

The Clive

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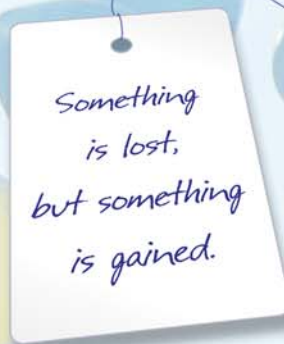
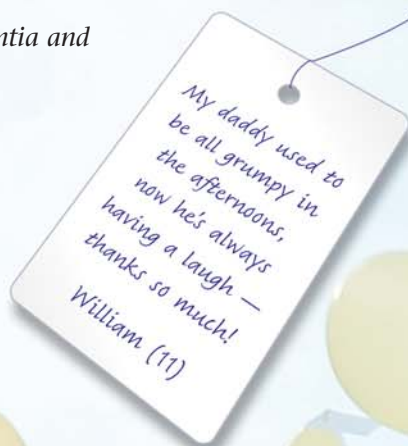
2007–2008



Celebrating 10 years supporting younger people with dementia!

For ten years the One to One Service has been bringing activity, support and fun into the lives of younger people with dementia. The relationships between support workers and members provide positive choices and respond to what people really want. Each partnership is unique, each person finds fulfilment in their own way. Everyone has a chance to enjoy their lives.

The anniversary year was marked on 1 April 2008 with a spectacular balloon launch. Every balloon carried a special message to raise awareness of early onset dementia and The Clive Project.



A message from Helen Beaumont—a Founder of The Clive Project

When Clive was diagnosed with dementia in 1993, there was little assistance available, and none of it appropriate. We were left with two small children to 'get on with it'. Clive very soon lost the ability to drive, or to read or write. His speech was limited, and his understanding of what was said more so. I had a job, and we



Clive (45) with his children in 1992

needed the money it brought in. Clive was still a very active man, with boundless energy, no job, and it was almost impossible to find ways to fill his days with activities that stimulated him and yet kept him safe. Apart from the limited time I could spare from everyday necessities, he seemed to be merely passing the time until the illness eventually killed him. We were helped when some of his past colleagues arranged to take him out for a few hours on a regular basis—an arrangement which gave us the idea for the One to One Service. Sadly Clive was never able to use the support offered by The Clive Project, but we have been able to support many others in a similar position over the past 10 years. May The Clive Project continue to thrive and grow in the future as it has in the past.

Chair's welcome

As we start the next decade of the One to One Service it provides the perfect excuse for a celebration. It also gives us an opportunity to reflect on the fantastic achievements of all those who were involved in setting up and running the service in the early days. It is thanks to their vision and determination that The Clive Project is able to reach out and enhance the lives of so many people through the One to One Service.

The work of The Clive Project has expanded every year with the introduction of new services and support groups. Whilst celebrating our

achievements it is also important to look forward to find ways to support more people and extend the length of time we are able to provide that support. We recognise that there is still much more we could be doing for younger people with dementia and their families. Reaching the 10th anniversary is not a time for complacency. There are many more challenges ahead and new opportunities for us to develop. By harnessing the energy, experience and commitment of our staff, volunteers, supporters and trustees, together we plan to achieve even more in the next ten years.

The Clive Project

More than 15,000 people in the UK are known to experience dementia between the ages of 30 and 65. There are many more who are not seen in the statistics because their dementia is part of a bigger picture such as living with Huntington's disease, Parkinson's disease or multiple sclerosis.

For younger people and their families and friends this is a devastating change to their lives. They find themselves isolated, unable to follow

their interests, unable to work, or enjoy their often young families. The financial implications are frightening. Everything they expected from the future is altered.

But this review tells another story; a story of hope, how new pleasures can be discovered, skills maintained, understanding gained, and friends and support found to live a life of choice for as long as possible.

One to One

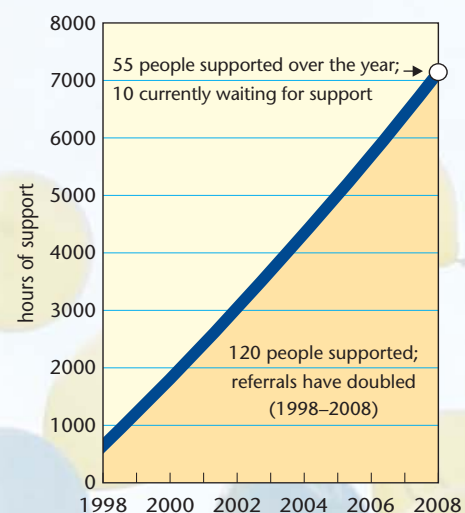


John with Kay at t

The past year has seen the One to One Service grow and develop. Fourteen trained support workers have worked alongside 55 Clive Project members, providing almost 150 hours of informed and specialist support each week. The way this time is enjoyed is as varied as the people, and adapts as their needs and wishes change over time.

Here are just a few members' achievements during the past year. Some may seem small, but mean something more significant. Imagine how it felt going into Oxford city centre for the first time in seven years, spending a morning away from home, watching England play cricket at the Oval, having a weekend in Gloucestershire, taking up photography.

Hours of support provided, 1998–2008



One to One Service



the balloon launch

Often people have found new areas of enjoyment:

'Since J developed his condition, The Clive Project has supported him in new interests. He has learned to love music and singing. When it's hard getting dressed in the morning, singing songs can get us through it. J loves horses, again introduced through The Clive Project, and he has learned to paint and now works regularly with an artist at home. The support workers have a very special way of working and always treat him with the utmost respect.' **AF, J's wife**

Plans for the future include bringing the One to One Service to more people, and earlier. The aim is to be available to people as soon as dementia is identified so that their lives can be enriched for longer.

The Project hopes to expand Life Story work by recruiting more skilled volunteers. This highly creative and enjoyable activity produces a finished story that can be used in many ways as a resource for shared family memories.

The One to One Service is looking forward to the next ten years with optimism.

'I love Wednesdays. When I get home he will be buzzing, waiting to tell me what he's done today. We'd be lost without them.' **RB**

Family and Friends Service

It's been an exciting year for the Family and Friends Service, adding a new way of working through running coffee mornings and lunches around Oxfordshire. The events are informal, small, local and 'normal'. New for 2008 are a series of themed evenings, the first one on an Italian theme complete with Pavarotti and pasta!

The service works with more than sixty families, offering practical and emotional support to partners, brothers, sisters, children and friends of younger people with dementia from diagnosis to beyond bereavement, supporting people individually and in groups, encouraging mutual support and enjoyment.

The group support happens in two ways. Exchange meetings bring Family and Friends Service members together to learn about issues important to them, for example the new Mental Capacity Act and the cost of care. The support workers also set up social occasions and gatherings.

The work with groups goes hand in hand with individual support, making sure people have the information and knowledge they need, helping them make connections and to find ways to get through the hard times and share successes and



Rita and Mark (48) at the Italian evening

achievements. The Family and Friends service has supported people through some of the most difficult times they have to face.

'You always make me laugh, it's like a tonic, I thought I'd forgotten how.' **PS**

'Without The Clive Project our 'journey' would have been almost unbearable. I would have gone under.' **SBW**

For the future, there is a need for more specialised support for Huntington's disease and for specialist skills to support young people and children who have a parent with dementia.

The Clive Project Club

The Clive Project Club brings everyone together to share in events and occasions throughout the year. This year there have been outings, a pantomime visit, the Founders' Garden Party, and a Christmas party with Irish music and dancing.

'You don't necessarily lose your ability to dance with dementia, in fact it can be enhanced as you lose inhibition. The Christmas party was brilliant.' **AE**

The events help to develop understanding and friendships between Clive Project members, staff and trustees, and trigger new ideas for the Project.

Plans for celebrating this anniversary include hosting a 'Question Time' event about issues relating to dementia, with a panel of experts

answering questions from the audience. The events will be fun and informative, and will address needs to be highlighted in the first ever National Dementia Strategy published in 2008.



The Founders' Garden Party

Clive Homes

For eight years The Clive Project has worked towards designing and developing a place where younger people with dementia can stay for short breaks, or live on a long-term basis. There is no doubt about the need for this facility—nationally only 20 per cent of care beds needed for younger people with dementia are in place.

The Clive Project formed a partnership with Heathfield House, a private care home in Oxfordshire, and with an architect they produced a beautiful, innovative design. A covered atrium incorporates cottage communities, water features, an activity centre and, vitally, internal and

external walkways which never reach an end. Gardens and natural light complete the atmosphere, and all under a grass roof to fit in with the surrounding countryside. Space will be provided for five people to go for short breaks, and 20 to live long term.

This year the dream has taken a huge leap towards reality. Oxfordshire County Council, Oxfordshire Primary Care Trust and Oxfordshire and Buckinghamshire Mental Healthcare Foundation Trust all gave their support, and the planning authorities gave approval at the end of March 2008.

Networking with others

The Clive Project continues to nurture good working relationships with Oxfordshire's statutory and voluntary organisations. Strong links with the local and regional Alzheimer's Society, Huntington Disease Association, and the county's Carers' Centres work well for Clive Project members and are the foundation for planned collaborations. Oxfordshire's Early Onset Dementia

Network, a multidisciplinary group of professionals, is focusing on defining a clear care pathway for younger people with dementia. This Network, with the planned growth of The Clive Project, should ensure that early onset dementia is a prominent part of local health and social care plans as the first National Dementia Strategy is launched.

A note from Val Wilson

I was asked to help co-ordinate this Annual Review for The Clive Project and have enjoyed so much learning about what the Project does and meeting the people involved.

As a development worker in mental health in Oxfordshire for eighteen years, I've seen statutory and voluntary services at all stages of their growth. There is a

difficult balance to be found between providing flexible services with warmth and humanity, and establishing an efficient, effective, strong organisation.

Being involved with this Review has given me insight into a group of people who I think have the balance just right—The Clive Project.

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Trustees (2007–2008): Alison Talbot (Chair), Vaughan Billings (Treasurer), Alison Blight, Elizabeth King, Helen Mann (resigned January 2008), Graham Shaw, Jean Ware-Morphy • **Founders:** Helen Baker, Helen Beaumont, David Birch, Betty Rostance • **Director:** Tessa Gutteridge

One to One Service: Anna Eden (Co-ordinator), Linda Ambler, Marianne Ballantyne, Sarah Bishop, Terry Carpenter, Jill Cowland, Jill Crowther, Jo Davies, Alex Evers, Marilyn Finbow, Kaija Graham, Nicky Henderson, Ronnie Jones, Kay Maguire, Lyne Richards, Bernie Stevenson, Gill Stopps, Simon Warren

Family and Friends Service: Sue Hosty, Diana Letchford, June Smith • **Life Story Volunteer:** Rachel Irven

Administration: Sharman Oldham • **Finance:** Karen Warner