# January 2006

"When one door of happiness closes another opens; but often we look so long at the closed door that we do not see the one that has been opened for us" Helen Keller

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'do' was held in Cassington village hall as we are now too many for Headington Hill Hall. This was followed by Hugh Marriot's talk – when we shared his relief that he didn't end up as dinner for a crocodile in Australia – and the Christmas party.

In between, I attended the national Alzheimer's Society conference for younger people with dementia. Over coffee I mentioned The Clive Project to one delegate, who disparagingly commented "Oh yes – very labour-intensive" and walked away. We have in the past been described in a similar tone as a "Rolls-Royce" project. Well, we are "labour-intensive", but I don't see how one can provide "personcentred care", which is the government's declared aim, without being so. I am proud to be associated with a Rolls-Royce project, and think anyone diagnosed with dementia deserves nothing less. See you in 2006.

Helen Beaumont



fresh air and lovely outings whatever the weather. Even a trip to the breezy Brecon Beacons was enjoyed. Thank you for keeping us fit! (Excluding Tessa of course who sits at a computer way too long!!)

Two support workers are leaving us shortly – Gill Stopps is taking up a full-time job and Nicky Henderson has begun a new job working with children. They have both offered so much to the One to One Service and we will miss them. Nicky has written in this newsletter about the cosy coffee mornings she hosted during 2005. Kaija has also hosted a 'tea and chat'. If anyone else would like to hold a similar small gathering I am sure it would be welcomed by members and support workers alike.

Plans for expansion are underway to enable us to partner more people – there is quite a demand for the service now. By April 2006 we hope to have a Co-ordinator and four additional support workers. The advertisement will be published in January 2006 so do alert anyone you know who may be interested in these roles.

TG



Yoga Update

We have a small group of four people who are willing to give this a go in the New Year. We will now be checking out with Bernard Pottle The negotiations are taking a while to sort so I will keep you posted on news.

\*\*\*Latest: See Judie Waldemann's update on page .\*\*\*

ΤG



Fundraising Plea

Can you help us?

Would you mind sending Sharman (address inside the back page) any local publications which show details of groups active in your area. In Witney, for example, we have an **OX28** monthly magazine and the Witney Gazette which lists all sorts of organisations that include fundraising as part of their activities. We would like to bring The Clive Project to the notice of the local community to attract more funds. Areas such as Banbury, Henley, Oxford city, Abingdon, Thame, Didcot or Woodstock must have local publications and we would very much appreciate your help in gathering these for us. *TG* 

### Family & Friends Service

I don't believe it! The 'new' service has now been running for nine months! Diana and I are continuing to build up our contacts with Clive Project members old and new, and trying to provide a mix of individual support, structured and informal group support, and social weeks which some of you already attend. The next two are on *Fri* 27 *January* and *Fri* 17 *February* from 11.30am, in the Collinwood United Reformed Church Hall in Risinghurst, Oxford. If you would like to know more or book in for lunch, contact Meg Barbour, ISIS coordinator, on 01865 872433

Several Clive families attended the ISIS Group Christmas Lunch where Diana revealed her hitherto unknown song and dance talents; a great time was had by all! We are planning to invite all ISIS Group Members to a social event at Benson in the Spring.

#### **Exchange Programme**

The Exchange Programme for April – September 2006 is included with this Newsletter, so do note the dates in your diaries.

We are trying a new venue for the Exchange Information Meetings – holding the next few at Wolfson College, in the cul de sac at the end of Linton Road and Bardwell Road, off Banbury Road in Oxford so do join us there if you can. Parking is available in the college grounds.

### PLEASE NOTE:

### Change to February Meeting

Due to circumstances beyond our control there is a change of topic and speaker for the February Exchange Meeting. In place of the advertised talk, Kirsty Darvill, nurse and trainer in moving and handling with Oxfordshire County Council Social & Community Services, will discuss and demonstrate moving and handling techniques in the Elercy Poem at Wolfson College A lovely letter from a Family & Friends member describing this event is included in the Letters section of this newsletter, so it only remains for Diana and I to thank all those who lent a hand before, during and after the event – especially Michael Wall who gave some stalwart help with the washing up.

We look forward to seeing you all at our next event.

JS & DL

### Contact the Family and Friends Service by phone or email:

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

June (South Oxfordshire) Tel: 01865 301636 (Tues, Weds, Fri) Email: junesmith@thecliveproject.org.uk

## The Clive Project Club

### The Clive Project Annual Special Lecture - November 16th 2005.

A large audience came to The Four Pillars Hotel to listen to Hugh Marriott talk about his experiences as a carer for over 14 years and what he wished he had known at the beginning. A fascinating talk – in parts very frank and in parts very funny – Hugh gave everyone plenty of food for thought and brought many a nod of confirmation from the audience who could identify with his comments. His book is reviewed separately in this Newsletter.

He also briefly recounted some of his sailing experiences drawn from



This year's Christmas party, held at Cassington Village Hall, was attended by over 60 people.

As always when we hold a 'bring and share' event guests excelled themselves with delicious offerings to tempt the palate and pile on the pounds! On arrival a glass of wine or punch and the wonderful sound of the Paraguayan harps of 'Cascade of Strings' set the relaxed, cheerful atmosphere for the evening. Margaret and Rosemary Scruby performed in beautiful Paraguayan national costumes and then stayed for some supper afterwards.

Plenty of time to chat was the request made at an earlier gathering, so for over an hour once we'd pulled our crackers until the raffle was drawn that's what we did!

To bring the evening to a stirring close, Elizabeth (Trustee) and Paul King had brought some of their singing friends and an accompanist to serenade us royally and then lead us in a round of traditional carols. All too soon it was time to go home, but hopefully everyone took with them a sizeable helping of Christmas cheer.



Thanks to everyone who brought food, helped get the room ready, served drinks, entertained us, or did anything to help make the evening as with a swing. You made it a lovely evening!

Helen Beaumont attended this year's Alzheimer's Society National Conference

It was a very good day. I have been to this conference in the past, and all the talks were of research. This year most of the talks described active projects. The expectation is now that younger people with dementia are entitled to specialist services that involve them and their She had some moving quotes:

'I kind of got written of when I had the depression':

'Of course, you know, these meetings with the family and the carers... they leave the room sometimes...and I

# ZKK Documentary on the early onset of dementia

ZKK is a documentary production company which has close ties with Channel 4. As you may already know, they have approached us as they would like to make a film about the early onset of dementia. The idea is to work closely and collaboratively with someone with dementia and their family – not only to increase awareness of the issues raised by early dementia but also to challenge the preconceptions about dementia.

Thanks to all of you who have already contacted Daniel, at ZKK, to offer background information and potential contacts for the film. We will keep in touch with you on this in future newsletters.

Jean Ware-Morphy, currently co-chair of The Clive Project, Trustee and long-term supporter.



I am going to write a very few words about myself and how my interests led me to become involved in The Clive Project.

Way back, when The Clive Project was just an unnamed idea, I worked with Betty Rostance (a founding Trustee of the Project), who brought the plight of Clive Beaumont to the Oxfordshire branch of the Alzheimer's Society. We produced a paper on the needs of younger people with dementia, which I presented it to the Mental Health Trust fondly assuming they would jump at the chance of setting up a service to meet these needs. Unfortunately, I was hopelessly naïve and they did not have the funds, and so began the long process – involving a great many enthusiastic and very skilled people – which has resulted in what we have today.

I trained as a Mental Health Nurse and have worked for 20 years with people who have dementia including: helping to set up ADAPt, an advocacy project; time as Ward Manager of a Day Hospital; working as a Community Psychiatric Nurse, becoming founding trustee of 'Daybreak', a charity providing day centres in Oxfordshire; and working as a trainer providing specialist training in dementia care to care homes, hospitals and domiciliary care agencies. I won't go on but you can see where my interests lie!

I have for some time found the idea of Life Story work fascinating and, alongside my role as a Clive Project Trustee, continue to support people to do this within The Clive Project

### Dear All,

The Exhibition of photographs, which so many of you have been helping me with, should go ahead during Artweeks in May 2006 in the Jacqueline du Pre Music Building, St. Hilda's College, Oxford. Final dates and details will be sent out later Our Exhibition will include some of your photographs, my photographs, a video piece and an installation piece made from a chest of drawers! This may sound rather strange but hopefully it will make sense when you see it! (I am making it in collaboration with another artist). We intend to adapt a piece of furniture - which we have yet to beg or buy! We are looking for a piece of wooden furniture with several drawers in any condition. The drawers could be a chest of drawers or smaller drawers from a dresser or drawers that rest on a table top. We will know if it is suitable when we see it! So if you could help or know someone who deals in bric-a-brac please contact me on 01865 553822.

I will be contacting all the people who have been involved in the photographic project soon to get permission for the photographs that I would like to show in the exhibition. Many choices still have to be made.

Thank you so much for your help,

we are always looking out for new materials to add to me clive Project Library. In the meantime, the 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. June Smith is currently our Librarian so if you would like to borrow or return a book in between Exchange meetings, please contact her by phone on: 01865 301636 (Tues, Weds, Fri). A complete list of the resources is included in the library box which June brings to Exchange meetings.

Meanwhile Vaughan Billings has read and reviewed two books for us:

### The Selfish Pig's Guide to Caring by Hugh Marriott.

Published by Polperro Heritage Press. Price £9.95 (paperback) ISBN: 0954423313

### Background.

The author has been a carer for many years. Around the time Cathie Marriott began to have symptoms of Huntingdon's Disease they sold their house, bought a sailing boat, and embarked on a nine year voyage of discovery. Now having returned to live ashore once more Hugh wrote this book in part to try to pass on to others the advice he would like to have been given while he was struggling to learn new skills and find his way in an unfamiliar role as a carer.

### Comments.

A very interesting and demanding book. Not one to read all at once but to read a relevant chapter at a time. Hugh's straight talking style pulls no punches and covers every issue that may affect carers. Although his style of writing may be too frank for some, the author covers every aspect of caring and is very funny and moving. This book is based on research funded by the Alzheimer's Society and conducted by Ethox Centre, Department of Health and Primary Health care at the University of Oxford. Over 60 carers were interviewed from all backgrounds and across the country. The book includes quotations from the carers illustrating their wealth of experience and covers the many decisions that carers have to make – including difficult ethical issues. The book acknowledges that every situation is unique and that issues that are crucial for some carers will not be for others. It includes some general principles of decision making.

### Comments.

I found this an excellent publication as it gives carers an insight into fellow carers' problems and how they have resolved them. It gives both sides of the situation. It is a very practical book, and very reassuring as many of the comments quoted relate very closely to ones own situation. Very easy to read and well set out. I think this book really is a must.

VKB



### Your turn?

If *you* would like to review or recommend a book to be added to the library, do get in touch with June or Sharman (01235 763968).

On Wednesday 5<sup>th</sup> October The Clive Project Family & Friends held an evening get together at The Coach House, in Headington. The evening, which we all enjoyed, was called 'A Touch of Sunshine'.

The hall was very inviting and cosy. The tasty supper had a Mediterranean flavour and was very enjoyable. Maria Jurd played the piano, which was excellent – in fact a lot of us could not resist getting up and having a dance! The evening was very much appreciated.

We all met some new faces, and it was good to see them again at the Annual Meeting in October at Cassington – a lovely village. This evening also went well, and we were entertained by two lovely singers and a keyboard player. The buffet was very inviting and by the end of the evening everyone was chatting and enjoying but worthwhile social event. Each gathering consisted of about 6-8 people, which seemed a comfortable number. I provided tea, coffee and cakes and biscuits – which seemed to go down very well indeed!

It was an idea which I hoped would prove successful, as I felt that sometimes it was valuable for us all to share these social, relaxed and accepting opportunities with others in like situations. I know that this sort of informal gathering isn't appropriate for everyone in The Clive Project, but those who were able to come seemed to enjoy themselves, and the feedback was very positive.

NH

Sandy Billings. Died 24th November 2005.

Sandy was involved with The Clive Project for many years and the friendship and support given by her personal support workers and all other Clive members helped her enjoy and get the most out of life. I know she will be remembered for her sense of fun, her laughter and her beaming smile. She was always pleased to see everybody.

I should like to thank everybody connected with The Clive Project for all their kind comments and letters. They have been of tremendous help and support. We were married for 41 years and I am now beginning to be able to look back and remember all the good times we had together over the years. The last ten meetings are informal and will happen at The Turnpike Inn, in Woodstock Road, Yarnton, near Oxford.

The need for this group arose as what these members need is not always appropriate to carers at earlier stages – 'I would rather not know about these things at present'.

We hope to gather at The Turnpike Inn on the first Tuesday of each month. Please contact Sheila Bailey-Watts for further information on 01869 345505.

SB-W



## USEFUL WEBSITES

Check out these two new web sites for useful information:

*www.dementiaweb.org.uk* - newly launched site for information on dementia services in Oxfordshire. Valuable for anyone living with dementia and professionals working with dementia. The Clive Project has been instrumental in initiating this website as part of the Oxfordshire Dementia Forum

*www.oxoncarers.org.uk* is part of the service provided by the Carers Centres in Oxfordshire

Also our own web site *www.thecliveproject.org.uk* has just been updated, so you might want to pay a visit to see how the rest of the world might see us! As usual, your views and ideas are always welcome.

of them recent approaches. However, we cannot give details in this newsletter, but will update you as soon as possible.

HΒ



And finally ...

Do you have something you'd like to share through the pages of the Newsletter? To be in print for the next issue, please email or post your handwritten or typed copy to Sharman by

Wednesday 12 April

Sharman Oldham Admin Support Worker, The Clive Project 39 Palmers Wantage 0X12 7HA Phone: 01235 763968 Email: sharmanoldham@thecliveproject.org.uk trainer Kirsty Darvill will discuss and demonstrate moving and handling techniques in The Florey Room, Wolfson College, Oxford (Parking in college)

*Thurs 9 March 7.00- 9.00pm* – Social 'An evening of Eastern promise': supper and music at Benson Village Hall, Benson – invitation & map to follow.

*Weds 12 April* – Copy deadline for next issue of The Clive Project Newsletter

**13** May – 4 June – Oxfordshire Artweeks. Open days and exhibitions across the country, including our own exhibition in the Jacqueline du Pre Concert Hall, St Hilda's College, Oxford. (Further details to follow)

<u>April – September 2006 The Clive Project Exchange Programme</u> (detailed programme published separately)

*Thurs 13 April 7-9.00pm* – '*Financing Care' with Rachel Bolland of Age Concern* at Thames Four Pillars Hotel, Sandford-on-Thames.

*Thurs 11 May 7.00-9.00pm* – 'Relaxation Therapies with Bob Inston at Wolfson College, Oxford (Parking in college).

*Thurs 8 June7-9.00pm* – 'A bit of a chinwag' informal discussion and support at Wolfson College, Oxford.

*Fri 21 July (daytime)* – A practical workshop on therapies for carers with Bob Inston.

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