

CFU Carers' Support Group



For carers and relatives of people with fronto-temporal dementia and semantic dementia

Newsletter

FEBRUARY 2007

Welcome

Welcome to the February edition of our CFU Carers Support Group Newsletter! We hope you have all had an enjoyable festive season and wish you the very best for 2007! A big thank you to all of you who came to our Carers' meeting on 25th January. Caroline Davies, a Case Worker from the Citizens' Advice Bureau gave a very informative and helpful talk on financial implications of residential and respite care, a burning issue for many carers. We've provided a short summary of the main points she made

regarding continuing care and paying for care. These are very complex issues and she advised anyone considering care options to seek specialist advice. There are many organisations who can provide free and independent advice to carers, and we have included their contact details in the 'Useful Contacts' section. We have many meetings and interesting talks planned for 2007, so please take a look at our Carers' Agenda for dates and details of our future meetings.

Contents

Welcome	2
Financial implications of residential and respite care	3
Useful contacts	5
Did you know? Help with heating and home costs	6
Changes to the Mental Capacity Act	7
New CFU Carer Group Website	7

Financial Implications of Residential and Respite Care

Caroline Davies, Citizens Advice Bureau Case Worker

Introduction

There are several options available for residential and respite care. It is possible to receive NHS care free of charge if a person is eligible for Continuing Health Care or if they have a low income. In other cases, financial contributions to health care are means-tested. Financial issues relating to care are extremely complex. The information below is just a brief introduction and we strongly urge anyone considering applying for respite or residential care to seek independent advice regarding their case.

Continuing Health Care

What is Continuing Health Care?

Continuing Health Care is a general term that describes the care that people need over an extended period of time as a result of illness, accident or disability. It can address both physical and mental health needs. Continuing Care can be provided in a range of settings, such as a hospital, a registered care home or a person's own home. The

type of health care services provided include primary health care, respite health care, community health services, health care equipment. The range and amount of NHS services provided varies in each case. Continuing Health Care can either be fully funded by the NHS or jointly funded by the NHS and Social Services.

Who can apply?

In order to receive Continuing Health Care, a person must fit the eligibility criteria. A person's diagnosis (e.g. Frontotemporal dementia) does not on its own make them eligible for Continuing Care. At the moment, eligibility criteria differ between regional Strategic Health Authorities. However, as from April 2007, new national criteria will come into place. An important aspect of these new criteria is that they will outline provisions for people with dementia, something that is not included in the current criteria.

As an example, in the Greater Manchester area, a person is considered to be eligible for Continuing Care if they fulfil the following criteria:

1. The person has a health condition resulting in:
 - complex health care needs&/or
 - intensive health care needs&/or
 - unstable / unpredictable health care needs
 - rapid deterioration

AND

2. The person requires significant health care inputs, such as:
 - regular supervision by a member of the NHS care team (e.g. a consultant, therapist)
 - routine use of specialist health care equipment

How do you apply?

Any person, relative, carer or service provider can request an assessment for Continuing Care. The first point of contact will generally be your GP. He/she will discuss the eligibility criteria, and if it is possible that the person's needs fit the Continuing Care criteria, they

will contact the Continuing Care Lead in the Primary Care Trust (PCT). You can also contact your local Continuing Care Lead directly to kick-start the process.

Who performs the assessment?

All professionals concerned with a person's care (Consultant, Social Worker, Therapist) take part in the assessment process. The person and their family's wishes are also taken into account. A meeting is then held to discuss the assessments. If it is thought that the person's health care needs meet criteria for Continuing Care, a recommendation is made to the Continuing Care Lead at the PCT. The person will then receive a letter from the PCT informing them of the decision for Continuing Care.

What if my application is rejected?

If you have been assessed and have not been found eligible for Continuing Care, you may request a review of the decision concerning your eligibility. To request a review you should contact your Continuing Care Lead at your local PCT. They will then forward your request on to

the Review Panel at the Strategic Health Authority.

Paying for Care

If your partner/relative does not fulfil the criteria for Continuing Care, they will have to contribute financially towards their own personal care and accommodation costs. Paying for care is assessed on a case-by-case basis and takes into account the type of care required (temporary or permanent residential care), the person's contributions as well as their financial assets.

What is temporary and permanent residential care?

Temporary care is a stay in residential care of less than 52 weeks. Residential care becomes permanent if it exceeds 52 weeks.

How much will I have to pay?

If the person holds assets of more than £21000, they will have to pay the full fee. If their assets are less than £12000, they receive care free of charge. For assets of £12000 to £21000, a scaled income tariff applies (please check for exact tariffs).

How are financial means assessed?

Only the person's financial assets, not their partner's or relatives' assets, are assessed. If the person holds a joint account with their partner, only the person's share of the account (half) will be assessed. Charges on the person's property are only placed if it is currently unoccupied. Property is disregarded if the spouse or a relative under 60 (e.g. children) is currently living in it.

Useful Contacts



Continuing Care North West Strategic Health Authority

For more information concerning Continuing Care and the review procedure.

Website: www.northwest.nhs.uk

Carers Federation

Provides a wide range of support services and useful information. Their Independent Complaint Advocacy Service provides advice to patients and relatives concerning decisions made by the NHS.

Website: www.carersfederation.co.uk

Tel: 0845 120 3735

Combined Hospitals CAB

Independent free advice and representation to patients, carers and visitors at Hope Hospital. The CAB Community Carer can advise on Continuing Care issues.

Tel: 0161 206 4713

Caroline Davies, CAB case worker, can also come to the CFU clinics to give you free, individual advice. If you would like to meet her, please notify Brenda, our CFU social worker, in advance on 0161 206 2175.

Care Home Standards

Social Care Institute for Excellence

An independent registered charity whose role is to develop and promote knowledge about best practice in social care.

Website: www.scie.org.uk



Did you know that, as a carer, you can receive help towards improving your home and heating costs? We've outlined below some of the

Help with heating costs

If you or your partner receives attendance allowance or disability living allowance, you can apply for a Warm Front grant to help with your heating bills as well as insulation and heating improvements to your home. All you need to do is fill in their application form. A Home Energy Adviser will then visit you at home and recommend work for your property. To find out more, you can call Eaga Partnership on freephone 0800 316 6011 (lines open 8am to 6pm Monday to Friday) or visit the Warm Front website at: www.eagagroup.com/grants/warmfront

free services that carers from the group have used. If you know of any other services that are free for carers, then please let us know.

Home Improvements

If you are caring for someone at home, you may be entitled to help with small home improvements. Anchor is a non-profit organisation which aims to help older people or disabled people with whatever repairs, improvements or adaptations are necessary to help them continue to stay at home. Typical jobs include insulation, security improvements, plumbing, damp proofing and electrical work. For more information and to find your local Anchor agency, visit the Anchor Staying Put website at: www.stayingput.org.uk or call 0191 270 6069.

The Mental Capacity Act

The Mental Capacity Act affecting the Appointment of Attorney comes into force on 1st October 2007. The following apply:

- 1) An Enduring Power of Attorney (E.P.A) will be valid after 1st October 2007 and can be registered after this date.
- 2) It will not be possible to create an E.P.A. after 1st October 2007. It will be replaced by a Lasting Power of Attorney (L.P.A). In addition to property and affairs, a person can empower an attorney to make health and welfare decisions. Before it can be used, an L.P.A. must be registered with the new office of the Public Guardian.
- 3) If you are thinking of making an E.P.A., it would be sensible therefore to consider doing this before 1st October 2007.

In a straightforward case where there is no doubt that a person has capacity to make an E.P.A., the form can be downloaded from the website at www.guardianship.gov.uk, can be purchased at WHSmith or OyezStraker. Complete it in accordance with instructions provided. However, please seek legal advice if there are concerns about a person's mental ability to

give consent or if there are substantial assets. Good Luck!

Margaret Seed, a solicitor who has given talks on legal matters for CFU carers in the past will be giving a talk later this year on the implications of the new Mental Capacity Act for carers (See list of talks on p.9).

Website

We now have a brand new website for the CFU Carers Support Group! Our new address is: www.cfucarers.org.uk

The website address is also printed at the front of our newsletters. The website contains information about our support group as well as copies of our previous newsletters and summaries of all the talks we have had by invited speakers. There is also a Carers' Questions page listing

questions that have been frequently asked in the group. You can access the main website for the Cerebral Function Unit, where more information for patients, carers and clinicians is available.

Communicating with Clinicians and Health Care Professionals

At our Carers' meeting last November, many of you expressed your frustration at how difficult it

was to communicate with clinical and health care professionals. Some carers found that professionals in charge of their relative/partner's care showed little awareness or interest in their condition, making them feel isolated and unsupported. In an attempt to remedy this, we have compiled some information sheets about frontotemporal dementia and semantic dementia designed specifically for clinicians involved in the care of a person with one of these conditions. The information sheets will shortly be available on the Cerebral Function

Unit website at:
www.cerebralfunctionunit.co.uk

We have asked the CFU Consultants to refer to these information sheets in their future correspondence with clinicians involved in the care of people with frontotemporal dementia and semantic dementia. These leaflets can be printed directly off the website and circulated to anyone you feel would benefit from them. The website also includes information sheets specifically designed for carers and relatives of people with these conditions.

Donations

The CFU Carers Support Group is run on a purely voluntary basis by Brenda, Camille and Cheryl and receives no external funding. We greatly appreciate the donation of £1 from carers who attend the meetings. This goes towards providing teas and coffees at the meetings and offering a small gift to invited speakers who kindly give their time to come and speak to our group.