



September 2007

*Every moment a golden one for him
who has the vision to recognise it as such.
Henry Miller*

Registered Charity 1085595

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CONTENTS

From the Editor	4
Direct Line – News from the Director	5
One to One Service	6
ADAPt – the All Age Dementia Advocacy Project	8
Family & Friends Service	9
Clive Project Club	10
Follow On Group	10
Kingston Bagpuize House and Gardens	11
Not So NICE	12
Staff Profile – Bernie Stevenson	14
All Change for Helen Baker	15
Mental Capacity Act	15
Life’s Journey	16
Clive Homes Update	17
Fundraising Update	18
Farewell Message from Sue Thomas	19
Book Review	19
Diary Dates	20

From the Editor

Newsletters are supposed to have news in them, and this one certainly does just that. As is the way of news, some is good and some not so good. Good news for Helen Baker is her very high-profile and challenging new position. Unfortunately for The Clive Project, this means she will no longer be one of our Trustees. Helen has been with The Clive Project since the very beginning, and she will be very much missed. We wish her all the best, and would like to thank her for her hard work in the past. We are also saying goodbye to three support workers, but hello to four more. And it is really good to see Tessa back with us again and looking so well.

One of the big pieces of news is the update on the Clive Homes. It has been very difficult knowing that talks were going on, but not being able to share the possibly excellent news with everyone. There is still no certainty things will go ahead (the plans call for new buildings in the green belt!), but we can all hope.

Sandy's book has been published, and is helping to raise the profile of Huntington's disease and The Clive Project. Congratulations to Sandy and her family.

The October Do is fast approaching. Alas, I shall not be able to join you, as I will be ringing church bells in the wilds of Staffordshire, but my thoughts will be with you, The November lecture is by a team from Admiral Nurses. I first heard of these in the early stage of Clive's illness, and I was very disappointed when I realised we lived outside their area. I shall look forward to hearing from them, and hope to see lots of you there, or at the Christmas party.

All the best to you all.
Helen Beaumont

Direct Line – News from the Director

Again, and by amazing coincidence, the sun is shining as I write – just as it was in May time when I last put pen to paper, or more accurately, fingertips to keyboard. True, the days are shortening now and the berries ripening, but late summer days can sometimes be wonderfully mellow, can't they?

After 12 months away from The Clive Project having medical treatment, I am now building up strength and energy for rejoining normal life and work again. It is a real joy to do so.

I wonder if you too feel there is a silver lining to every cloud. I believe this. Once I was over the worst of the treatment, I thoroughly enjoyed spending time with friends and renewed some old pleasures such as reading and cinema. Forced to take a slower pace, I appreciated the calm mind that this brought me. The trick will be to continue with the new me for the next 12 months. I'll let you know if I succeed!

I am gradually meeting up with all The Clive Project members and team again. My colleagues helped me so much by taking on my responsibilities so that I could just concentrate on getting well again. Now I am enjoying taking up the work and will be testing myself out on a full-time basis through the autumn. Will I see you all at the October event? – I hope so.

All the best, Tessa

PS Just to confirm that I will be keeping a very close eye on Reading Football Club's second season in the Premiership – from row X, seat 149 (the comfy one!), to be precise. Apologies to all Oxford United supporters.



PPS Also to confirm that in all those 12 months - 365 days – 21,900 minutes, I cleaned the windows just once, and never did wax the wood or polyfilla the holes. And, as my friends and colleagues will vouch, the cobwebs are still here too!

One to One Service

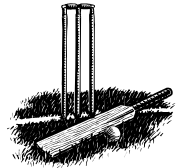
Once again, I am sitting while the sun is shining – but what a wet, wet summer it has been! Let's hope that the Indian Summer is starting now and will continue till Xmas. I don't see why not, do you?

As the last edition of the newsletter went to print, Jo, Marilyn and I were immensely privileged to go to London to the launch of Sandy Sulaiman's book. It was a wonderful evening and it is fantastic to know that the book has sold very well here, as well as being taken up in Australia and the USA. It is a very moving and highly readable account of Sandy's illness and its effect on her family, and is a huge credit to them all. I recommend it to everyone associated with Huntington's Disease. As a result of the book, Sandy has been asked to speak at the HDA conference in Edinburgh and has asked Jo, her support worker, to go with her and talk about The Clive Project.



There have been other fun events with another concert at the Jacqueline Du Pre Building – this time with even more singing along – though it was sometimes hard to hear ourselves singing over the brass players! Sadly, the rain made us stay indoors, but everyone enjoyed themselves. Watch out for more concerts coming up.

Jason, Simon and Doug had a chauffeur-driven trip to The Oval to see England vs West Indies in June! (All thanks to a charity which supports younger people with disabilities). It was a great day out and everyone thoroughly enjoyed it. Jill, Roz and Brian had a few days holiday in the Cotswolds. They also enjoyed getting away – but the weather could have been kinder!



As usual there have been team meetings and training sessions. We were delighted to have Pemma Spencer Chapman talk about the music therapy that she provides for a number of people. We also had a session on Life Story Work run by Jean Ware-Morphy; that was also very helpful. Jo summed up the value of life story work:

'When people end up without the ability to talk easily about their lives, their children, their jobs, their homes, their loves and hates and all the things that have mattered to them and given them a sense of identity;

at that point of loss... we will have helped provide a voice for them. So that when they have difficulty remembering, or explaining things to their family, friends or ultimately have to go into a home, somebody will take the time to read these stories and know to a small extent, who they are. Photos, post cards, smells...(a favourite perfume)....music/ CD.... poem.... hobby.... sport...job... all these things can be collected into a small box of treasures.

It can be done with or without the help of the person's family..... but it is important that the memories are recorded in the way the person would voice them.... we all remember things in different ways'.

Thanks go to Pemma and Jean for giving their time and expertise.

And finally, the last three months have seen more changes to the team. We have sadly seen Sue Thomas and Nic Brunwin leaving us. Sue gave a tremendous amount to The Clive Project over a number of years but had gradually reduced her time so that she was just visiting one person. When that person no longer needed her support, it seemed the right time to leave. Nic had only been with us for a year but had an opportunity for further training and a full time job. She had been seeing four people over the year who have all missed her. And very recently, Alex has also decided to leave us. Alex started with The Clive Project many moons ago and then went off to Australia for a number of years. She rejoined us last April and has supported five people on a regular basis as well as doing lots of holiday cover. She will be hugely missed! Good luck for the future, Alex. We wish them all very well.

With these changes, we realised it was time to recruit new workers and in September Amanda Horlor, Wendy Chadwick, Sarah Bishop and Ronnie Jones will be trained and will hopefully start work by the end of the month. It is lovely to welcome them to The Clive Project and I hope they will be very happy here.

Anna, One to One Co-ordinator

Readers' letters, contributions and suggestions

Thank you to those who have written items for this newsletter – it really livens up the news when it comes from you, the readers. If anyone would like to send in something for the January 2008 issue, post it longhand or typed, to:

Sharman Oldham, 39 Palmers, Wantage, Oxon OX12 7HA

or email it to: sharmanoldham@thecliveproject.org.uk.

Copy deadline for the next newsletter is Friday 29th December.

ADAPt – the All-Age Dementia Advocacy Project

In Oxfordshire we have a valuable service, the All-Age Dementia Advocacy Project (ADAPt). This project helps those with dementia to make their voices heard and have their wishes considered. Advocacy is especially important in times of change, when choices are being made for people without any consultation.

Sometimes a number of people can be working very hard for what they think is right for their friend, relative or client with dementia, and yet find themselves pulling in opposite directions. Advocacy can help to find out what the person at the centre of all this activity would like.

The advocate works with many people with dementia and will spend time with each one individually finding out their views and wishes and the best way of expressing them.

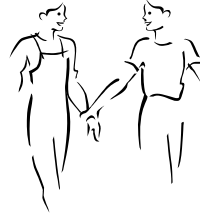
The project is a free, countywide service. If you know someone who might need advocacy, or would like more information, please ring 01865 742745 or email: adapt@oadg.org.uk.

Ginny Black
ADAPt

Family & Friends Service

Hello to you all

We hope you survived the wet summer and have enjoyed some late but appreciated sunnier weather!



We would like to welcome our new family and friends members and are looking forward to meeting you all soon.

Some local events have been held around the county which have been well attended and enjoyed by families north, west and south of the county. We will let you know about events in your locality as they are organised.

The planning of next year's Family & Friends programme is now underway. Please do contact us with any ideas or thoughts you may have which we can include in our Exchange meetings.

During the past few months we have been reviewing the service, looking at what works for you and what we can improve upon. Even when the formal review and evaluation has been complete, we would still like to hear your views so do feel free to call us, or Tessa.

Please Note:

Our Bring and Share Supper for 3rd October has been cancelled as we want everyone to come to the annual 'Get Together' on 11th October. We wondered if we were making your diaries too busy! We hope many of you are able to come and we look forward to catching up with you there.

Sue, Family & Friends Support Worker – South Oxon

Tel 01865 821699

Diana, Family & Friends Support Worker – North Oxon

Tel 01993 891955

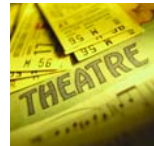
Clive Project Club

Since the last newsletter we have enjoyed a private visit to Kingston Bagpuize House and Gardens and our Annual Founders' Garden Party. The visit to Kingston Bagpuize is admirably described by a couple who attended (see their letter on page 11) so I need add nothing to their account.

For the Founders' Garden Party, despite the unsettled days beforehand, we were blessed with a fine, dry day for the event which John and Gwynneth Goss kindly hosted, for the third year running, in their beautiful garden at Tubney. There was a great mix of familiar faces and people who are relatively new to The Clive Project and everyone seemed to enjoy the delicious lunch and the chance of an outing among old and new friends. It was lovely to see Tessa, our Director, who is returning from a period of long term sick leave and thankfully seems to have lost none of her enthusiasm for life, The Clive Project – and largely ignoring her dirty windows! (We love you the way you are Tessa – so just keep ignoring them!) The music was provided by a trio comprising our own support worker Jo, with her husband and a jazz buff friend. Their brand of light, lively jazz played with much aplomb fitted the mood of the day perfectly, so our thanks to them all.



Plans are well underway for the Christmas party and a pantomime visit has been arranged to see Aladdin at the Oxford Playhouse (see the Diary page for dates)



Sharman, Admin Support Worker

The Clive Project Follow On Group

Just a reminder that the Follow On Group continues to meet at 1.15pm on the third Monday of each month at our usual venue – The Turnpike Public House, beside the Yarnton roundabout on the A44 Woodstock to Oxford Road.

We get together to provide help and support to one another through the difficult times of bereavement or a loved one going into permanent nursing care. New people are welcome at anytime, so, if you'd like to

come along for lunch, a chance to talk with others in a similar situation and often some laughter – just turn up.

Alternatively, contact Sheila Bailey-Watts for more information on 01869 345 505.

SB-W

Kingston Bagpuize House & Gardens

Two members who joined our Club visit and cream tea at Kingston Bagpuize House and Garden have written about it for those who could not come.

'On Wednesday 20th June we went to The Clive Project afternoon visit to Kingston Bagpuize House and Gardens. The weather was kind and the rain kept away - it was just windy. We met up with old and new friends. The grounds and woodland were lovely and peaceful to walk round.

The herb garden was a picture with the different lavenders. I didn't know you could grow white lavenders. Running around the herb garden was a lovely golden cockerel, very proud of his home.

At three o'clock we all went to the tea room for cream tea and home-made cakes which we all sat and enjoyed. The afternoon went too quickly, but was enjoyed by everyone.'

PE/BF

Not So NICE

Some years ago the National Institute for Clinical Excellence NICE made some very controversial recommendations about access to the anti-dementia drugs. These were challenged in the High Court by the Alzheimer's Society, among others, and the judgement was announced in early August.

The drugs at the heart of the dispute are the anti-cholinesterase inhibitors: **Aricept, Exelon and Reminyl**. They don't stop the progress of the illness, they can have nasty side-effects, and they don't work for everyone, but for some people they can decrease the symptoms of AD for a few years. The drugs cost about £2.50 per person per day.

NICE was set up by the government to make decisions on new treatments, so that there are national standards on available treatments. Their guidance on the drugs was that they should only be used in the middle stages of the illness, and not in the very early stages. Their argument was not that the drugs were not effective, but that they were not **cost-effective**. They defined the stages of the illness using one particular test, the mini-mental state exam (MMSE), and used very rigid scores to decide whether or not the drugs should be used.

The costs they considered in reaching their decision were never very clear: rumour has it that they included the cost of nursing home care at £387 per week. If anyone knows a place that will care well for someone with early onset dementia for such a low sum, please let us all know. When Clive was in care 10 years ago, the bill was more like £700 per week.

The court case was brought on two grounds: that the MMSE was not a good test of the severity of dementia, and that the cost calculation was not clear, and not accurate. The judgement was announced on August 10th, and allowed everyone involved in the case to claim victory. The main recommendation was not changed: the drugs are still not available for people in the early stages of Alzheimer's disease.

However, the definition of 'moderate AD' was changed to be less rigidly dependent on the MMSE score. The court recognised that this test is not a good test for some people, e.g. where people's first language is not English, and consultants are now allowed to prescribe for people who 'score greater than 20 but who have moderate dementia as judged by significant impairments in functional ability and personal and social function'.

The other argument was on costing, and here NICE won. The review found that NICE took 'appropriate account' of benefits to carers, and the costs of long term care.

So, bad news. Someone who develops dementia has to wait until the illness is having a serious effect on their abilities to get by in normal life before the only effective drugs can be prescribed. Nothing is likely to change until more research is published. The decision does not affect someone who is already being prescribed the drugs and we will have to wait and see how the Oxfordshire consultants interpret the guidance. However, this is not all NICE has to say on dementia. In November last year it produced an enormously long document (nearly 400 pages) of advice and recommendations for the diagnosis and treatment of people with dementia. There is a summary available (people who can use the web can find it at

<http://guidance.nice.org.uk/cg42/publicinfo/pdf/English>, or you can order a copy by calling the NHS Response line on 0870 155 5455 and asking for document 'CG42 Dementia: Understanding NICE guidance'. This document is much more positive, and I will just quote a few of its points:

- People with dementia should not be excluded from any services because of their diagnosis, age or coexisting learning difficulties (p 4)
- Specialist multidisciplinary services, allied to existing dementia services, should be developed for the assessment, diagnosis and care of younger people with dementia (p7)
- Health and social care staff should aim to promote and maintain the independence, including mobility, of people with dementia (p13)
- People with mild-to-moderate dementia should be offered the opportunity to participate in a structured group cognitive stimulation program... (p 14)
- Carers of people with dementia should have access to a range of respite or short-break services... respite/short-break care should include therapeutic activities tailored to the person with dementia provided in an environment that meets their needs (the person's own home wherever possible). (p21)

The last paragraph seems to describe the support offered by The Clive Project, and wouldn't it be nice if such support could be available for all people with dementia, young or old.

Helen, Founder Member

Staff Profile: Bernie Stevenson

My name is Bernie Stevenson and I have had the pleasure and privilege of working for The Clive Project for well over four years now. I worked for 18 years within the finance industry as a "Hunter of New Business" before joining the charity.



I became involved in The Clive Project partly due to my mother having had dementia. I felt that maybe it was time to re-evaluate my life and to start putting things in to perspective and to start putting something back into the community. I felt that the fun and laughter and the experiences that my mother and I had together could be put to good use with other people with similar conditions. This proved to be very true and I have met many courageous, fun-loving and amazing people and their families over the years and have thoroughly enjoyed every minute of it, well almost!!!

I live in Abingdon and I have one daughter and two lovely grandchildren, a boy and a girl. When I am not working for The Clive Project I look after my grandchildren one and a half days a week which is great fun and keeps you feeling young. I love to travel and holidays are my passion. I am at present learning Polish which is a big challenge but one which I enjoy.

Bernie

All Change for Helen Baker

Congratulations to Helen Baker, Trustee and long-term supporter of The Clive Project, on her appointment as interim Commissioner for the Compact, and Non-Executive Board Member. This appointment will keep Helen busy so she has resigned from The Clive Project. We will miss Helen's indefatigable enthusiasm and highly valued breadth of experience. Helen was one of the forces behind the start of The Clive Project back in the mid-90s so has given amazingly loyal and committed service for a very long time. She plans to remain in contact with us.



C4C oversees the relationship on behalf of the Cabinet Office between government and the voluntary sector to ensure fair play for the latter. You have probably noticed either personally or through local and national media that public sector services are increasingly provided by external organisations and agencies rather than directly by the public service. C4C will ensure that government treats voluntary sector on an equal footing to private organisations. This is highly relevant and topical for The Clive Project.

Mental Capacity Act

The new law comes into effect on 1st October and enshrines some principles which are important to us all.

1. Every adult has the right to make his or her own decisions, and capacity must be assumed unless it is proved otherwise;
2. People must be helped as much as possible to make their own decisions before it is decided that they cannot do so;
3. People have the right to make what others may feel are unwise decisions and that on its own does not mean the person lacks mental capacity.
4. Decisions made for a person who lacks capacity must be in the person's 'best interests'.

We hope to set up a session for you to explore what this all means in greater depth.

Life's Journey

A Clive Project member shares some of her thoughts in a poem.

Sheila Jane.....My thoughts I've had about life's journey.

Could have been so nice to have shared more of my life with the world,

It's there to share, enjoy, explore.

The secrets of this earth, oceans and their shores,

Mountains so high we could touch the very sky.

Busy cities, hot desolate deserts to the green peace of the forests.

From rippling brooks to the ocean deep,

To share the wind, rain, storms and sunshine high in the heavens.

We have the stars, we have the moonlight...ah! There is a falling star.

Cold sun drenched virgin sparking snow to share but.....

there's no one there

To see a frosted spider's web, a bird on the wing

And those who would die in the street, journey completed

To fly forever in another life.

Each one of us have to share the special things in life,

Hopes, dreams all disappear in the sands of time,

No Summer sun, no moonlight sky, don't even see the flowers grow

Only colour in the Autumn leaves to die, but to live again.

In the tranquility of peace and harmony, love, gentle, special, soft as butterfly wings.



Clive Homes - Update

Over the past 6-9 months, The Clive Project has been in detailed discussions with Heathfield House in Bletchinghamdon regarding the development of a Clive Homes facility. Pippa and Clive Hawes, who own Heathfield, have shown great enthusiasm for the project and have invested in the services of a professional architect and planning consultant, the latter to assist with the formal planning application to Cherwell District Council.

The proposals are for accommodation for 25 residents located in five 'cottages' around a central atrium within the Heathfield site. Each cottage will be identified by its own colour and design scheme and all will have access to secure but extensive outside grounds and the recreational facilities provided at Heathfield House. The intention is to create a 'village' community with plenty of opportunity for interaction but also privacy.

The individual bedrooms will be fairly large in size with their own en-suite facilities. The central atrium will have a continuous circulation route, activity areas and a high level of internal landscape. The gardens will have informal walking and exercise routes, raised flowerbeds, an orchard, a small pond, herb garden and a barbecue area.

Plans are currently being finalised for submission to the local planning committee. Heathfield has worked closely with staff and trustees from The Clive Project to develop a design that draws on our experience of the needs of younger people with dementia and their families. We hope to be able to share our plans with you in more detail over the coming weeks.

Graham, Trustee



Fundraising Update

This year we need to raise at least £60,000 on top of other income to make sure that we can cover all our costs. The good news is that we have, so far raised about £40,000 towards this, including £20,000 from the



J Paul Getty Jr. Charitable Trust to allow us to increase the one-to-one hours we offer and £17,500 from the Lloyds TSB Foundations to cover the costs of employing our co-ordinator with some extras thrown in. Even better, the first grant should be available to us for two more years after this one and we will also get a second instalment of £7,500 from Lloyds TSB for 2008/9!

We continue to receive donations from individuals, families and local organisations who know about us which are always particularly welcome. We are especially appreciative of the very kind and generous 'In Memoriam' donations received recently from Clive Project members. We shared the takings from a special concert held earlier this year to mark the closure of the Radcliffe Infirmary site. This was a musical celebration of all that had been achieved there including, of course, the work of OPTIMA which has had a close connection with The Clive Project for many years. A really enjoyable concert too!

If any of you have good ideas about other bodies we could approach please do let us know.

Helen Baker



STOP PRESS: STOP PRESS: STOP PRESS: STOP PRESS:

A fabulous gift of £25,000 has been received from an anonymous donor – 'I hope it will assist you in keeping up your fantastic work.' Brilliant news – I could hug the person, if only I knew who it was

Tessa, Director

Thankyou and Good Luck: A Farewell from Sue Thomas

Former Support Worker Sue wrote this letter to wish us all goodbye and good luck ...

Seeing the first snowdrops of the year on a frosty January morning; having girlie, gossipy chats over coffee and chocolate biscuits; getting a fit of giggles with my companion in a coffee shop over something totally inappropriate and both laughing all the way back to the car; finding someone else who also likes Neil Diamond and Beethoven and both humming tunelessly! I could go on and on recounting my memories of my time with The Clive Project. It has been a privilege to be a small part of such a special organisation and I will continue to take an interest in any developments and news. However, I am now looking forward to having a spare day a week to spend time with my family (large) and animals (too many!), and maybe even doing a spot of housework!

*My best wishes to you all. Keep up the good work!
With love, Sue*

Book Review



The Forgetting: Understanding Alzheimer's – A Biography of a Disease

David Shenk, ISBN-10: 0002571749

This book won the British Medical Association's popular medicine book of the Year Award which encouraged me to start it. I would highly recommend it to anyone wanting to know more about the history and possible future of Alzheimer's disease. It is very easy reading and very interesting. Available in The Clive Project resource box.

Anna, One to One Co-Ordinator

Diary Dates

Wed 3 October – Bring and Share cancelled

Thurs 11 October 7.00-9.00pm – Annual Get-Together and Consultation Evening at *Cassington Village Hall*. *Invitations to follow.*

Weds 14 November 7.30-9.30pm – Annual Special Lecture, with a team from *Admiral Nursing, dementia care specialists at Cassington Village Hall*. *Invitations to follow.*

Weds 5 December 7.00-9.00pm – Christmas Party. Start the festivities early at our seasonal bring and share gathering at *Cassington Village Hall* – *invitations to follow.*

Weds 19 December 2.00pm – A Christmas Pantomime trip to *Aladdin*, at the *Oxford Playhouse*. Complete and return reply slip inside this Newsletter to book your seat.

As we go to press the Family & Friends team are organising some local events in the North and South of the county, and are preparing a programme for the New Year, details to follow.

The next dates we have for an ISIS Group lunches are Friday November 2 and Friday December 14. To confirm these and find out more, contact Meg Barbour on 01865 872433

