

The Debenham Project

(Dementia - Caring for the Carers)

1. Telephone Support Line

The confidential telephone support line is a key element of the Project. It will be there to provide an understanding and listening ear for carers who are finding it hard to cope with the practical and emotional difficulties of caring for someone with dementia. The task involves being “on standby” in your own home to receive calls from carers who need reassurance that they are not alone and that there are avenues that can lead to some easing of their problems and distress. It is also likely that it will be used by carers as a “first port of call” to get information and to find out how to access support services. So those who are answering the calls will have to guide carers to others who will be able to help with specific enquiries. The support line will become one of the most important interfaces between carers and the Project.

Volunteers for this task can be anyone who is compassionate but also needs to be robust enough to listen to, sometimes, traumatic calls and gently support the caller. To do this counselling skills would be helpful but not essential as a short training in telephone counselling, and an introduction to Dementia will be provided. The main involvement lies in being able to reasonably regularly “be at home”, perhaps a half day per week, to answer calls in a room free from interruption. We suspect that in the early days of the project there will be only a few contacts, and many of these will be requests for information, but as awareness of the Project increases the number of calls will rise steadily.

2. Activities and Social Support Sessions

We intend to run a regular set of activity sessions in Dove Cottage. The exact format of these may vary according to the clients. Because this is a cooperative exercise between CAMEO, The Debenham Project and The Resource Centre it will seek to appeal to the full spectrum of intellectual and physical abilities and to provide a social dimension for both carers and cared for. Activities are likely to include Scrabble, Sudoku, Towers of Hanoi, Skittles, memory games and many others. It will need about four people on a regular basis, initially fortnightly but probably, with time, every week.

Volunteers only need to be able to participate in activities and to socialise with those who come. Some experience of contact with someone with Dementia will help but is by no means necessary as we can provide a short training in the skills required - basically, the most important skill is to care.

3. Luncheon Club

In cooperation with Age Concern the project is going to run a regular series of luncheons, hosted by, probably two volunteers each time. Initially this will be on a monthly basis but, if there are sufficient volunteers and sufficient demand, it could be more frequent. For the time being these will be held on a weekday in Dove Cottage. The clientel will be, again, inclusive of all the elderly and their carers but with a clear remit to support the carers of those with Dementia, and an emphasis on maintaining social contact in the community.

Volunteers need to be able to provide luncheon for up to eight clients - although four would not be abnormal. If the venue is the volunteer's home, and this is in some ways preferable, then due consideration needs to be given to access for those with more limited mobility.

4. Story Board

One of the things that is apparent is that carers for those with Dementia feel alone and often just the knowledge that others are going through the same difficulties and emotional turmoil can be a great support. Developing a body of carers' personal experiences - the problems, the heartaches, the hilarious moments, the feelings of guilt, the anger, the frustrations, etc and sharing them with other carers is believed to be effective in reducing tension and stress. Such an exercise has been carried out

by the Suffolk Mental Health Trust in cooperation with Suffolk Family Carers, The Alzheimer's Society and Age Concern. We will provide access to this work but we also want to add to it and provide a community flavour.

This a creative task for one or two volunteers and will involve talking to and recording their experiences. Respect for confidentiality and anonymity will be vital. A good level of literary skill is required together with the ability to encourage carers to relax and "open up". This activity may well prove cathartic in the same way as counselling may be. A short training in counselling skills can be given if required.

5. Information and Advice Centre

The Information and Advice Centre is viewed as a central feature of the project. Most carers express frustration with the difficulty of easily accessing quality information and support. There will be three aspects to this activity which is being developed cooperatively with the Debenham Resource Centre. 1. A prominent display highlighting the Debenham Project and providing a range of useful leaflets and booklets. 2. An "Information Access" area on the Website which will provide ready access to accredited information and important support websites - a key feature will be direct links to Suffolk Libraries' Dementia database. 3. A personal service provided by the library staff to guide carers in their request for information and in making contact with support agencies.

This is a task for one volunteer who will need to maintain contact with key charitable and local government agencies and make sure that the information/leaflets/booklets are up to date and that new material is added on a regular basis. They will also need to liaise with the library staff and with the website manager. Some computer skills would be needed i.e. to access websites, use e-mail and download information.

6. Website Support and Content Management

The Project's website will be central to the success of the endeavour. It will not only give carers ready access to information, experience, advice, contacts, etc but also demonstrate the professional nature of the Project to potential contacts and funding agencies. The activity involves two main aspects. 1. The technical tasks of programming, developing and maintaining the website. Chris Bishop has this well in hand but another volunteer to help would be useful. 2. Managing what goes onto the site. This role is fairly similar to that for the Information Centre and the skills required also much the same. The two roles might be combined.

7. Fund-raising and Social Functions

Without funds there can be no project. We need to cover setting up and routine expenditure in the short term and we can guess that this means raising enough money to pay for the telephone line, activities equipment, accommodation, CRB checks, administration, etc. We are very fortunate to be able to cover these costs for about the first year through the sponsorship of the church, a substantial private donation and funding by the library service. However, we must start thinking about local fundraising functions because these not only bring in money but are valuable publicity for the activities within the Project.

To achieve our long term aims we will require funding on an altogether larger scale and needs a group of volunteers who have experience in large scale financial projects.

8. Administration and Clerical Support

This activity speaks for itself. It may not be high profile but it is nonetheless essential. We already have someone who has offered to take on the role of minutes secretary but we need a volunteer who would like to take up a role which is that of a general project secretary - I'm just about managing at the moment with Sue's help but it would be good to spread the load and have some extra capacity.

9. Publicity and Advertising

This is the essential task of promoting the project at all levels but especially at local and county levels. The "Identity" of the project is very important in convincing professional organisations and charities that we are worth funding, and in "selling" the project to carers and those agencies that provide support services. It needs someone with skills in marketing and commercial design.

10. Research

We cannot overstress the importance, when dealing with potential funding organisations, of having the

best possible understanding and quantitative data - especially the likely present scale of the problem and how this is expected to change over the next 10 to 20 years. We also need to be thoroughly aware of the services (NHS, Local Authority and Charitable) that exist and how their provision might alter over the next 5 years or so. There is also a need to explore best practice in home, day, residential and nursing care for Dementia. Finally, professional costings for the long term objectives must be obtained.