

Direct Payment Support Group

Is open to all including people thinking of using DP. The group will meet on the following dates at the Ormonde Centre, Newbury College, Monks Lane, Newbury, Berkshire RG14 7TD The meetings are from 1.30pm – 3pm.

Future **2008** meetings:

4 November

2009

27 January

24 February

24 March

21 April

19 May

16 June

If you are interested in coming along to find out more, please 'phone 01189 419183

Christmas Get Together

We have provisionally booked the Rowbargate for 9th December, 12 noon.

Anyone interested in coming along should phone 18002 01189 419183.

NB this replaces the advertised meeting date of 2 December which has been cancelled.



A Direct Payment User's Experience

Our Story

My dear, 93 year old Aunt Cissie has Alzheimer's disease and vascular dementia but I feel is happy and contented. However, it has not been easy!

We have come to our current happy situation only really in the last year and this is down to the team of people who support and care for her. It is also significant that we are receiving direct payments, and although sorting this was not that easy either, we are glad to be where we are now

Aunt Cissie's Circumstances

Aunt Cissie is receiving a Direct Payment for 14.25 hours of support in her own, warden managed home and to which she makes a personal contribution. Her home care is provided through a local agency in the town. She has visits each morning and evening and at lunch times on weekends and bank holidays to make meals as necessary. She has Meals on Wheels during the week - and particularly loves the puddings! The agency does shopping as necessary (for weekend lunches and evening snack) and we have regular reviews. Aunt Cissie also has help with personal care and housework from two other dear people who are now good friends. She also has a visit from a wonderful lady from Crossroads. I sort out appointments, do outings and all other things 'manage' our wonderful team and sort the paperwork.

Aunt Cissie has had some previous care support arranged through West Berkshire with a care agency but this proved to be problematic.

How I sorted out our Direct Payment

I found out about Direct Payments from a paragraph at the bottom of Aunt Cissie's initial assessment at the Memory Clinic. I did an internet search which provided a plethora of documentation from Government and West Berkshire. The most important documents were *Direct Payments Guidance Community Care, Services for Carers and Children's Services (Direct Payments) Guidance, England 2003*; and *West Berkshire Community Care and Housing, Direct Payments Policy, March 2005, amended Jan 06*.

We are also very fortunate to have an excellent Care Manager who is based at Aunt Cissie's surgery and she came and did a detailed assessment of Aunt Cissie's needs. Her help and guidance has been a personal life saver for me during the 'early days' and continues now if I need her help.

From the documentation I learnt that a direct payment would allow me to either employ people myself or use an agency. As I was still working and juggling my own life, I needed to know that carer's sickness and holidays were covered and that my own holidays were easily managed with familiar people. I therefore decided that using an agency was the best course for us.

Continued on page 2

A Message from Nina Wheeler

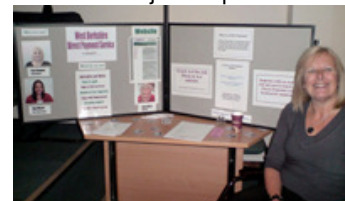
Many of you will know that in December last year the Captel Phone service was withdrawn in the UK due to inadequate funding. This has had some impact on my ability to perform my role as the only alternative service, Typetalk, involves a three-way conversation and is not as suited to business use.

A campaign to get Captel technology financially supported in the UK, as it is in the US and Australia where it is free to users, was started immediately and as I have previously reported has involved a nationwide lobbying of MP's. The latest initiative was a parliamentary reception that took place on 15 October in London, which I was invited to attend.

The reception highlighted the indirect workplace discrimination that not having the technology available has caused as well as showcasing further technological developments. Attendees included MP's, Ofcom and representatives of various charities for the deaf and hearing impaired. See a BBC report on the event, <http://news.bbc.co.uk/1/hi/technology/7670175.stm>

Recruitment Fair 3rd October

This is an annual event organised by West Berkshire Council that provides a platform for various organisations, commercial and voluntary, to raise their profile as employers as well as advertise any current vacancies. Although we do not currently have any vacancies in the Support Service we felt that this was the ideal opportunity for us to highlight the benefits of working for a Direct Payment user including, the one-to-one employer/employee relationship and the likelihood of more varied job responsibilities.



A Direct Payment User's Experience - continued

The West Berkshire document provided the guidance that I 'should obtain three quotes from independent providers that would be able to provide the service, they should submit these with proposed benefits'. However, I soon found that actually getting quotes was not as straightforward as I had thought and it became clear that there was no such thing as being able to compare hourly rates!

In the end I obtained quotes and brochures from five agencies. An initial difficulty was that some agencies were reluctant to divulge their rates and one never did, however my comparison this year was easier. It was also difficult to get a clear picture of what the actual cost would be. Most charged different rates for an hour, more pro rate for a half hour and yet more for a quarter hour, weekends and bank holidays. Some made an additional charge for travel and some did not guarantee an 'honest' time saying that travelling time might impinge. Additionally most said that they had a team of many several members and could not guarantee who would call.

In order to compare costs I compiled a table of both rates and services and worked out the charges over a full year. This gave the cost effectiveness of each agency and showed which had small teams, could be accessed locally and provided 'honest hours'. My preferred agency came out as costing a little more for the hours needed than the cheapest provider, with the most expensive costing an additional £30 a week more.

I attached this table to a letter with the reasons for choosing this agency and Aunt Cissie's Care Manager submitted this to the funding panel. I also completed a financial assessment for West Berks to establish how much Aunt Cissie should contribute to her care.

Where we are now

I have now set up standing orders to pay the care agency from Aunt Cissie's Care Account, one from Aunt Cissie's bank to West Berks for her personal contribution and one to the care agency. I make a return, via email, once a month to West Berks with a Screen dump of Aunt Cissie's bank statement, although this could be done by post. If Aunt Cissie has any outgoings that might alter her contribution, for example when her rent was increased, I email West Berks and an adjustment is made. I then need to change the standing orders. There is also an annual review of this contribution.

Is it working?

A resounding YES, at the moment! So much so that Aunt Cissie's 'score' at the memory clinic has increased! She is happier and more settled and has been able to remain in her own home, which would otherwise not have been the case.

I have regular meetings with the care agency, usually before I go away and on my return, and then at either my or their request. We also have email contact as necessary. I have had conference meetings with all the agency staff who might need to 'cover' Aunt Cissie's care if emergencies arise with any of the regular team so that there is a collective understanding of her care needs. However, as their staff turnover is virtually nil this has not been an issue in the 12 months we have been 'partners'. Our (I really think she 'belongs' to us!) care manager makes regular checks about how things are going, West Berkshire care finance department staff have been prompt and responsive to circumstantial changes and forgiven my own 'slippages' in accounting! *Name changed to preserve anonymity*

INFORMATION CORNER

Background to the landmark Coleman case which could lead to new rights for millions of carers.

What was the case about? Sharon Coleman worked as a legal secretary for a law firm. She left her job and took her employer to court for constructive dismissal claiming she had suffered disability discrimination because she had a disabled son. This is termed 'discrimination by association'.

Why did she feel she had to leave her job and take legal action? When her son was born disabled she felt her employers began to treat her differently. When she asked for time off to deal with her caring responsibilities she was described as 'lazy'. She said she was not allowed as much flexibility as parents of other children.

Why is it in the European courts? Under UK law, disability discrimination laws apply only to the disabled person themselves. The employment tribunal in London which heard Sharon's case decided to refer the case to Europe because the European Union's Equal Treatment Directive interprets disability discrimination more widely than the UK.

What has this judgement said? An Advocate-General, the most senior law officer of the European Court of Justice, has now agreed that the Equal Treatment Directive makes "discrimination by association" unlawful in the same way as discrimination against the disabled person themselves. This statement of a legal principle is an important landmark in the case but it is not yet the final decision. A panel of European judges will make a final ruling on the issue later this year.

Does this mean UK discrimination law is now different? Not yet, but the case will have huge implications for carers in the UK if the European Court of Justice follows the Advocate General's advice.