

The Clive



P R O J E C T

2003–2004

Enriching the lives of younger people with dementia, their families and their friends across Oxfordshire.

Message from the Chair

The Clive Project is a hard act to follow, even when you are The Clive Project. We have earned an excellent reputation, both among people using our services and the local and national dementia-care community. Success in delivering support that really makes a difference to people's lives brings its own challenges. The Clive Project is growing to meet the increased demand for its specialist services: more people to support; a bigger team; development of new services for those who care at home and our involvement in creating a long-term care facility. Throughout these changing times, the quality and personal focus of our support remains our priority.

Fortunately we have a stable Trustee Board providing continuity, experience and ongoing commitment, since our initial research in 1996, and the beginnings of our first service in 1998. This year, one of our founder members, Betty Rostance, retired, and her contribution is much missed. However we welcomed two new Trustees who bring their own personal experience to help shape our work.

I am confident that we can manage this growth. The Clive Project has always depended on a strong team, and I think the team is more knowledgeable and experienced than ever. Indeed the team provides a resource of expertise on early onset dementia which has been of great value to other professionals as well as those who are personally involved. We

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Steph

Steph is supported by The Clive Project: she has Huntington's disease. This affects, amongst other things, the ability to think, reason, communicate and remember. Steph plans to live as rich a life as she can. The Clive Project support worker, Gill, understands how the condition may affect Steph now and in the future. They are working together to help Steph live life to the full.

... Message from the Chair (continued from page 1)

will be careful not to stretch too far, while spreading the message that it is possible to make a real difference to the quality of life of those affected by early onset dementia.

I wish that The Clive Project had existed while Clive [the charity is named in tribute to Clive Beaumont] was still living at home. Clive's illness isolated him from work and friends,

and he was never prepared to accept that he needed 'help'. A support worker could have enabled Clive to maintain his activities and interests for longer than he did, and perhaps we could have kept Clive at home with his family until he died, which had always been our expectation.

Helen Beaumont, Chair

About early onset dementia

Dementia is a term used for a range of conditions resulting from the progressive, physical deterioration of the brain. It is likely to affect communication, memory, personality, behaviour, and cognitive and physical abilities. If you experience dementia when you are in your thirties, forties, fifties or sixties then this is termed

'early onset'. The impact on the younger person's life is devastating—the expectations of a full working, social, community, family and personal life are challenged. No part of life is left untouched by dementia and those affected require and deserve specialist support services.

The Clive Project Exchange — support for family and friends

Over the past three years the Exchange meetings have been a fountain of helpful information and support to carers when struggling with the many life changes dementia brings. I always look forward to the varied subjects we discuss, the shared support and new friendships, and to learning from others how to make life more stimulating and interesting for my husband. Some of the subjects chosen by those attending included: a discussion on early onset dementia and the support needed by the whole family; coping strategies due to loss and change; and information and direction on how to get financial support and occupational therapy input. An occasional Newsletter reminds me of times and topics shared and there are social events arranged for carers and their partners.

Sally Bradbury, Carer and Trustee

'It's so important in my life, just to get out and meet such nice people — I don't know how I managed before I found The Clive Project.' **Sheila**

'The Clive Project is my lifeline and it helps that others are of a similar age and understand what I'm going through.' **Diane**

We plan to enrich the work of The Clive Project Exchange with additional events this year. In addition, we asked for a research worker from the South Oxfordshire Primary Care Trust to investigate effective ways of supporting the carers (partners, family and friends) of people with early onset dementia. The research findings provide the foundation for a new service for Spring 2005, initially to be funded by The Big Lottery Fund.

'Learning Together' Workshop

Last July our workshop for the team and for the families and friends of those we support focused on life story work. Charlie Murphy of Stirling Dementia Service Development Centre guided us through the very real benefits of creating a life story piece with the person with dementia. The session was inspirational and encouraged participants to make a start.

The Exchange Annual Lecture

In November we welcomed Professor Smith from OPTIMA, the long-term Oxford Project to Investigate Memory and Ageing, who lectured on optimistic research in the field of Alzheimers Disease.

Steph shares a regular session every week with her support worker. The support tunes in to what is important to Steph at the time.



She feels able to share her thoughts and concerns; and is helped to pursue her great love — horse riding. With the support worker alongside, Steph and her family have created 'Steph's life story' — to help Steph preserve her own memories, and as a



memory gift for her young son, Aiden and husband, Doug. And the support lifts everyone's spirits too — they have fun together!





Building a strong relationship with continuous, skilled contact enables this to work well for her.



One-to-One Active Support Service — support for the individual

This service aims to support the person with dementia in living the life of their choice. The support partnership involves working alongside the person consistently over the longer term, and enables each individual to adapt to the changes in their abilities as the dementia progresses. The sessions offer time for talking and listening, for achieving everyday tasks and contributions to home and family, for enjoyable social contact, pursuing leisure activities and interests, and for maintaining physical and mental well-being.

With around 200 younger people in Oxfordshire with a primary diagnosis of dementia including Alzheimer's Disease, vascular disease and frontal lobe changes, and many more with cognitive impairment linked to conditions such as Huntington's Disease and multiple sclerosis, the need for specialist support is considerable and increasing.

In its sixth year of service The Clive Project provided between two and nine hours of support each week to 41 people; this amounted to 4000 hours of direct support in total. Twenty-three new people were referred to the service and, with notice of an additional 15 people needing support, plans for expanding the support team to 11 began in late Spring 2004. We aim to provide more than 5000 hours of direct support in the year 2004-05.

This service was set up in response to the needs expressed by younger people and their families. In Autumn 2004 they will contribute to an independent evaluation to ensure that the service continues to meet their needs.

'Made a difference to my life. I don't feel so lonely. I felt empty before. It's like having a new friend. It's good to have someone outside the family to talk to.' Gillian

The Clive Project Club — support for all

Dementia may cause loss of communication and social skills. This, together with the loss of memory, undermines the person's relationships with family and friends. Loss of confidence and self-esteem make it difficult to continue or develop social contacts. The Clive Project addresses this by presenting well-supported relaxed opportunities to enjoy social events. Throughout the year, there have been several theatre trips, an outing to a wildlife park, picnics, garden parties, restaurant and

pub socials, and activity-based sessions such as bowling and painting to bring pleasure to the people we support, and to their family and friends. We also joined a sports and leisure centre so that all The Clive Project members can have access to this community facility.

'I feel like the other carers and other clients are in a similar position, and other people I know, and family, don't know how it affects your life.' Roz

The Clive Homes Project — short- and long-term care and accommodation

The Clive Homes Project has made substantial progress this year. We have been working closely with a national partner, Sanctuary Housing Association, and local social and health care commissioners to develop the design and funding of a specialist resource offering long-term and respite care in Oxfordshire. People using our services, The Clive Project team and a wide range of colleagues from across the statutory, voluntary and independent sectors contributed ideas through two open forums in the autumn. We also ran

a national conference in April to share models of best practice and expertise in this field. A number of potential sites in the county are currently being investigated by Sanctuary who will provide the capital to purchase the land and build the new resource. They plan to manage the service when it is completed with continuing input from The Clive Project and likely revenue commitment from Social and Health Care and the local Primary Care Trusts.

Helen Baker, Trustee

The Clive Project — working with others

We continue to work with Oxfordshire Health and Social Care and Oxfordshire Mental Health Care Trust locally, as well as counties in the central region, to improve the range of services for younger people. As a result of local collaborative work a multi-disciplinary network of expertise is developing, providing a resource of specialist knowledge for professionals within the county. The network members are currently developing referral protocols to clarify the otherwise painfully slow route to diagnosis experienced by the

younger person. Beyond Oxfordshire, we continued to meet up with organizations at an early stage of development to share our experience and our 'model' of support.

During the year we strengthened our work with the orchestra, Oxford Philomusica, and with local Alzheimer Society branches. These relationships have had a direct value to individuals using the service, enriching and deepening the support provided.

The Clive Project Team

Trustees

Helen Baker
Helen Beaumont (Chair)
Vaughan Billings
David Birch
Sally Bradbury
Elizabeth King
Betty Rostance (retired July 2003)
Jean Ware-Morphy

Staff

Tessa Gutteridge (Director)
Caroline Bloomfield (until February 2004)
Jill Cowland
Jill Green
Bernie Stevenson
Gill Stopps
Linda Wallis (until February 2004)
Simon Warren
Kathy Yorke
~
Karen Warner (Finance)

New staff—summer 2004

Terry Carpenter
Joanna Davis
Marilyn Finbow
Kaija Graham
Nicky Henderson
Susan Thomas
~
Sharman Oldham (Administration)

Contact details

The Clive Project, 7 Mount Pleasant, Crawley Road, Witney, Oxfordshire OX28 1JE
Tel: 01993 776295 • mail@thecliveproject.org.uk • www.thecliveproject.org.uk