

# CFU Carers' Support Group



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

## **Newsletter**

**February 2008**

**[www.cfucarers.org.uk](http://www.cfucarers.org.uk)**

# Welcome

Hello and welcome to the February edition of the CFU Carers' Newsletter. We'd like to wish everyone all the best for the New Year and hope 2008 will be a good year for you. Many thanks to all of you who came to our last meeting in January. We'd like to say a special thank you to Irene and Sarah, both members of the CFU Carer Support Group, who came to talk to us about their experience of caring for their loved one. They have very kindly written their thoughts and feelings

about caring to share with readers of the newsletter. If any of you would also like to share your experience or your thoughts through this newsletter, then please send us a letter (see contact information in Carer Information Cards section). At the last meeting, we also discussed what kind of meetings carers would like in 2008. We've listened to your suggestions and have drawn up an agenda of meetings for the year ahead. We hope you find these helpful.

## Contents

Welcome	2
Sarah's story	3
Irene's story	4
Did you know? IMCA	5

# Carers' Stories

## **Sarah's Story**

My carers story is about my Mum Marjorie.

When I think back, Mum's Frontal Temporal Dementia journey began at least 4 years ago. Little things such as an increased appetite for sweet foods and drinking coffee and eating ice-cream for the first time in over 20 years (these were the nicer symptoms). Mum "dipped" in an alarming manner whilst I was at University about 2 years ago.

I struggled to remain on my course whilst fighting for a diagnosis for her. During which time Mum was on a women's mental health ward that was inappropriate. Like a number of

people with FTD, the Psychiatrists attempted to mis-diagnose Mum as psychotic and schizophrenic. Unfortunately for them, I had 2 things in my favour; (1). I had at my finger tips an army of the latest medical information. (2) This was my Mum, my Mum who had always been there for me, who had patched up my grazes when I fell and told me everything was going to be alright.

Now it was my turn. We were referred to the CFU unit following an MRI scan and I felt so relieved that my Mum was "officially" diagnosed. I found Mum a really good residential care home with staff trained in person centred dementia care,

with a resident there with FTD. I love Mum so very much and at the same time I hate what FTD has done to us. I love that we

are closer now than ever but I hate how many tears I've cried and I still cry.

## **Irene's Story**

Frontotemporal and semantic dementia is the worst illness possible, as it affects the carer as much or even more than your loved one. Nothing appears to bother them and we are pulling our hair out over a situation. It is a life-changing experience for everyone. So much happens in a short time. We experience all emotions possible, face situations we have never encountered before and never will again. In all of this we need to keep a sense of humour and try to see the funny

side. We have to have time for ourselves to recharge the battery or else we are unable to cope.

John has had frontotemporal dementia for five years and what a learning curve it has been. It is certainly the Long Goodbye. Without Professor Neary's diagnosis and all the help and support from the team at the CFU I don't know where we would be today. My sincere thanks to you all.

*The Mental*



*Capacity Act*

Dealing with financial affairs can be a very confusing and costly process. As Margaret Seed explained in her last talk, the New Lasting Power of Attorney is a complicated document,

which is puzzling even for many in the legal profession. There are however a few organisations that you can access, which will give you more information.

### **Independent Mental Capacity Advocacy (I.M.C.A.)**

Under the new act, the NHS Local Authorities have a duty to provide advocacy and representation service for people who lack mental capacity and for whom the following applies:

- They are due to receive serious medical treatment
- An NHS body is proposing a stay in hospital for the person for more than 28 days or more than 3 weeks in a care home
- A local authority is proposing to move a person to a care home for longer than 8 weeks.

A person has a statutory right to an IMCA in the above circumstances if they have no family or friends, or if their family/friends are inappropriate.

To find out more about IMCA, contact North West Advocacy Services:

Tel: 0845 680 0513

Web: <http://www.nwas.org.uk/imca.html>

You can also contact the Public Guardianship Office:

Tel: 0845 330 2900

Web: [www.guardianship.gov.uk](http://www.guardianship.gov.uk)