i> <i>27 Horse Fair</i> <i>Banbury OX16 0AE</i> <i>Carers Line: 0845 7125546</i>	<i>South and Vale Carers Centre</i> <i>5 Lydalls Road</i> <i>Didcot OX11 7HX</i> <i>01235 510212</i>
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Oxford Carers Centre
174a Cowley Road
Oxford OX4 1UE
01865 205192

The Clive Project One-to-One Support Service

This service benefits people caring for younger people with dementia by sharing the care and support of the person. Across the county, trained support workers partner people who, on referral, are experiencing mild to moderate symptoms of dementia. Sessions are usually between two and four hours duration, weekly or more frequently, so provide a regular, reliable break for the carer. Through the changing illness, continuity of contact with the individual, their family and friends is provided. Emotional, practical and health promoting support is offered. *The Clive Project* can also assist with finding extra support and information when it is needed.

i *The Clive Project*
7 Mount Pleasant
Crawley Road
Witney OX28 1JE
01993 776295
www.thecliveproject.org.uk

Day Hospitals—Oxfordshire Mental Healthcare Trust

The day hospitals assess individual needs and offer rehabilitation and treatment, usually for time-limited periods, to help people to stay at home. Most attendees are older people, though younger people have valued this service. Referral is through the GP or community psychiatric nurse, and attendance is assessed and reviewed regularly. Apart from providing an opportunity for a break, the service encourages the development of supportive relationships between staff and families.



City

*The Manzil Resource Centre
Manzil Way
Cowley
Oxford OX4 1XE
01865 455800*

North

*The Fiennes Centre
Hightown Road
Banbury OX16 9BF
01295 229672*

South

*Vale Day Hospital
Community Mental Health Centre
Abingdon Hospital
Marcham Road
Abingdon OX14 1AG
01235 205700*

*Wykeham Park Day Hospital
Community Hospital Site
East Street
Thame OX9 3JT
01844 260729*

*Ridgeway Day Hospital
Wantage Road
Didcot OX11 OAF
01235 810574*

*Moorview
Moorland Road
Witney OX28 6LF
01993 202100*

Flexible Care Service

This countywide service offers regular support to enhance the quality of life primarily of older people with mental health problems. Weekly or fortnightly visits, usually of one to two hours, are offered to support the person at home. The service is free, and is accessible through community psychiatric nurses, and care managers. Younger people with dementia have successfully used this person-centred service.



Flexible Care Service

*Age Concern/Oxfordshire
St Edmunds House
39 West St Helen's Street
Abingdon OX15 5BW
01235 849400
www.ageconcern.org.uk*

Independent agencies

Private and voluntary organisations accredited by Social and Health Care offer carers' breaks from an hour or so to overnight if required. Fees and mileage are charged. A list is available from Social and Health Care.

Relief to Carers Service

A Social and Health Care service, care is provided to individuals who would be at risk if left on their own for more than a short period of time. A trained care assistant relieves the family carer of their responsibilities for a short interval. Up to three hours care a week may be provided. This can be used in a block for special occasions. Personal care is provided as required, or support to engage in the person's recreational activities. The service is countywide and referral is through your Social and Health care manager.



Social and Health Care, Relief to Carers Service: 01993 706392

Respite beds—short stay

Social and Health Care funds a few beds in care homes for short term respite care. They are available through your Social and Health Care care manager.

● Care homes

Short term respite care or long term care may be an option for the person with dementia. Although there are no specialist homes for people with early onset dementia in Oxfordshire yet, there are homes which may be suitable depending on the wishes and needs of the person. Social and Health Care can help in assessing the type of care needed and matching it as far as possible to what is available in care homes. Then it is important to visit all potential homes to find out whether the home seems right for the person concerned.

The Clive Homes Project

The Clive Project is working to develop appropriate accommodation for younger people with dementia in Oxfordshire. The aim is to provide independent supported living, short breaks and enhanced long-term support. For current information on this development, contact:

 ***The Clive Project: 01993 776295***
www.thecliveproject.org.uk

Care home fees

Nursing Home Fees Agency and the *CareAware Helpline* offer advice on how to meet the costs of long-term care. It is important to take impartial advice on care costs as the rules are complex. People with early onset dementia may qualify for hospital-type care, rather than nursing home care, even if there is no suitable hospital bed available.

 ***NHFA***
St Leonards House
Mill Street
Eynsham OX29 4JX
01865 750665

CareAware Helpline
08705 134925
www.careaware.co.uk

Guideposts Teaching Nursing Home

A recently established purpose built care home on the site of the Churchill Hospital. Its aim is to provide longer-term care for people with severe mental health needs. The Oxfordshire Mental Healthcare Trust has a number of beds within the resource.

 ***Guideposts Teaching Nursing Home***
Roosevelt Drive
Headington
Oxford OX3 7XR
01865 760075

National Care Standards Commission

From April 2002 Oxfordshire care homes are inspected by the *National Care Standards Commission*. They regularly visit and report on a group of care homes within a geographical location, and will discuss concerns about particular homes with you.

 **National Care Standards Commission**
 4630 Kingsgate
 Cascade Way
 Oxford Business Park South
 Oxford OX4 2SJ
 01865 397750
 e-mail: enquiries@ncsc.gsi.uk
www.carestandards.org.uk

Nursing care—funding

The amount of registered nursing care for each person in a care home is assessed. The levels of nursing care correspond to three bands of NHS funding towards the person's care home fees, currently from £35 to £110 per week.

Oxfordshire Care Association 'Bedline'

This information service run by the *Oxfordshire Association of Registered Nursing Homes and Hospitals* offers impartial advice on the availability of short and long stay care in Oxfordshire.

 **Bedline:** 0871 7174303

The Relatives Association

This is a national charity offering support to relatives and friends of people in care homes. The Association's helpline has contacts in Oxfordshire.

 **Relatives Association**
 5 Tavistock Place
 London WC1H 9SN
 Helpline: 020 7916 6055

Vale House

Vale House is an independent care home offering long term and respite care to people in the later stages of dementia. Working on the principles of privacy, dignity, independence and choice, the home offers hospice-type care in a safe and comfortable environment.

 **Vale House**
 The Botley Alzheimer's Home
 West Way
 Botley
 Oxford OX2 9UD
 01865 794096



Financial and practical matters

Introduction

'It is so easy to put off any financial or legal decisions, but it is one of the most important matters that have to be dealt with, and the sooner the better. If you know that all eventualities are covered then it is one less worry. We are all concerned as carers about our partner, but sometimes forget that we are just as vulnerable. A recent serious operation brought this home to me and made me tie up all the loose ends. I was also years late in applying for invalid care allowance, and the award cannot be backdated! We are sometimes very reticent about applying for benefits. They are however there for us, and should be applied for, as there are many additional costs associated with caring for a younger person with dementia.'

VKB

Advocacy

All individuals, whether living at home, in hospital, or in care homes, have a right to be heard and to influence decisions about their lives. For people with dementia it is more difficult to exercise these rights. Advocates offer independent, confidential support to individuals to help them speak for themselves. Or the advocate acts as the person with dementia's representative and speaks on their behalf.

ADAPT—All-Age Dementia Advocacy Project

The *All-Age Dementia Advocacy Project* is run by *Oxfordshire Advocacy Development Group (OADG)* in co-operation with the *Alzheimer's Society* and *The Clive Project*. *ADAPT* provides advocacy specifically designed to support people with dementia. The advocates take time to get to know and understand the wishes of the person with dementia (the partner). They then help their partner to express those wishes in the most appropriate way for them to be heard. Only the views of the partner are expressed. The advocate does not make judgements or decisions for their partner.



ADAPT Co-ordinator

*Barton Neighbourhood Centre
Underhill Circus
Headington
Oxford OX3 9LS
01865 742745*

OSTAS—Oxfordshire Short-Term Advocacy Service

A short-term, single issue advocacy service run by *OADG*. It enables people with all kinds of communication difficulties to identify their most pressing issue. The advocate supports them to communicate effectively with all concerned to resolve the problem.



OSTAS

*19 Paradise Street
Oxford OX1 1LD
01865 250102*

Employment

● At work and leaving work

It may be possible for the person with dementia to continue working for a while even after diagnosis. This depends on how the symptoms of dementia affect them and what their job involves. Informing the employer may offer an opportunity to discuss the responsibilities, risks, advantages and disadvantages of continuing work. Competence at work can then be judged in the light of personal circumstances, job requirements and potential risks.

Disability employment advice

Perhaps the person with dementia could move to a more suitable job with the same employer or work with additional support. If a less demanding job means that income drops then it is important to work out the repercussions of this on current finances and pension entitlement. The disability employment service helps tailor support packages under the **Access to Work** scheme and negotiates with the employer. There are three disability advisors based at the main **Job Centres** in Oxfordshire.



Jobcentre
38–44 Stert Street
Abingdon OX14 5QS
01235 703000

Jobcentre
47 South Bar Street
Banbury OX16 9YQ
01295 455300

Jobcentre
7 Worcester Street,
Gloucester Green
Oxford OX1 2BX
01865 445000

When it is time to leave work it is important to negotiate the early retirement or retirement/dismissal due to sickness terms with the employer. Much depends on the individual's terms and conditions, the employer and any pension agreement that is applicable. Contact the trade union if there is one. The local representative may be able to negotiate with the employer on behalf of the person with dementia. Many large industries and public sector employers have benevolent funds to help with financial hardship.

Pensions

Try to encourage the employer to enhance pension rights if early retirement on the grounds of ill health occurs. Again a union representative may be able to assist. The state retirement pension is payable on retirement age (currently 60 for women and 65 for men) if sufficient national insurance contributions have been paid. When early retirement occurs through ill health or caring for someone then claiming national insurance credits may protect the right to a state pension. Anyone deemed 'incapable of work' by the Department of Work and Pensions would automatically receive credits.

Carer's employment

There are many employment issues for the person caring which need careful consideration. For people in full or part-time employment, it may be possible to negotiate reduced or flexible hours of working and some unpaid or dependant's leave to cope with crises. With a network of dependable day and home services, continuing working is an option. Employment is not just a source of finance and occupation; it often provides necessary social contact and intellectual stimulation and continuing work in some form is often beneficial.

● Getting state benefits

Income may reduce if you or your partner need to give up work or work less. At the same time there may be additional care costs incurred. There are benefits available to supplement your income. *Citizens Advice Bureaux*, *Local Advice Centres*, and *Carers Centres* will advise on what benefits are applicable, how to maximise your income and with making applications. This experienced help increases your chances of making successful applications. As with all benefits entitlement, the *Department of Work and Pensions* require notification of any change in circumstances.

A Freephone Benefits Enquiry Line for people with disabilities offers general advice.

 *Freephone Benefit Enquiry Line: 0800 882200*

Agency

The most secure way of receiving benefits is by automated credit transfer directly into a bank account. Alternatively you can receive cash from the post office or someone else, the agent, can pick up the money instead. The person entitled to the benefit can sign a form in the pension/benefit book.

Appointeeship

If the person with dementia is unable to manage their own money, an appointee can be authorised by the Department of Work and Pensions. The appointee receives and administers benefits on behalf of the person with dementia. Appointeeship forms are available from the local *Benefit Agency*. Anyone with enduring power of attorney or as receiver with the Court of Protection automatically replaces the appointee.

● Benefits available

Disability living allowance (DLA)—for the younger person with dementia

This is a tax-free, non-means tested benefit for people under 65 who need help with mobility and/or personal care. *DLA* is paid at different rates according to need. If a successful claim is made by the 65th birthday the benefit entitlement continues for life. Attendance Allowance is available for people over 65, but the mobility component and the low rate of care is not included. Call the National Helpline for a date-recorded application form. The benefit is paid from that date if it is awarded. Take the forms and relevant personal financial information to

your local *Advice Centre* or *Citizens Advice Bureau*. Their experience with *DLA* will increase your chance of a making a successful application.

 *National DLA Helpline: 0845 123456*

Statutory sick pay—person with dementia

This taxable benefit is paid by employers for up to 28 weeks in any one period of sickness.

Incapacity benefit—person with dementia

This benefit is for those who are incapable of working because of disability, and who are not receiving statutory sick pay. People who are over 25, employed, self-employed, or who have no current employer can claim. Entitlement depends on national insurance contributions. It is not generally affected by income or savings but may be taxable. A claim form should be available from your employer, or from your nearest Department of Work and Pensions office.

 *Banbury Office: 01295 455000*
Oxford office: 01865 443333

Invalid care allowance—person caring

This is a taxable, means tested benefit for carers of people receiving Disability Living Allowance care component at the middle or higher rates. To be eligible the carer must be spending at least 35 hours caring and be earning less than £75.00 per week. Claiming this benefit gives the carer Class 1 national insurance contribution credits to help protect retirement pension rights. The claim form is available from Department of Work and Pensions office as above.

● **Benefits available for people on low incomes**

Income support—person with dementia and/or person caring

This is a means tested benefit to help with basic living expenses for people caring for others, or people deemed incapable of work. Income support can be paid in full or used to top up other benefits or income. In addition, help with interest payments on mortgages and loans for certain repairs and home improvements may be given. The claim form is available from the Department of Work and Pensions offices as above.

Housing Benefit—person with dementia and/or person caring

This is a means tested, tax-free benefit for people on low income to help pay rent. An application form is available from the housing benefit office of your local Council.

Council Tax Benefit—person with dementia and/or carer

This is a means tested, tax-free benefit for people on low income to help pay for council tax.

Council tax relief

People who are deemed to be 'severely mentally impaired', and the person caring, when living at the same address, are entitled to a reduction in their council tax bill. Anyone with dementia living alone and in receipt of a disability benefit is exempt from council tax. In addition council tax is reduced by 25% if one adult lives alone. Your local **Advice Centre**, **Carers Centre**, or **Citizens Advice Bureau** will help if you have any trouble in obtaining this. Forms are available from your local council.



Alzheimer's Society Helpline: 0845 300 0336

Citizens Advice Bureaux and Local Advice centres: See Yellow Pages

Disability Rights: 020 7247 8776

Department of Work and Pensions/Disability and Carers Service: www.dwp.gov.uk

Financial and legal plans

There will come a time when the person with dementia is unable to manage their affairs. Planning for this time as early as possible will help ensure that legal and financial arrangements are made to protect the person and their family during the course of the illness. It is useful to know where all the financial documentation is stored and be aware of all financial commitments.

● Discretionary trusts

A useful tool can be the creation of a discretionary trust. This can be set up by anyone, either by deeds during their lifetime or by making the appropriate provision in their Will. A person setting up the trust is called 'the settlor' and the people benefiting, 'the beneficiaries'. The trust will state that the trustees, who will be in charge of administering the money and the trust, have discretion whether or not to make any payments, and, if they do, who receives the payments. It is important to discuss with the trustees your particular wishes in relation to the trust. The benefit of a discretionary trust is that the money held does not belong to any one person and cannot be taken into account, in, for instance, assessing whether or not a disabled person should receive State Benefits. A discretionary trust can be set up specifically naming a particular disabled person. As a special concession the trust is still considered to be completely discretionary and none of the money is treated as belonging specifically to the disabled person. This also has tax benefits. Setting up a discretionary trust, either by deed or Will is a complex procedure. Please seek legal advice.

● Enduring Power of Attorney (EPA)

This enables a person with dementia to appoint someone, an 'attorney', to look after their financial affairs. An **EPA** can be signed at any time whilst the person with dementia still has 'mental capacity'. Special forms are available from solicitors or legal stationers and the costs are low. It is a good idea for the person to appoint two people, in case one becomes ill or loses contact. Unless a restriction is included, the **EPA** comes into effect immediately. To continue to be valid the **EPA** has to be registered at the Public Guardianship Office by the time the person with dementia is unable to deal with his/her financial affairs. It can be registered at any time

when the Attorney believes that the person with dementia is, or is becoming, unable to deal with financial matters because of mental incapacity. **The Public Guardianship Office** is responsible for the registration of enduring powers of attorney, and there is currently a fee of £220.00 for the administration of the process.

i **The Public Guardianship Office**
 Archway Tower
 2 Junction Road
 London N19 5SZ
 0207 664 7000

● Finding the right solicitor

The **Alzheimer's Society** has up-to-date information about solicitors in Oxfordshire with experience and training in all legal matters relating to dementia, including making a Will. You can also contact **LAW NET** for this information via the following website address.

i **Alzheimers Society Helpline:** 0845 300 0336
LAW NET: www.lawnet.co.uk

● Guardianship

Guardianship orders are rarely used now but may be useful to protect people with dementia if other methods have failed. A guardian might be, for example, Social and Health Care or someone appointed by them. Guardians can decide where a person should live; they can require but not insist on attendance for medical treatment and they can ensure that a doctor, care manager or anyone else named by the guardian has right of access to the person with dementia.

● Joint bank accounts

Joint accounts are no longer valid if one of the holders becomes mentally incapacitated. It is important to seek legal advice to ensure that joint income and assets continue to meet the financial commitments. Talk to the bank manager early since it may be possible to arrange the account so that the person with dementia has access to limited funds. This will help maintain independence and choice for as long as possible.

● Living will

This is a statement made by someone whilst still mentally capable, about the kind of medical treatment they would wish to receive or refuse later. Living wills are not legal documents and are not legally binding on the medical profession. However, if you discuss it with your GP at the time you draw it up and ask the practice to hold an up-to-date copy, it is likely to be taken seriously. Detail about your needs and wishes relating to future care can be included as advance directives. The **Terence Higgins Trust** with **The Centre of Medical Law and Ethics** have drawn up forms for use as your **Living Will**. Forms and guidance are available from the **Terence Higgins Trust**. The Alzheimer's Society also has information on Living Wills.

i **Terence Higgins Trust**
 52–54 Grays Inn Road
 London WC1X 8JU
 Helpline: 020 7242 1010
 e-mail: info@ttht.org.uk
 website: www.ttht.org.uk

Alzheimers Society Helpline: 0845 300 0336

● Making a will

Today we are all encouraged to make a will. People with dementia need to do this at the earliest opportunity. They need to understand what is involved and make their wishes clear. It is equally important for the person caring to make a will to ensure that the person with dementia and any children under 18 are cared for.

● Receivership

If no enduring power of attorney exists when the person with dementia becomes mentally incapable, it may be necessary to consider applying to the **Court of Protection** for management of finance and property. Any willing person can apply to become the **Receiver** to the **Public Guardianship Office**. The commencement fee is currently £65.00, with £500.00 payable when a receiver is appointed. See enduring power of attorney entry above for contact details.

● When someone dies

There is financial and legal work to be done when somebody dies. The **Benefits Agency** publish a guide—leaflet D49 available from the **Department of Work and Pensions**.

i **Banbury:** 01295 455000
Oxford: 01865 443333

Help the Aged publish a leaflet written in association with **Cruse Bereavement Care** called 'Bereavement'. It focuses more on some of the complex feelings that may be involved in bereavement, including shock, emotional and physical demands. Practical advice about what you need to do is included. The leaflet has a gentler approach than that of the **Benefits Agency** which focuses strictly on the practical issues.

i **Help the Aged,**
 207–221 Pentonville Road,
 London N1 9UZ
 020 7278 1114
www.helptheaged.org.uk



Getting out and about

Introduction

'Last February I learnt something about on-board airline toilet facilities—they are in no way meant to accommodate two persons!! I have always found people very understanding and keen to help in any way possible, but you can't get a pint into a half pint pot!!

The diagnosis of dementia is a signal to get on with any trips at home or abroad as soon as you are able, and to be aware that all things are possible, but get more difficult as time goes by.

I have been lucky, in that my dear man will normally hold my hand, and accede to my wishes, but for him walking on a beach in the moonlight has to be more enjoyable than being wheeled along the promenade in a wheelchair. I have reached a point where I really don't know if he enjoys his outings any more, as his walking is so difficult.

So, in short, Carpe diem, and enjoy sooner rather than later!!

Meg Barbour

Establishing a regular routine during the day is really important. Part of the day will be spent on domestic and personal necessities. Allotting plenty of time for each element will enable the person with dementia to work at their own pace and so reduce anxiety and frustration. Beyond that there will be time for socialising and leisure activities outside the home. This is an important part of the weekly timetable for all concerned. We quickly lose confidence and may become isolated and lonely if we stop going out. Participating in the life of the community feels more challenging though if you have a disability. What and who will you meet? Will you cope with the demands that are outside of your control? This section offers some ideas about where to find support with going out. Selecting and undertaking activities out of the house continues to be a source of pleasure for many people if outings are well-planned and flexible.

Mobility

● Driving

Dementia has a detrimental effect on the ability to drive and can raise serious safety issues, even in the early stage of the disease. Lapses in memory, impaired judgement and slower reactions could have serious repercussions on the road. Seek advice from the Medical Branch of the **Driver and Vehicle Licensing Agency** or from your GP. Although it may be possible to continue driving for a while if competence can be proven, the person with dementia will need to give up driving at some point. It is also essential to notify the car insurance company since a diagnosis of dementia will affect the insurance cover.



Driver and Vehicle Licensing Agency

Drivers Medical Branch

Swansea SA99 1TV

0870 600 0301

● Other transport issues

Blue Badge scheme

Oxfordshire County Council issue blue badges for passengers or drivers with certain mobility or sensory difficulties living within Oxfordshire. This is part of a national arrangement of parking concessions for people with mobility problems. The scheme allows badge holders to park closer to their destination and in some areas offers free parking. Application forms and explanatory leaflets are available from Social and Health Care. You can download the ***Disabled Parking Application Pack*** through the County Council website, via Caring and Protecting, Disabled people, at:

 www.oxfordshire.gov.uk

Social and Health Care Directorate
PO Box 221
Kidlington
Oxfordshire OX5 1YB
01865 854409

Breakdown cover

AA Disability Helpline provides information on facilities at motorway service areas as well as other mobility-related questions. Taking out breakdown cover with the AA or one of the other breakdown organisations offers reassurance when driving with a person with dementia.

 *AA Disability Helpline: 0800 444999*

Oxfordshire Council for Voluntary Action (OCVA)

OCVA provides information in their directory of Voluntary Organisations about all voluntary and public transport services available in the county. Available in print in libraries, or on their website.

 *OCVA: 01865 251946*
www.ocva.org.uk

Oxfordshire Rural Community Council

A directory of community transport schemes for shopping and health appointments is available. Volunteer groups, *Fish* and *Good Neighbour* schemes are all listed.

 *Oxfordshire Rural Community Council*
Jericho Farm
Worton, near Cassington
Witney OX29 4SZ
01865 883488

Public transport

To maintain mobility and independence for as long as possible, get to know the local public transport system. Alternatively it may be possible to find a local taxi firm and open an account with a trusted driver. Taxi firms are in the Yellow Pages and the main bus operators can supply you with their timetables on request.

 **The Oxford Bus Company:** 01865 785400
Stagecoach: 01865 772250

Ring-a-ride services

These are door-to-door, individual services for people who cannot use public transport due to mobility or sensory difficulties and for someone accompanying them. It can be used for shopping, visiting friends, and GP and dental appointments. The service cost is comparable to a regular bus fare and must be booked in advance. For full details of services in the local area call the **OCVA** transport co-ordinator as above.

Toilets

Public toilets for the disabled offer more space for a helper and are not specifically assigned to males or females. A **RADAR** key may be needed to access disabled toilets in some areas. This can be obtained direct from **RADAR—National Key Scheme**. Local councils will also have lists of locations of disabled toilets in their area.

 **Royal Association for Disability and Rehabilitation**
12 City Forum
250 City Road
London EC1V 8AF
020 7250 3222

Leisure activities

Many activities continue to be enjoyable for people with early onset dementia especially during the early to middle stages of the disease. Increased support will be required as abilities are affected. This helps the person spend time in a stimulating, positive and pleasing way. Planning ahead, being flexible and responsive to the person's mood contributes to an enjoyable time. Concessions on fares and admission may be available either for the person themselves or the person accompanying them. **The Clive Project** support team recommend walks, rural or urban—guided or with a map, tours of National Trust and historical properties, museums, galleries, concerts, Open Gardens and places where it is possible to stop for a rest, a chat and a coffee! These are just a few items to note in an otherwise limitless section. For additional ideas on activities at home try the **Alzheimer's Helpline**. They can also recommend publications to use as a reference for activities.

 **Alzheimer's Helpline:** 0845 300 0336

● Leisure from home

The Clive Project One-to-One Support Service

This service supports individuals in pursuing activities of their choice. A broad range of practical, leisure, health and cultural pursuits are enjoyed in partnership with trained support workers across Oxfordshire (see page 35).

The Clive Project Social Club

This club, linked to the *One-to-One Service*, meets occasionally at different locations throughout Oxfordshire. The activity and location is selected by Club members and offers an opportunity to meet up socially with other people with early onset dementia.

 **The Clive Project**
7 Mount Pleasant
Crawley Road
Witney OX28 1JE
01993 776295
www.thecliveproject.org.uk

Calibre cassette library

Provides books on cassette for anyone with reading problems. The service is free of charge.

 **Calibre cassette library:** 01296 432339

Local libraries

Reading may become difficult but books with visual content may continue to please, particularly those that recall long term memories. Music on cassette or compact discs, and videos and books on cassette are available from local libraries. Many Oxfordshire towns have a library and they are listed in the Yellow Pages. It may be possible to use a mobile library if transport is a problem.

Music therapy

Music therapy can help people with dementia to relieve anxiety and frustration. It helps people to communicate without words, to make choices, and to feel their identity affirmed through music and songs known from the past. Making and appreciating music can give great pleasure to people with advanced dementia. For local therapists with experience of dementia contact:

 **Association of Professional Music Therapists**
26 Hamlyn Road
Glastonbury, Somerset BA6 8HT
01458 834919
www.apmt.org.uk

Oxford and district talking news

Oxtalk is a local weekly newspaper on standard cassettes for people who cannot read a printed paper. Although usually available for those who are registered blind, this service can make the news accessible to others. There are talking newspaper groups in other areas of Oxfordshire and contacts for these are available from *Oxtalk*.

 **Oxtalk:** 01865 766442

Riding for the disabled

An outdoor activity with the benefit of fresh air and contact with animals. This can be an enjoyable activity for people with dementia if they are well supported.

 *Riding for the disabled: 01235 763731*

Swimming

Again, this is excellent exercise for people with dementia if they are well supported. Find a time when the pool is quiet. Many pools have special sessions for disabled people and their carers which may be a useful option. Family changing rooms and changing rooms for disabled people have more space to support the person if they need help. This is a relaxing activity for many, and it has been found to be successful and empowering for people with advanced dementia.

Holidays

Carers UK

The obstacles to taking a holiday are often due to restrictions of free time or finances. *Carers UK* offers information on 'how to find out about holidays'. It covers topics such as finding the money using trust funds, house exchanges, taking holidays alone and taking holidays together.

 *Carers UK*
20/25 Glasshouse Yard
London EC1A 4JS
0171 490 8818

Holiday Care Service

Holiday and travel information for disabled people and carers is provided. This includes regional information, overseas destinations and how to apply for financial help.

 *Holiday Care Service*
2nd Floor, Imperial Buildings
Victoria Road, Horley
Surrey RH6 7PZ
01293 774535

Winged Fellowship Trust

Winged Fellowship provides respite for carers and holidays for people with a wide range of disabilities. The holidays provide an enjoyable break in well-designed venues with professional and volunteer support teams on hand. There is a period specifically for younger people with dementia.

 *Winged Fellowship Trust*
Angel House
20-32 Pentonville Road
London N1 9XD
020 7833 2594

● Personal safety

Mobile phones, pagers and static phones using memory codes have all eased communication. However nothing replaces the sense of security offered by a partner, friend or neighbour calling in to ensure that all is well. Going out alone can become hazardous for the younger person with dementia. Leaving home, coping with traffic, crowded places, and handling money all present potential security risks. Any strategy that maintains the person's safety, confidence and independence is worth considering. A simple aid is to carry a card with the person's name and telephone number on, and perhaps the name and telephone number of someone who can help. Alternatively a SOS talisman bracelet or necklet with a contact number on can be used. Again the **Alzheimer's Society Helpline** offer tried and tested options. Below are listed just some of the possible sources of help.

 **Alzheimer's Society Helpline:** 0845 300 0336

Local council housing departments and the crime prevention unit may be able to offer advice about securing the house.

 **Cherwell/Banbury:** 01295 252253/5
Oxford: 01865 760733
South Oxfordshire: 01235 527331
Witney: 01993 702941

Medic Alert

Medic Alert provide identity bracelets/pendants which can be worn all the time by the person with dementia. It displays the wearer's name and holds a code, which allows authorities such as the police or a hospital to access the wearer's Medic Alert file and gain information regarding their medical condition.

 **Medic Alert Foundation**
 1 Bridge Wharf
 156 Caledonian Road
 London N1 9UU
 020 7833 3034

Alternatively, use an engraved disc with the person with dementia's name, telephone number, main carer telephone number and any significant medication for the emergency services (such as insulin, warfarin). If the person is missing, the police can be informed. Paramedics always look for such a disc if they have difficulty communicating with the person requiring emergency treatment or care.

Message in a Bottle scheme

A simple idea designed to encourage people living on their own to keep their basic personal and medical details in a common location where they can easily be found in an emergency. The scheme was developed by **Oxfordshire Lions Clubs**. There is no cost to the user, and your Health Centre or chemist will have supplies of bottles and forms.

 **Oxfordshire Lions Clubs:** 01235 531921

Vital-Call

This is a telephone based alarm system for vulnerable people living in their own homes. A unit is connected to an ordinary BT telephone socket and the personal alarm is worn as a pendant by the vulnerable person. The alarm is triggered by the person when an emergency occurs. This alerts a central operator who can then take appropriate action. Personal alarms may be useful in the earlier stages of dementia.

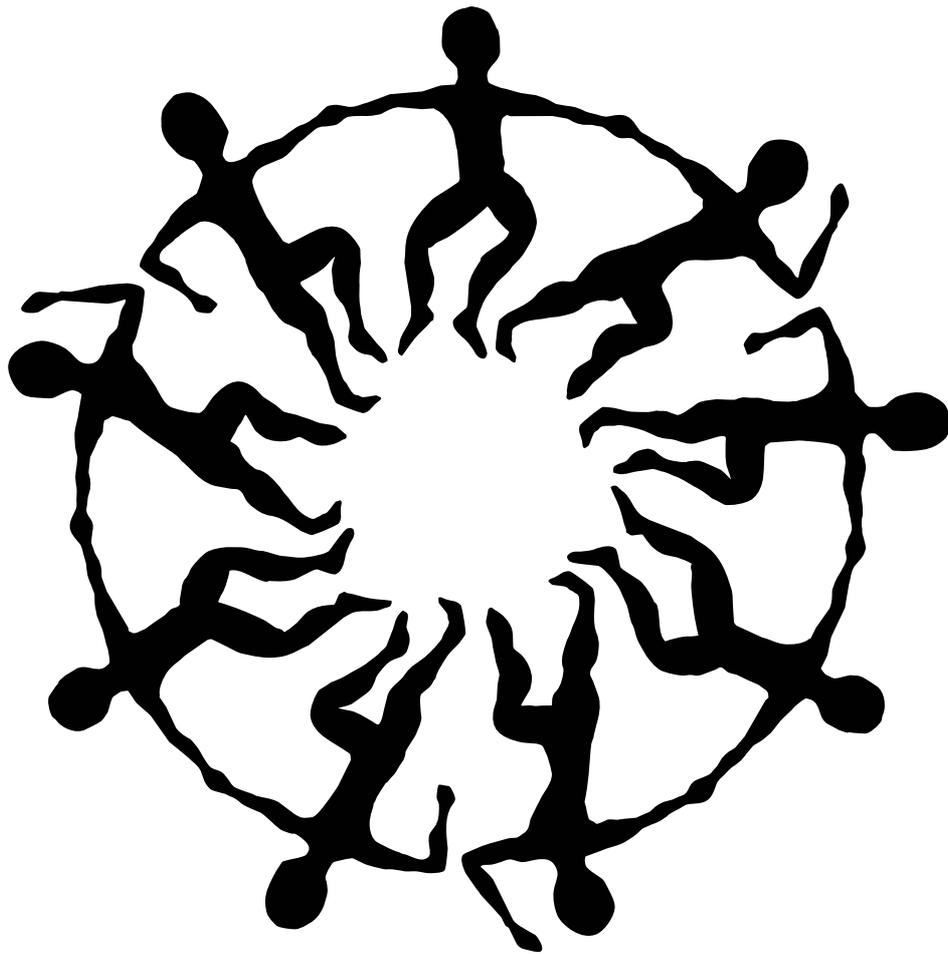


Cherwell: 01295 252535

Oxford City and Control Centre: 01865 760733

South and Vale (Community Alarm Telephone Services): 01235 527331

West Oxfordshire: 01993 702941



Campaigning, challenging and commenting

Introduction

Life does not always go according to plan. You may need support to obtain a proper diagnosis and to receive treatment or care. You may find there are insufficient appropriate resources for younger people with dementia and that they are expected to share resources with people a generation, or more, older than themselves. The individual needs of a younger person are likely to be quite different to those of older people with dementia. Younger people may have particularly acute problems in parenting, employment and finances as well as needing the right kind of day-to-day support for their own particular circumstances. It is possible to influence what help is available. This can be achieved in various ways. This chapter signposts you to people and organisations who may be able to help you get what you need.

● Campaigning

Carers UK

Carers UK provides information to carers, supports carers' group and organisations and campaigns for a better deal for carers.



Carers UK

*20/25 Glasshouse yard
London EC1A 4JS
020 7490 8818*

The Clive Project

Families and friends can join the campaign for a more comprehensive range of services for younger people with dementia in Oxfordshire. Campaigning is always most effective when led by 'service users' rather than by professionals. You can make a strong case individually and an even more powerful case as a group. *The Clive Project* is willing to facilitate discussion between those who provide services and those who use them. For this reason we have developed strong links with Oxfordshire's health organisations and Oxfordshire Social and Health Care Directorate.



The Clive Project

*7 Mount Pleasant
Crawley Road
Witney OX28 1JE
01993 776295
www.thecliveproject.org.uk*

Oxford Dementia Centre

Not strictly a campaigning body, but a resource for planners, managers and practitioners in health, housing and Social and Health Care who themselves commission and provide care for all people with dementia. The Centre is part of the *Institute of Public Care* at Oxford Brookes University. They provide research and consultancy, training and management development services for statutory, voluntary and independent sector organisations on primary care, social care and social care housing. The *Oxford Dementia Centre* works with health services, local councils and housing agencies to support the development of integrated services for people with dementia of all ages.

i **Institute of Public Care (ODC)**
 Roosevelt Drive
 Headington
 Oxford OX3 7XR
 01865 761798/761815
www.brookes.ac.uk/dementia

Oxfordshire Carers' Forum

An independent organisation of carers and ex-carers, the Forum promotes carers' interests with Health services, the Social and Health Care Directorate and other agencies, and ensures that the carers' voice is heard in any consultation process.

i **Oxfordshire Carers' Forum**
 The Elms
 9 Church Green
 Witney OX28 4AZ
 01993 706543

● Challenging

Community Health Council for Oxfordshire

The *Community Health Council* is a statutory independent 'consumer council' representing the interests of the public in the NHS. They ensure that the public voice is heard in the planning of health services. They monitor the quality and take up of local health services and aim to ensure equity in the use of services. The CHC will give advice and information on local health services and patients' rights. The CHC is being replaced in part by the Patient Advice and Liaison Service.

i **Community Health Council**
 5th floor, Seacourt Tower
 Botley Road
 Oxford OX2 0JG
 01865 723569
 email: xonchc@dial.pipex.com

County Councillors

County Councillors represent residents of Oxfordshire on a local basis and should be kept in touch with the needs of individuals within their constituency. For a full list of local County Councillors, contact:

i **County Hall**
 New Road
 Oxford OX1 1ND
 01865 792422

Members of Parliament

The local Members of Parliament are:

Banbury: Tony Baldry
Henley: Boris Johnson

Oxford East: Andrew Smith

Oxford West and Abingdon: Dr Evan Harris

Wantage: Robert Jackson

Witney: David Cameron

They have constituency offices and hold regular surgeries if you prefer a personal approach. Correspondence can be sent to the Houses of Parliament.

 **House of Commons**
Westminster
London SW1A 0AA

NHS Continuing Care

If there is a concern about whether a person meets the eligibility criteria for continuing NHS funded care, there is an appeal process.

 **Continuing Care Office**
Abingdon Hospital
Marcham Road
Abingdon
Oxon OX14 1AG
01235 205788

Oxfordshire Care Rights Service

If there are concerns about whether the rights of younger people with dementia are being upheld in respect of Care legislation, contact the **Care Rights Service**. They will support you to approach the Social and Health Care Directorate effectively to ensure that your rights are upheld.

 **Oxfordshire Care Rights**
St. Edmunds House
39 West St. Helen's Street
Abingdon, OX15 5BW
01235 849413
e-mail: rights@occag.fsnet.co.uk

Patient Advice and Liaison Service (PALS)

PALS provide confidential on-the-spot advice and support to help sort out any concerns with your NHS health care. They act independently on behalf of the patient, liaising with NHS staff and managers, to negotiate a solution.

 **Patient Advice and Liaison Service**
Cherwell Valley Primary Care Trust
Oxford Road
Banbury OX16 9GE
0800 783 6210

● Commenting

NHS Primary Care Trust services in Oxfordshire

These include GPs, community nurses and other health workers such as dentists, pharmacists and opticians. They work in partnership with local councils, the Social and Health Care Directorate and voluntary organisations to tackle broad issues that affect people's health. The *Patient Services Team* act on behalf of *Oxfordshire's Primary Care Trusts* and will help you make contact with the relevant Practice or arrange for conciliation. Conciliators are people appointed by the NHS to mediate between complainants and practitioners who are in dispute.

This service is currently being restructured with the move from the Oxfordshire Health Authority to the Regional Health Authority for Berks, Bucks and Oxon. If you have any difficulty contacting them on the numbers and address below, contact NHS Direct.



Patient Services Manager

*c/o Oxford City Primary Care Trust
Richards Building
Old Road, Headington
Oxford OX3 7LG
01865 226583/46*

NHS Direct Freephone: 0845 4647

Oxfordshire County Council Social and Health Care Directorate

If you experience difficulty in getting a community care assessment, if you disagree with its contents, or if you fail to obtain services that you feel are needed, you may wish to make a complaint. In the first instance ask for a complaints leaflet from Social and Health Care. This outlines the complaints process. *Oxfordshire Care Rights* can support you in making a complaint.



Customer Services: 01865 375515

Comments include compliments too. Social and Health Care, together with other Health Services and voluntary organisations, are happy to receive and act on positive and constructive comments.

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The Clive Project

The Clive Project began in spring 1998 to develop and provide a range of integrated, specialist and flexible services for younger people with dementia and their families and friends in Oxfordshire. This followed a research study into the needs and location of younger people funded by the Oxfordshire Branch of the Alzheimer's Society.

After working as a service within a local charity for three years, The Clive Project was established as an independent charitable company in 2001. The charity supports and cares for people with early onset dementia and related disorders, and their families and friends.

The Clive Project welcomes donations supporting our work on behalf of younger people with dementia.

The Clive Project
7 Mount Pleasant, Crawley Road
Witney OX28 1JE
01993 776295
www.thecliveproject.org.uk

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