

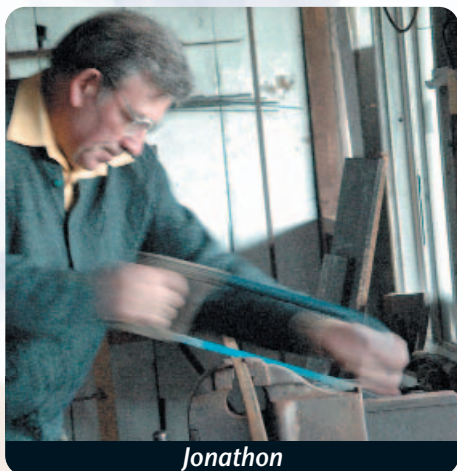
The Clive



P R O J E C T

2004–2005

Enabling people in Oxfordshire living with early onset dementia to live life to the full



Jonathon



Tony



Sandy

Dementia affects the ability to **remember, think, reason** and **communicate**.

Experiencing early onset dementia **challenges every expectation** of mid to later life.

The Clive Project offers **a positive approach** to living with dementia ...

... and promotes **better understanding** amongst others to create **a more supportive society**.

Welcome

Another action-packed year has passed. The Clive Project has been very busy—the One-to-One service has expanded and is providing more support than ever before, yet still the demand for the service grows. The Family and Friends service was launched in April 2005, and is working with the One-to-One team to deliver as complete and seamless a service as possible.

In recognition of the value of our specialist experience, Oxfordshire Health and Social Services are now funding part of our one-to-one work. However, welcome as this funding is, we still need to raise the majority of our funds, in particular for the support of people early after diagnosis.

Our model of support has been adopted elsewhere in the UK, including Al's Way in Worcestershire. People from Al's Way joined our induction training and keep in touch with us on their progress.

Beyond our own work, there are changes affecting those we support. The recent Mental Capacity Act offers people with dementia and their families more protection and choice. The Alzheimer's Society has re-issued guidelines for the treatment of younger people with dementia, and there is a new National Service Framework on long-term neurological conditions, including dementia. On the other hand as I write, we are anxiously awaiting the National Institute for Clinical Excellence guidelines on the prescription of anti-dementia drugs.

The Clive Project works to promote awareness of young-onset dementia, and to work with others to help improve treatment and care. In the year ahead this will become an even more important focus of work, and I hope we can spread the message of The Clive Project; that there is life after a diagnosis of dementia.

Helen Beaumont, Chair

Family and Friends Service

Two dedicated workers now offer information, and practical and emotional support to those in a caring role. This new service builds on the existing Clive Project Exchange and aims to equip partners and families with the confidence and tools to enable them to live well with the person with dementia.

'I am very grateful to all the people in The Clive Project for talking to Jonathon and me in such a way that we feel 'normal'. AF

This year's Exchange programme offered opportunities to focus on topics such as memory strategies, respite, legal planning,

family relationships and community care rights as well as facilitating mutual support.

Learning Together Workshop

Musicians from Oxford Philomusica and Music for Life facilitated a session for families, friends, trustees and the support team to explore the potential in music for communication, play, expression and connection.

Annual Exchange Lecture

The Exchange Annual Lecture by Baroness Susan Greenfield, our Patron, on future treatments for dementia attracted more than 50 family, friends and professionals.

Dementia—an older

*More than 18,500 people in
between 30 and
Dementia progressively*

*Think about the challenges of life
Younger people*

*... have dependent
Dementia radically
relationships*

*... be in work at the
Dementia affects your
income and*

*... have heavy financial
Dementia changes your
finances and plans*

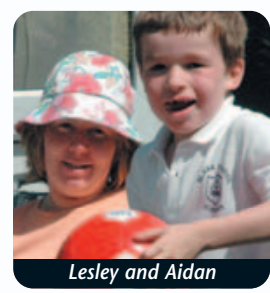
*... expect an age
Dementia alters
communication*

*... be physically
Dementia affects your
and independence*

*... receive inappropriate
Dementia services
to older, fr*

*... have a rarer form
This may be more
and is less likely*

*The Clive Project provides
and information based on a real
younger people with dementia
How do we know what is needed?*



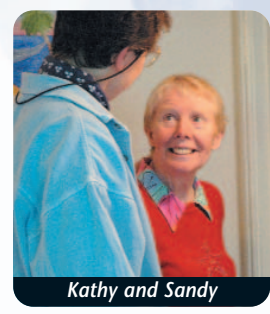
Lesley and Aidan



Nicky and Phil



Marilyn and Hilly



Kathy and Sandy

*'I think without what we've got now, it's so
I'm bowled over by it sometimes—it
RM, One-to-*

person's condition?

the UK experience dementia

65 years of age.

affects every part of life.

living with early onset dementia.

are likely to:

children and family.

ically alters your

os and roles

time of diagnosis.

r employment, status,

ad security

ncial commitments.

r capacity to manage

an for the future

ctive social life.

s your ability to

e with people

fit and energetic.

initiative, motivation

udent action

and inadequate services.

are normally geared

rail people

orm of dementia.

ifficult to live with,

to be understood

vides specialist support

l understanding of the issues for

ementia and their families.

? People using the services tell us.

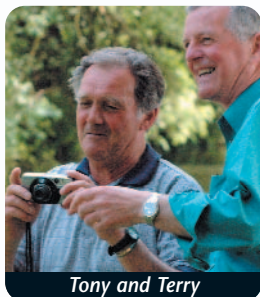
super, if it didn't exist, it's so important ...

it is not always perfect, it is special.'

One member



Des and Sue



Tony and Terry



Steph and Jill



Norman and Jo

One-to-One Service

Our team of eleven trained support workers have provided more than 5000 hours of individual support to forty-two people with dementia during the past year, with an increase to 6300 hours planned for the coming year. Currently we support people with Alzheimer's, vascular dementia, frontal lobe dementia, CADASIL, other rarer dementias, and those with cognitive impairment linked to Huntington's disease and multiple sclerosis. The sessional support covered a broad range according to each person's changing needs and wishes, and this year included support with paid and voluntary work for the first time, as well enjoying the outdoors in all forms. We also ensured that three people were able to attend and enjoy Bridewell Organic Garden every week.

For other people, the service means that they are able to stay at home, living alone or with their families, for longer. The service shared the responsibility of care with the partner and family and provided breaks from care. The successful fulfillment of everyday tasks together has been very important this year to those who live alone.

She's with me as a person. Although I was having trouble, she came in beautifully and was for the people'.

One-to-One member

It was a creative year too with people exploring photography as a means of expression. Having seen the beautiful results, others are now joining in with the fun. Trying out something new has boosted self-esteem and confidence. This project continues and will culminate in public exhibitions, including our first entry in Artweek 2006.

Having the nasty, I feel vulnerable. I have to put my trust in people and that's hard to do. I feel very safe with her (support worker), she's encouraging, she gives me options ... she doesn't drag me back like others'.

One-to-One member

For the future, our challenge is to introduce the support at an early stage to establish a strong relationship with the expanding number of new people identifying themselves, as well as flexibly responding to those already using the service as their needs increase. An independent evaluation affirmed the validity and benefits of our approach as well as giving contributors a further opportunity to suggest changes that would make the service even more useful to them. The report, authored by a Mental Health Joint Commissioning representative, is available from The Clive Project by email.

The Clive Project Club

Social isolation is a real risk for the person with dementia and their partner and family. Theatre trips, pub lunches, Valentine and Christmas celebrations, shared suppers, picnics, walks and concerts were all thoroughly enjoyed

during the year. Our annual consultation event with everyone using the Project focused on social activities and this gave us lots of ideas for the coming year. And to keep everyone in touch, we have refreshed our newsletter and website.

Working with others

The Clive Home Project

We have continued to work closely during the year with national partners including Sanctuary Housing Association and the Order of St John Care Trust and with local health and social care commissioners to develop the design and funding of a specialist resource offering long-term and respite care for younger people with dementia. A number of leads have been followed up in the hunt for the right site, including land in Burford, Chipping Norton, Wantage and several possibilities in Oxford itself. It is a very competitive market and many of the sites investigated so far have raised difficult planning issues, but our network of contacts is still growing and new options are still emerging. We are determined that this is a development we will achieve however long it takes!

Oxfordshire Early Onset Dementia Network

Work with a multi-disciplinary team of professionals from Oxfordshire Mental Health Care Trust and Oxfordshire Social and Health Care continues to develop expertise on

the issues facing younger people and their families. Challenging inequitable services and the cost of services to families has been a major feature this year.

Oxfordshire Dementia Forum

The Clive Project is working with other organizations including the local Alzheimer Society branches, SPECAL (Specialized Early Care for ALzheimers), and DISC (Dementia Information Service for Carers) to develop an interactive website enabling easier access to services, resources and facilities for all people with dementia, their carers and professionals in Oxfordshire.

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Beyond the county, we have continued our links with the Central Regional Forum for early onset dementia which encourages the exchange of information about innovative services and best practice. We actively seek out ways of encouraging a better understanding of early onset dementia through publications, conferences and workshops.

The Clive Project Team

Trustees: Helen Baker • Helen Beaumont (Chair) • Vaughan Billings (Treasurer) • David Birch • Sally Bradbury
Elizabeth King • Alison Talbot (*from January 2005*) • Jean Ware-Morphy

Director: Tessa Gutteridge

One to One: Terry Carpenter • Jill Cowland • Jo Davis • Marilyn Finbow • Kaija Graham • Jill Green (*retired August 2004*) • Nicky Henderson • Bernie Stevenson • Gill Stopps • Sue Thomas • Simon Warren
Kathy Yorke

Family and Friends: Diana Letchford • June Smith

Administration: Sharman Oldham

Finance: Karen Warner

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