

May 2006

*'Friendship makes prosperity shine more and lessens adversity
by dividing and sharing it.'*
Cicero on 'Friendship' 44BC

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From the Editor

Spring is here at last, and it's time for another newsletter. Am I alone in thinking that this has been one of the longest and most miserable winters for a long time? However, the sunshine has arrived at last, the lawn needs cutting again, and it's time for me to stop hibernating. Sorry I haven't seen many of you recently – I've been very busy with work and other commitments. Fortunately the rest of The Clive Project team has been much more active, with new One-to-One support workers, a new Family & Friends support worker, and new trustees. I did get the chance to meet many of these at a training session, and I'm sure they will help maintain the excellent service the charity provides.

The long-awaited report into “Services for younger people with Alzheimer's disease and other dementias”, published by the Royal College of Psychiatrists and the Alzheimer's Society was published in March. For those of you with internet access, the web address is www.rcpsych.ac.uk/publications/collegereports/cr/cr135.aspx and for others there will be a copy in the public library. This is official policy on the services that ought to be provided for younger people with dementia, and it is very clear on the need for specialised services from diagnosis onwards.

I am looking forward to seeing the exhibition that Judie Waldman has put together after working with Clive Project members. This is part of the Oxfordshire Art Weeks festival, and you should have received your invitation to a special Clive Project viewing. Hope to see some of you there. If you can't make the special viewing, the exhibition is open to the public until 4th June.

Helen Beaumont

One to One Service

Latest news

We were really fortunate to bring in five new support workers, rather than the four we originally planned, and of course, a co-ordinator for the service too. Anna Eden takes on this new role. It is very reassuring to know that the service can continue to grow, as it needs to, with Anna at the helm. More from Anna in this newsletter, and from Kay Maguire, Nicola Brunwin, Linda Ambler, Alex Evers (returned to work for us from Australia) and Reuben Purchase in later editions. They have just completed the induction programme and you will meet them at future events and perhaps individually too.

Do you realise that ours is the largest support team for early onset dementia in the UK?

For those of you who like to know the numbers: we shared 6000 hours of individual visits with you in the last twelve months and plan to offer 7000 in the next.

We are just introducing ourselves to several people who are new to the One to One service, and hope to partner around 50-55 people across the county very shortly.

As always, do say if there is anything we can do to improve what we do, or if you are uncertain about the service and how it works. We want to do our best for you.

Anna will keep you up-to-date on the One to One Service in the next edition of the Newsletter

What's Happening

Coffee and chat: Kaija hosted the May coffee morning for members of the One to One Service. Just a reminder that these are relaxed opportunities to meet up for coffee, cake and a bit of a chat, so watch out for future dates.

TG

Artweeks 2006

By the time you read this, I hope lots of you will have had a chance to visit the exhibition staged by Judie Waldmann which features the wonderful work of some keen Clive Project photographers. Our Private View is on 26 May, but the exhibition remains open at the Jacqueline du Pre Concert Hall in St Hilda's College, Oxford, until Saturday 4th June.

***** See Judie Waldemann's update on page 9 .*****

TG



Fundraising

Our outgoings for the next financial year are around £250,000, and we need to raise about £60,000-£70,000 during the year. I am sure we can achieve part of this through requests to Charitable Trusts. However they do like to see local support too, and our case to them would certainly be strengthened through the involvement of CP members and local people in our fundraising. Any help through small events or leads to fundraising opportunities would be welcomed.

TG

New Trustee

Graham Shaw, from Dorchester-on-Thames, is joining us as Trustee in July 2006. He brings with him a wealth of experience as a company MD and charity supporter.

New Family & Friends support worker

We are also delighted to welcome Sue Hosty as our new Family & Friends support worker. Sue will be settling into her new post in June, but may well have met some of you before then, during her handover from June Smith at the end of May.

TG



Family & Friends Service

Over recent months we have continued to see many of you on a regular basis, sometimes individually and often at social events. Recent events have included learning about lifting and handling, as well as socials - the Bring & Share Supper and the Eastern supper at Benson. Members of the ISIS group joined us at Benson and everyone seemed to enjoy the musical entertainment provided by Millennium Two. Music, food and the chance to chat in a relaxed atmosphere seem to be a successful combination when it comes to helping people unwind and make friends.

Events planned for the next three months include: the Exchange meetings on Financing Care, Relaxation Therapies, and an Open Meeting for mutual support; as well as a barbeque in July. Check the Diary dates at the back of the Newsletter for dates and times. At the time of writing, we are preparing for the second Carer's Conference (organised jointly by Age Concern and ourselves) on Friday 12 May.

But I can't write this Family and Friends update without talking about June, who, as many of you will know, is sadly scaling back her involvement with The Clive Project for family reasons. It seems impossible that June and I started the Family and Friends Support Service a year ago, on April 7th 2005 in fact. Looking back in my diary we had a three week induction period, and lots of support from Elizabeth King and Tessa to get started in our new role. We met VB and SB who shared their stories with us and all the 1 to 1 support team greeted us so warmly at our first team meeting.

We were slightly apprehensive, and excited of course, but I knew I was sharing the experience with someone special. June has been a perfect partner. She has a wonderful sense of humour, she is kind, thoughtful and always there, no matter what the problem. She has been delightful to work with and to know as a friend. I have learned so much from her that will stay with me.

As the Family & Friends service moves into its second year, we welcome Sue Hosty on board to help us develop the service according to your responses to the recent questionnaire. Sue will be covering South Oxfordshire and is looking forward to meeting many of you over the coming weeks.

DL

Family and Friends Exchange Meetings Questionnaire.

We are gathering lots of valuable information as your forms are returned. Thank you all so much for finding the time to share your ideas and comments with us.

As we collate the information, we hope to tailor the service to meet as many of your needs and interests as possible.

JS & DL

Exchange Programme

Massage Therapy provided a real 'hands on' meeting – 11th May.

Helen Bloomfield demonstrated hand, neck and head massage at The Coach House in the county museum at Woodstock.

We experienced how to give and receive massage therapy, learnt the benefits, tried some of the skills and felt a real sense of well being. The laughter and the company helped of course but Helen's expertise and enthusiasm rippled through the group. She has offered to extend her knowledge to massage, relaxation and meditation at our family and friends 'Learning Together' workshop on 21st July at the United Reformed Church Hall, in Cumnor.

Thanks go to Helen for giving us such an enjoyable evening and to every one who came to sample the therapy – it was such an enjoyable evening.

JS & DL



An 'Eastern' Supper at Benson

On March 9th June and I planned a social evening around a supper which had a hint of "Eastern Flavour" with entertainment from Diane and Ian Woods - The Millennium Two. We extended our invitation to the Isis Lunch Club, as we have shared so many gastronomic delights and enjoyable entertainments with them over the past few months. We have grown to enjoy their company and the friendships we have made at their social events.

It was a lively evening of dancing and singing with an abundance of laughter enjoyed by all. Vaughan and Sharman entertained us in the kitchen which made light of the catering, Sheila Bailey-Watts helped with the preparations while Veta and Jill contributed to the laughter! Thank you all for coming and to the Isis group for joining us. We look forward to future events.

JS & DL

PLEASE NOTE:

*****Change of Venue*****

Please note that the Exchange meeting for Thursday 8th June will now be held at The Coach House Room, at The Oxfordshire County Museum, in Woodstock. The museum is signposted on the brown tourist signs once you get into Woodstock, and parking is either on the street outside the museum, or in the public car park, a short walk away. The meeting is for supper and a chinwag.

ISIS Group Links

The next two dates we have for ISIS lunches are on Friday 2nd June, and Friday 22nd September. Please contact Meg Barbour (Tel: 01865 872433) for further information, as she may change the venue to avoid people having to negotiate the major roadworks at the Headington roundabout on their way to the usual venue at the United Reformed Church Hall in Risinghurst.

Contact the Family and Friends Service by phone or email:

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

Sue (South Oxfordshire) Tel: 01865 821699 (from 7th June 2006)



Pictures at an Exhibition: the big day is here!

After all the hard work, at long last the Exhibition of our photographs comes together this month, from 13th May-4th June at the Jacqueline du Pre Music Building, in Oxford. It is part of Artweeks and the Music Building is a named Special Venue.

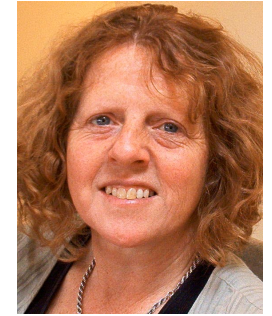
The Clive Project Private View is on Friday 26th May at 10-30 am until 12. I am really looking forward to seeing you then or maybe earlier in the Exhibition as well! In addition to our photographs there will be some 3D pieces and a short video. The latter can only be shown at weekends for practical reasons.

I am hoping that the general public , who do not know much about memory loss or about The Clive Project, will find the Exhibition informative and stimulating.

Many, many thanks to all of you who made this project possible.

With very best wishes,
Judie

A letter from Anna Eden
One to One Service Co-Ordinator



Hello, I have recently joined The Clive Project as the One to One Service Co-ordinator and thought that I should introduce myself to you.

I have lived in Oxford for the past 15 years. For 11 of them I co-ordinated support for people living with HIV/AIDS for The Terrence Higgins Trust. I then had the opportunity to work in East Africa developing HIV related training programmes. This meant that I spent almost 6 months of each year abroad but while it was a fantastic experience, it was fairly disruptive to my ordinary life. So I was delighted to be offered the job at The Clive Project and to be able to settle down again in Oxfordshire.

Although HIV and dementia are very different illnesses, I have already begun to see many similarities in the difficulties people face. I have particularly noticed the uncertainty about the future and the way in which those affected have to deal with so many different people from health, social and voluntary services. But perhaps more than anything, I am becoming aware of the isolation that many people experience when support from friends or family falls away. I know that The Clive Project makes a real difference to this and I am very pleased to be part of it.

As the moment it feels a rather daunting task to get to know all the people connected with the Project, but everyone I have met has been so warm and friendly that I know that I will really enjoy it. Many thanks for making me so welcome!

Anna

01865 794311

annaeden@thecliveproject.org.uk

Staff Profile:

Marilyn Finbow tells us how she came to The Clive Project



Before moving to Oxfordshire, I lived in Essex and worked as a one to one support assistant at an East London school, giving support to two boys with behaviour problems – very bad behaviour problems!

When interviewed for The Clive Project I was advised that the job could be very stressful. Yes, maybe, but I think working one to one with the two boys (who I kept in contact with, while living there, until they left school) was far more stressful – and not so enjoyable as working for The Clive Project.

I had some experience of dementia, having looked after a number of relatives with dementia over the years, all of them over 70 years old, but I didn't realise dementia happened to younger people until my sister-in-law was diagnosed with it at the age of 50, so it came as quite a shock.

Since working for The Clive Project many people I have met have reminded me of my sister-in-law – intelligent, loving people, who have had very responsible jobs. Each Clive Project member I support has been very special in their own way – all completely different, all with different needs and quite different personalities. I spend my time doing such a mixture of things with them. Some like to take long walks, others like horseriding or gardening. I have also done quite a lot of DIY, from painting and tiling to even fitting a toilet seat – that job really left me flushed with success! (Sorry for the deadpan humour, but just think of the people I support – they put up with it for three hours at a time!)

I mustn't forget The Clive Project team too, who are wonderful people to work with. They are very special – kind, helpful and very interesting people. So you can see that the variety of activities and people I work with make it enjoyable and rewarding to be a part of The Clive Project.

Marilyn Finbow
April 2006

June Smith reflects on her work with the Family & Friends Service

I find that changing personal circumstances dictate that I need to greatly reduce my involvement with The Clive Project. However, I do hope to help out at social events from time to time so I hope I will still see some of you. I will also be continuing to support one family in the North of the county.

*While I have been preparing to hand over to the new Family & Friends support worker, I have been thinking about my work with all of you and I would just like to say how lucky I feel to have been part of The Clive Project. Thank you for welcoming me into your homes and giving me the opportunity to support you where I could. I cannot tell you how much I have been touched by the courage and fortitude I have seen and by the ability to cope with things day after day **and** to still laugh and show concern for others. This is something that will always be with me.*

I hope I will see many of you again but for now may I wish you all well in the future.

With best wishes,

June

The Clive Project Follow On Group

Mistakenly called the 'Carry On Group' in the last newsletter, the **Follow On Group** is continuing to meet and share experiences among those whose loved ones are now in nursing care, or have passed away. The meetings are informal and usually held at The Turnpike Inn, in Woodstock Road, Yarnton, near Oxford. Do contact Sheila Bailey-Watts for further information or the next date/venue, on: 01869 345505.

SB-W

Oxfordshire Early Onset Dementia Network

I am not sure if I have mentioned this Network before. In a few areas of the UK, there are specialist multi-disciplinary health and social service teams offering all-round, well-co-ordinated support to people with early onset dementia, and their families. Included in those teams would be a consultant psychiatrist, a psychologist, community psychiatric nurses, social workers, occupational therapists, sometimes support workers (sometimes using the CP model), and allocated time from other health professionals. In Oxfordshire, we have a 'virtual' version of this, with The Clive Project as an integral part of the team. The aim of the Network is to act as a knowledgeable resource for professionals who may otherwise find themselves working in this area but without having had the opportunity to build up experience in the field. The relative rarity of experiencing dementia in younger and middle years means that GPs, for example, may only have knowledge of one person, throughout their career.

We are hoping that the 'virtual' team may convert into a specialist countywide team who concentrate on offering the kind of well co-ordinated health and social input that you have asked for over a period of time.

The various shiftings in the local and regional statutory services which you have heard about through the media may actually create this opportunity with your views, as expressed to us at The Clive Project, at the heart of it. I will keep you up-to-date on this.

TG

Alzheimer Society National Conference for Younger People with Dementia

Thursday 16 November, 2006 at The Oxford Hotel, Oxford.

'We'll be working to a theme of 'partnership', both in terms of professional partnerships in developing services, and emphasising the important roles of younger people with dementia and their families - informing service development, and also offering peer support and partnership to each other.' Colin Cosgrove, Information Officer, Alzheimer Society.

This is the first time the national conference is to be held in Oxford, and we hope that many CP members will be able to attend and contribute views. The Clive Project has been invited to take a prominent part in this conference – an opportunity we are very glad to grasp on your behalf. Of course, we will keep you in touch with developments.

TG



Music Therapy for People Living With Dementia

There is a pilot project to work out what kind music therapy works best, what venue and so on – it runs from May to December 2006 and includes three free music sessions. So if you have ever wondered what its all about, or thought it might be interesting to explore your musical side (or find out whether you have one!), call Pemma Spencer-Chapman on 01865 775520 to find out more.

TG



The Clive Project Library

We are always looking out for new additions for The Clive Project Library. Library items (books, leaflets, and the odd video) are usually available at Exchange meetings. You may borrow items freely to read at 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 June brings to Exchange meetings.

Something well worth looking at is a recently updated booklet produced by the Department of Health:

'Who Cares? Information and support for carers of people with dementia: October 2005 (third revised) edition.

Aimed at carers, it provides information about dementia and caring for someone with dementia, and outlines the help available to them.

We have copies in the library, or they are available free from the DoH. Please quote the title and reference number 271352. You can place an order by post, telephone, fax or email, as follows:

Write to:

DH Publications Orderline
PO Box 777
London SE1 6XH

Telephone: 0870 155 54 55

Fax: 0162 372 45 24

Email: go to www.dh.gov.uk/PublicationsAndStatistics/Publications and follow the email ordering link.

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



Readers' letters, contributions and suggestions

Sadly, we have no contributions to include here this time, so get busy and let us know what you're up to and what you'd like to read here next time.

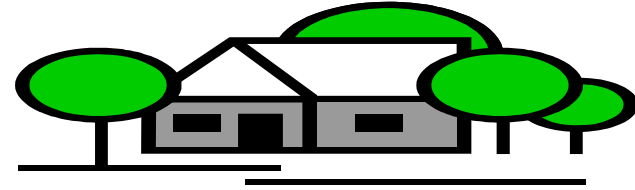
Copy deadline for the next newsletter is Monday 4th September, so send your scribings in to: Sharman Oldham, 39 Palmers, Wantage, Oxon OX12 7HA, or email to sharmanoldham@thecliveproject.org.uk.

ZKK Documentary on the early onset of dementia



A 'sample' has been filmed with Sandy Sulaiman, a CP member, and this is being used to attract commissions from the major channels. Fingers-crossed X!

TG



Clive Homes Update

The Clive Homes Group has been working since Christmas with a local nursing home who have expressed a serious interest in working alongside The Clive Project to set up the kind of specialist long term and respite care resource we have been discussing for a number of years now. There is space on the same land as the nursing home and the owners have experience in building and managing similar projects for older people.

We have some concerns about the location which is more rural than we had been planning for, but we are working hard on this with invaluable professional support from an architect who has offered us his time for free to help us to carry out an initial feasibility study covering the site, the building and management requirements and finance. We hope to have a clearer idea about how realistic the scheme would be by late May and will keep you all up to date.

HB

Diary Dates

Fri 2 June 11.30 onwards – ISIS lunch group. Contact Meg Barbour on 01865 872433 for further information

Tues 20 June 1.30-4pm – Garden tour and cream tea at Friars Court, Clanfield. Invitations and directions to follow.

Fri 11 August 12-300pm – Garden Party. A ‘bring & share’ picnic at Tubney Farm House, Nr Southmoor. Invitations & directions to follow.

Weds 30 August (eve) – Music Concert. To be confirmed.

Mon 4 & Mon 9 September – Music Workshops. To be confirmed.

Thurs 12 October (eve) – Consultation Evening at Cassington Village Hall. Further information to follow.

REMINDER – remaining events in the current Exchange Programme *(detailed programme published separately)*

Thurs 8 June 7-9.00pm – ‘A bit of a chinwag’ informal supper, discussion and support at The Coach House Room, in the Oxfordshire County Museum, at Woodstock.

Fri 21 July (daytime) – ‘Learning Together’, a practical workshop on therapies for carers with Helen Bloomfield. Please watch for invitation and directions.

Weds 26 July 7-9.00pm – Family & Friends Barbeque at The Abbey Centre, Audlett Drive, Abingdon.

Thurs 14 September 7-9pm – Exchange Meeting – details to be confirmed.

