



NEWSLETTER

January 2007

'Family isn't about whose blood you have. It's about who you care about.' Trey Parker & Matt Stone (South Park 1998)

The Clive Project
7 Mount Pleasant, Crawley Road, Witney, Oxfordshire OX28 1JE
Tel: 01993 776295
www.thecliveproject.org.uk
Registered Charity 1085595

From the Editor

Happy New Year, everyone. It seems a long time since the holiday, but I hope you all had a good time. The newsletter this time is so full that we have had to print the diary separately. I won't suggest you keep it somewhere safe, as for me that is a certain way of losing it, but keep it somewhere in view, as there are also a lot of events coming up.

Excellent news from Tessa inside, and I hope she will be back with us very soon. She must be feeling well, as she hosted her extended family Christmas lunch – something I have never been prepared to offer. Tessa is probably a better cook than I am.

I have been busy spreading The Clive Project ideas to other areas. Both Sutton and Ealing are hoping to set up services specifically for people with early onset dementia. It was very encouraging to see the numbers of people there, and the enthusiasm they all have to change things for the better. At one talk I met someone whose family is doubly affected by early onset dementia: she nursed her husband some time ago, and is now caring for her daughter. My heart went out to her as she put up a plea for a service that could stimulate her daughter, and use the abilities she still has. All that was offered seemed to be similar to “baby-sitting” – keeping the daughter safe, but with no thought of any activity other than sitting inside watching TV!

I also got up far too early one morning to go to a meeting in York with a group who are hoping to develop tools to see how “person-centered” the care offered by a nursing home or day centre really is. It seemed to me to be a very difficult task, but again those concerned had lots of good ideas, and I think will generate something worthwhile. It's horrible jargon, but “person-centered” is the essence of The Clive Project. While it is easy to say, it is not so easy to do!

All the best to you all, and I wish you a very happy 2007,
Helen Beaumont

Direct Line – News from the Director

Our Clive Project Newsletter, the first of 2007, provides a lovely way for me to say 'hello' to every Clive Project member and 'thanks' to all those who have been in touch with me. I have been through some ups and downs in the past few months since being diagnosed with cancer in August and your continuing contact and support has really lifted my spirits.

Having had some good news and hard evidence from scans that the dreaded chemotherapy was actually doing its job and I was improving in health, I had a really magical Christmas. It felt very special I must say, and I guess thoroughly enjoying whatever is happening today, celebration or not, is one lesson I really hope I can take through my life.

My colleagues are keeping me in regular touch with Clive Project news but I cannot join in the socials because of the chemo. However, I'm sending my warm wishes for a good 'do' each time. Although I am taking a break from work, I do miss the camaraderie and stimulation of work and look forward to life returning to normal for me, with Clive Project people resuming their important part in my life.

I was initially surprised to be having so much 'leisure' time but have adapted pretty well and am enjoying cooking, reading, chatting and even watching daytime TV! (I am developing an obsession with cookery programmes). I even found myself happily tackling a jigsaw the other day - how life changes! Strangely, I have not ever quite had time for cleaning windows ...



So, life and health is improving and I am hoping late Spring will see me fit and well and raring to go again.

In the meantime, may I wish you all well for the rest of 2007.

Tessa

One to One Service

As I write this, Christmas is just around the corner and everyone seems to be rushing around trying to get the last bits and pieces finished before the break. As you read this, it will be well into the New Year and the days will be getting longer at last.

It will soon be the time when I will have experienced a full year in the life of The Clive Project and feel fully immersed! The Christmas party was definitely a highlight and such a lovely opportunity to meet new faces, greet old friends and see some fantastic tricks performed by the magician (how did he do it???). I loved the carol singing too.

Update

The One to One service has been going from strength to strength. We are now supporting over 40 people and offering 57 sessions each week. Activities include walking, riding, swimming and playing pool, visiting galleries, art exhibitions, tourist sites and stately homes, going to open gardens, garden centres and doing gardening or other DIY at home, feeding the ducks, attending football matches, going shopping and of course stopping for tea and cakes!

As always support workers try to ensure that each person they support does something that they particularly enjoy. Nearly all the feedback I receive is that both have a very positive time together.

Training

Being a support worker however is not always easy and providing on-going training is essential if the One to One service is to work well. Over the past three months support workers have attended the Alzheimer's Society Annual Conference on Younger People with Dementia, an evening with Hugh Ellis – who focused on working with vulnerable adults, a day on Huntington's Disease as well as a training day on Life Story Work. All support workers have up to date first aid training and in the New Year we will be looking at further training on Huntington's disease, loss and bereavement, epilepsy and Downs Syndrome.

Anna

Family & Friends Service

A quick summary

Five new people have been introduced to the service recently. In addition, twenty eight individuals or families receive regular support, twenty nine receive occasional support, and two have left the service in the last three months. As you can see it has been a busy time.

Recent events

Last November we held our Annual Lecture on the subject of 'Laughter and its Benefits for Health' – a slightly different topic to past events. At the last minute, Kit Hammond from Wellbeing Services, bravely agreed to come and talk to us as Simon Sholl, our planned 'laughter' speaker, was unable attend. Kit talked about, and indeed demonstrated, how laughter really can be good medicine. Those of us brave enough joined in by miming some of our hobbies. Vaughan undoubtedly created the loudest laughter and left us in no doubt how he has spent his most enjoyable moments! The venue was The Oxford Spires Four Pillars Hotel, where they made us all welcome and we hope everyone left feeling light-hearted.

We continue to link with the Isis Lunch Group and we hear that three very young ladies provided some lively entertainment this Christmas!

Coming Up

Check the Diary insert in this newsletter for forthcoming events, including a reminder of the Exchange meetings. We have tried to organise these according to requests made in the questionnaires sent out last summer. Invitations will be sent to you prior to each event, which we hope will reflect your interests adequately. Please do contact us with any new ideas or comments at any time and we will try our best to provide something especially for you!

Thank you for all the help and support you have given us by turning out on dark cold evenings, welcoming new members and sharing your experiences, expertise and enthusiasm with them.

Looking forward to a great 2007 and sending you all good wishes,

Sue, Diana and June

Contact the Family and Friends Service by phone or email:

Diana (North Oxfordshire) Tel: 01993 891955 (Mon, Weds, Thurs)
Email: dianaletchford@theliveproject.org.uk

Sue (South Oxfordshire) Tel: 01865 821699 (Tues, Wed, Thurs)
Email: suehosty@theliveproject.org.uk



Clive Project Club

There was a great turnout for the Christmas party at Cassington Village Hall, where members, staff and trustees met for some supper, magical entertainment from James Bryan – who fooled us all with his ‘close-up’ magic – a raffle, and a rousing finale of Christmas carols. Thank you to all who contributed their food, chat, laughter and singing, as well as those who donated raffle prizes, and helped to set up and clear away at the hall.

Twenty-one people went to see ‘Cats’, at the New Theatre in Oxford, which I hear was an excellent show. We plan further social and cultural outings over the coming months, so watch your postbox for invitations!

SO

The Clive Project Follow On Group

It is a year since the formation of the Clive Project Follow On Group. The original group of three has increased to fourteen and new members are warmly welcomed. The initiative for the formation of the group arose to give support to one another after cared-for loved ones entered nursing homes or had sadly passed away. We often wish to discuss issues which are considered inappropriate or too sensitive for home-caring Clive Project members who are at a different stage in their caring.

The group meets at 1.15pm, on the third Monday of each month. Our venue is The Turnpike Public House, beside the Yarnton roundabout on the A44 Woodstock to Oxford road. For further information contact Sheila Bailey- Watts on 01869 345 505.

SB-W

Staff Profiles: Jo Davies and Kay Maguire introduce themselves

**Finding sunshine – even on a cloudy day
by Jo Davies, One to One Support Worker**

I think I am incredibly lucky to be working for The Clive Project. I was really surprised when Tess called me to say I was on board and I haven't looked back since.

I work with three very different people, all of whom are marvelous to know and who brave their situations with dignity, humour and the strong resolve to simply be allowed to 'get on with their lives'. We share great adventures together doing the things we love doing!!! From visiting the gorgeous Charlie (a horse!!!) to trips to the Brecon Beacons, White Horse Hill, Prinknash Abbey and hopefully to the seaside (soon), to 'makeovers' in Boots and trips to the theatre, pub grub and picnics. We look for and often find sunshine, even on cloudy days and it is my privilege to work with such lovely people. I hope that we will continue to get joy from one another's company for a long time.

I live in Hook Norton in an old cottage with a leaky toilet roof, surrounded by fields and sky. I feed 12 doves who visit me every morning for their breakfast and who are becoming more and more friendly. We also have 2 woodpeckers and a kestrel regularly saying hello.

In my spare time I occasionally see my 14 year old son Reuben, who lives in his bedroom! I play the guitar and sing in a jazz band along with my husband, who is a violinist. I also enjoy painting large pictures, but have become rather lazy recently, which could be due to tying the knot with Dave last June!

I am a big fan of the great outdoors and love walking, sitting in the sunshine and having bonfires in the garden. So roll on Summer!

All the best,
Jo.



My dog chews doorframes! by Kay Maguire, One to One Support Worker

Hi. My name is Kay Maguire. I'm married, with three children, three grandchildren and two dogs – including a rescue dog who loves to chew doorframes! I enjoy walking, exploring new and favourite places, gardening and socialising. I enjoy talking and listening – though those who know me might say I do more of the first than the second!



After many years working for a major bank, I decided I needed a change and eventually found myself working at a local residential home for people with challenging behaviour, learning and physical disabilities. It was a dramatic change from what I was used to, but once I had settled in I knew I could never work in an office again! I juggled family commitments around the shifts for about three years, before moving to work for Day Services – again helping people with learning difficulties/challenging behaviour, but this time based in the community. I gave one-to-one support to two people who had little or no speech, but despite this we had lots of laughs.

For a while, I gave up work to help out with my grandchildren, but once they no longer needed me quite so much I began looking for a new job. When I saw the CP job and found out a bit more about the Project, I thought it was a fantastic service and could be just the job for me. I kept everything crossed at the interview and was delighted to become part of The Clive Project. My mother-in-law has vascular dementia, so I have some knowledge of the effects dementia can have on individuals and their families.

Since joining the CP I have met some wonderful people and got to know their likes and dislikes. I have experienced the loss of one special lady. Despite speech having become difficult for her we shared lots of fun and laughter. I can only thank her lovely family for letting me be a part of her life for a short time.

I hope The Clive Project will continue to grow as there is such a need for its services among those with dementia and their families.

See you soon,
Kay

Trustee Profile

What a difference The Clive Project's work makes

by Helen Mann



I was delighted to join the Board of The Clive Project as a Trustee last Summer, as I know from personal experience what a difference its work makes.

I first came into contact with the Project about five years ago, when my late husband Roger and I were managing at home following the diagnosis of his early-onset dementia. The One-to-One Service played an important part in retaining his independence for as long as possible and gave me sound practical advice that helped me to deal with the everyday things that were becoming increasingly difficult for us.

I have previously served as Trustee on the board of the Oxford Playhouse and am Secretary to the Trustees of another charity - the Oxford Colleges' Admissions Office. My professional background is in communications and Public Relations; for the past seven years I have worked at the University of Oxford, where I am currently in charge of undergraduate admissions. Over the next nine months I will gradually be transferring from part-time work and part-time study, to become a full-time DPhil student in the University's Department of Educational Studies, where I am examining aspects of higher education management.

I look forward to meeting and working with all the many friends and supporters of The Clive Project, as we take forward new projects such as the proposed Clive Home.

With best wishes,
Helen

Life Story Work – a brief introduction

Jean Ware-Morphy explains what Life Story work can bring to anyone affected by dementia.

In The Clive project we have been considering Life Story work for some time; it is a really enjoyable and creative idea. We would like to see everyone using our service offered this as a matter of course and are considering how to achieve this in the future. Meanwhile it has been used very successfully by one to one support workers and is occasionally offered on an individual basis when resources are available.

The benefits for all involved in this work are considerable, from the pleasure we all get when given the opportunity to talk about our life and think about the bits we might want to record in some way, to the usefulness of having available something that says important things about you when maybe you are not so able to say them yourself.

It involves sitting down with someone and listening to their story. This is not always easy as some parts of any life will be sad or even frightening, but often people appreciate the opportunity to talk and experience emotional reactions which are very normal – as are the inevitable laughter and remembering of good times.

People choose different ways to record their stories: photographs, poems, newspaper cuttings, holiday snaps, baby paraphernalia, songs, stories, and the dreaded school reports sometimes surface. It can be recorded in different forms, not just in a book but maybe a photo montage or video recording, or a pin board kept close and up to date. Everyone is different and can choose what they want recorded and how they want to tell their story. It may be entirely in their own words, describing what is important in their life. Accuracy, dates and facts do not take centre stage; that is taken with what the person feels is important to them. I know one woman who told wonderful stories and that was what she wanted to record and leave to her children and grandchildren.

We all have precious memories which reflect and remind us of the past and present, and which colour our future; anything we can do to sustain and use these to help us in life has to be worthwhile.

We will keep you informed about future developments and if any one has a special interest in Life Story work I would love to hear from you.

J W-M

... and support worker Reuben endorses the value of such work following his recent training in Life Story work.

Life Story workshop – November 2006

Thanks to Charlie Murphy and all who organised the life-story workshop, because since attending it I have had the very great pleasure of doing some life story work with one of The Clive's clients, and now realise first-hand what a significant place such work deserves in dementia care.

I had long wanted to get my teeth into doing this work, and found the workshop was just the inspiration I needed to actually knuckle down. I found myself freed up by it. I don't think it matters *how* one gathers a person's reminiscences, but just that they are gathered and then actually *used*. If a person has lost the ability to retrieve or communicate their memories, how can they otherwise communicate their essential self to those who might be meeting for the first time? We at the Clive get to know people over quite long periods of time, and are in a unique and privileged position to help record such memories before they are gone. This is not an exercise in storytelling though; rather it is a strong manifestation of the dignity of the person with dementia, and should be handled (as well the workshop discussed) with care and joy combined. If a man without his words can instead call upon a book, a drawing, a collection of sounds or scents to illustrate the many and interesting facets of their life, how dignified a thing it is to help them do so!

RP

Alzheimers' Society National Conference for Younger People with Dementia.

CP member Sheila Glen and Founder member Helen Beaumont give us their thoughts on the conference. First-time delegate Sheila writes ...

In November I was privileged to attend The Alzheimers' Society National Conference for Younger People with Dementia. There were more than two hundred delegates most of whom were support workers but people with dementia and their carers were also welcomed – and attended free of charge.

This year the conference was hosted by The Clive Project and took the theme 'working together in partnership'.

There was one outstanding presentation by Ross Campbell. His subject was "Involving younger people with dementia in service development". His delivery was both lively and at times hesitant, and it was only after a while that I realised that he and his colleague, Ilsa MacFarlane, have both had dementia for some years. Instead of giving in to their problems they are actively involved with the Scottish Dementia Working Group.

Other presentations were entitled "Working across boundaries for better support", "Local partnerships: linking successfully with existing resources" and "Partners in care – being together with dementia". The text of these presentations can be found on:

http://www.alzheimers.org.uk/Younger_People_with_Dementia/NationalConferences/

At coffee time I looked at the beautifully displayed photography exhibition produced by Judie and our Clive Project members. I was intrigued by both the photographic skills and also the wonderfully sensitive way in which the photographs represent the core interests and lives of the photographers.

The facilities and organisation were impressive and lunch was well presented and tasty, and the attractive restaurant buzzed with eager

chat. I joined some of our Clive Project delegates and it was great to be able to exchange ideas and impressions of the conference.

We also had access to two of a choice of six seminar sessions and I had chosen "Supporting the children of younger people with dementia" which consisted of the summary of a psychologist's research paper and a brain storming session drawing on our own experiences. I also attended "Online networks: Talking Point and Alzheimers' Forum". This introduced me to these helpful online chatrooms, accessed through the AS website - well worth a look.

My overall impression was of a very friendly atmosphere and a very positive approach to living alongside dementia as opposed to battling against it, and I came away with a more informed and optimistic attitude. If the opportunity arises in the future I would recommend other Clive Project members to attend.

SG

And veteran delegate Helen's verdict ...

Last year this conference was in Liverpool, and I gave a seminar on The Clive Project. This year it was much closer to home, in Oxford, and ably chaired by Alison, Clive Project Chair.

The first talk was inspirational. Two people from the Scottish Dementia Working Group, both with dementia themselves, talked about the group's activities. Their campaigning has taken them to the Houses of Parliament and abroad to spread their message that people with dementia should be involved in decisions about their future. However, the group also has a very active social life, and it was obvious how much everyone gained from being part of the group. Perhaps we could steal some of their good ideas?

I found the second presentation more mundane. Julia Thompson from CSIP, a new government body, talked about the lack of communication among the various groups that should take responsibility for diagnosing and providing treatment and care for younger people with dementia. She described the problems of groups protecting their budgets; of not knowing about the work of others, and of how people with dementia can fall between the gaps of what should be a seamless service. Unfortunately she had no definite proposals for how to change this.

Still, at least the intention is there at a high level, and maybe things will improve.

By chance, I also went to the seminars on online support for people with dementia and their families, and supporting the children of younger people with dementia. There has been much talk in The Clive Project about starting some form of on-line support, and I am sure we will be able to start a forum in the near future. A chat room, where you can log on and type messages to other people in real time, is probably not possible until we have a certain number of users. Imagine going into a cafe to meet some friends, and never finding anyone there! The seminar on supporting children reported on research by Jacqui Allen and Jo Allen. This is obviously a difficult topic to research, but they had some interesting stories to tell. However, their suggestions for what support was necessary were very much in line with those from The Clive Project's October consultation evening.

The final presentations were from projects in Suffolk and Surrey providing activities for younger people with dementia.

The conference was attended by about 200 people, with some late applications having to be turned away. It was a very enjoyable and interesting day, where I got the opportunity to meet some old friends, but also saw many new faces.

HB



The Clive Project Library

In case you don't know, our Library items – books, leaflets, and the odd video are usually available at Exchange meetings. You may borrow items freely to take home, but please return them once you have finished with them so that they are available for others to use. A complete list of the resources is included in the library box which is brought to Exchange meetings.

If you'd like to recommend a book for the library, or to review something you've seen, contact Sharman for more information (01235 763968).



Photography Update

Although the space allocated to us at The Oxford Hotel could not match the wonderful setting of the Jacqueline de Pre Concert Hall last May, it was great to re-stage the exhibition of CP photographs for the Alzheimer's Society National Conference for Younger People, in Oxford, in November. There was much interest and admiration for the works themselves, which were seen by virtually all of the 200+ delegates who attended the conference. In addition, many delegates took away literature about The Clive Project, and some took donation forms too. A result on all fronts, don't you think?

I have observed what a powerful tool these works can be for conveying the interests, feelings and vitality of those with early onset dementia, so, with the permission of those involved, I am more than happy to re-stage it at other suitable venues (corporate events, conferences, arts events etc) in return for charitable donations. If such a request comes along, I will contact you individually about using your work. Meanwhile, I am sorry to have missed seeing you at the Christmas party, but look forward to catching up with you during 2007.

Happy New Year and very best wishes,
Judie.

Readers' letters, contributions and suggestions

Thanks this time to Sheila Glen for sharing her thoughts about the AS conference. Perhaps reading her report, and letters in past editions from members reporting on social events, you feel you could contribute some news, views or ideas for the next newsletter. Don't be shy! No matter how short, we'd love to have your thoughts, so send them to:

Sharman Oldham, 39 Palmers, Wantage, Oxon OX12 7HA, or email them to sharmanoldham@thecliveproject.org.uk.

Copy deadline for the next newsletter is Friday 30th March.

Diary Dates

CONFIRMED EVENTS:

Weds 21 February 7-9.00pm – Family & Friends Service Exchange meeting: Elizabeth King of The Clive Project will talk about the work of OPTIMA, at the *United Reformed Church Hall, Cumnor*.

Mon 5 March 2pm - Concert by professional musicians from The Orchestra of St John, at the *Jacqueline du Pre Concert Hall, Oxford*.
Invitations to follow.

Weds 21 March 7-9.00pm – Family & Friends Service Exchange Meeting: Dr Hugh Series, consultant psychiatrist, will talk about the diagnosis of dementia, at the *United Reformed Church Hall, Cumnor*.

Mon 2 April – Deadline for contributions for next edition of the Newsletter!

Weds 18 April 7-9.00pm – Friends & Family Service Exchange meeting: ‘Benefits and the work of the carers’ centres’, at the *United Reformed Church Hall, Cumnor*.

Weds 23 May 7-9.00pm – Friends & Family Service Exchange social: ‘Bring & Share’ supper and open meeting, at the *United Reformed Church Hall, Cumnor*.

WATCH OUT FOR FURTHER INFORMATION:

April/May – Clive Project Club social event, details to be confirmed.
Invitations to follow.

Diary Dates

CONFIRMED EVENTS:

Weds 21 February 7-9.00pm – Family & Friends Service Exchange meeting: Elizabeth King of The Clive Project will talk about the work of OPTIMA, *at the United Reformed Church Hall, Cumnor.*

Mon 5 March 2pm - Concert by professional musicians from The Orchestra of St John, *at the Jacqueline du Pre Concert Hall, Oxford.*
Invitations to follow.

Weds 21 March 7-9.00pm – Family & Friends Service Exchange Meeting: Dr Hugh Series, consultant psychiatrist, will talk about the diagnosis of dementia, *at the United Reformed Church Hall, Cumnor.*

Mon 2 April – Deadline for contributions for next edition of the Newsletter!

Weds 18 April 7-9.00pm – Friends & Family Service Exchange meeting: ‘Benefits and the work of the carers’ centres’, *at the United Reformed Church Hall, Cumnor.*

Weds 23 May 7-9.00pm – Friends & Family Service Exchange social: ‘Bring & Share’ supper and open meeting, *at the United Reformed Church Hall, Cumnor.*

WATCH OUT FOR FURTHER INFORMATION:

April/May – Clive Project Club social event, details to be confirmed.
Invitations to follow.