

PDSG *newsletter*

Welcome to this month's Pick's Disease Support Group Newsletter

This Month

May 2010

www.pdsg.org.uk

- **John Brown** tells the story of his wife and how together they strive to keep active

- **Julian Taylor** reviews the book 'Contented Dementia' by Oliver James
- **Emma Svanberg** considers a thesis that looks into how young people cope when a parent has dementia

- **Innovations in Dementia** a company working to enhance the lives of people with dementia
- **Money Matters** changes in Gift Aid and how you may be entitled to reduced charges for Gas and Electricity.

Restlessness

by John Brown whose wife has FTD

Boris Johnson, London's Lord Mayor is encouraging cycling only on certain days in London. It triggered a long-held dream for a pedal powered caravan, and with new materials and technologies now available I am hoping to find a firm or person to offer a prize for a machine as outlined below.

I am 81 and my wife, Irene 76. Way back in 1952 we took our £50 travel allowance, plus two old bikes, two youth hostel cards and minimal camping equipment, and got to know each other by making the travel allowance get us as far, and for as long, as was possible.

It took us three months to get to Naples via Amsterdam, Munich, The Gross Glockner Alpine Pass, Venice, Foggia, Naples, then return through Rome, Pisa, Genoa, Monte Carlo, Grenoble, Paris and UK.

We saw a Europe that has now disappeared, and met some wonderful people in country districts on the way.

We married in 1953 and produced five children between 1954 and 1962.

It seems that with illness of old age, we have just a chance to make a miracle happen by doing again what we did nearly 60 years ago, that is to take off together and see what happens.

Of course, we could not hope to repeat the 1952 experience, which a combination of youth and the most appalling ignorance made possible, but there is no reason why, we should not explore new horizons.

We do our own housekeeping, shopping, etc. Irene makes the bed and does the washing-up. I do the cooking and home upkeep. We cut each other's hair; I take charge of the various tablets prescribed for people like us. Irene puts in my daily eye drops and I hold her hand when necessary away from home.

Yet, we have always been active. For 10 years, Irene was 'Auntie Renee' writing a page for children in two local newspapers and visited schools to encourage children in creative writing. I was an insurance broker, but went to teacher training college and became Head of Business Studies in comprehensives at age 48. At ages, 58 and 54 we did a one year Commonwealth Teacher Exchange to Australia, and in 1988/9 we were VSO volunteers working in the remote Highlands of Papua New Guinea.

Now, for us, 'Retirement' is just a metaphor for 'unemployment', and we think the answer is a pedal-powered caravan. A machine that will let us sit side by side and meander through England and Europe without hindering other traffic; climb any hill, no matter how slowly; and keep us mobile whatever the weather. It must allow us to overnight in reasonable comfort in any pretty spot we may find ourselves in.

Our needs are simple, always have been, and so far life has been an adventure. I believe this is the best way to keep us healthy enough until a cure for Pick's Disease is discovered. Of course we know time is not on our side, there has never been anyone else for either of us, and I have a gut feeling that simplicity and a lack of caution could work for us.

Years ago I discussed this idea with a young German engineer, but he replied at length about power/weight ratios, etc. However, so many wonderful new things are now available, that maybe a sufficiently encouraging prize could stimulate the invention of a pedal-powered caravan that, with your encouragement, could send thousands of couples like us to take to the byways of this beautiful country.

Contented Dementia by Oliver James

ISBN 9780091901813

Julian Taylor

This book is about Penny Garner's work at a clinic and hospital near Oxford. It is about spoken words and conversation, thoughtfulness and imagination and tact and socializing with patients.

Extracts from the book: "By the end of the book you will see however advanced the illness, the real person who means so much to you is still there. So long as they are appropriately supported in their perception of what is happening they can find themselves living as happily as they ever did. There is no cure for

dementia or any sign of one. At best the drugs that have been developed to reduce the symptoms are only for a limited number of people and then only briefly."

The book gives many examples of very gentle words and tact to calm the people and prevent them becoming frustrated and bad tempered. The title gives the clue: tact, kindness, avoiding confrontation and thoughtfulness all contribute enormously to contented dementia.

From my point of view it is a rewarding achievement by carers to help a patient with dementia have comfort and happiness at the different stages of the disease; and good nursing, thoughtfulness and avoiding confrontation are the foundations of that care.

My wife Jackie died in 2008, aged 77. She was diagnosed with Pick's by

Professor Rossor 9 years earlier, and was nursed and died at home.

Besides chatter and laughter around her bed Jackie enjoyed listening to music and watching and hearing a cello. We hung her brightly coloured dresses where she could see them and also a Matisse poster for her to look at. A friend painted abstract figures also brightly coloured on her ceiling. The cat a small Burmese slept on her bed. We dressed her in bright colours and brushed her hair and polished her nails. There was almost no medication.

She died with DIGNITY, PEACEFULLY and I am sure she was contented.

I commend this book Contented Dementia by Oliver James to all carers of people with dementia.

'Just Helping': Children Coping with a Parent with Young Onset Dementia

Emma Svanberg

Overview

The recent publication of the National Dementia Strategy (Department of Health, 2009) heralded a new era for dementia services, but the strategy largely ignored the needs of younger people with dementia and their families. The

three parts of this thesis consider what those needs may be, in particular concerning the children of people with young onset dementia.

Part 1 is a literature review considering the impact of young onset dementia on the family. It reviews previous research into the effect of a diagnosis on the individual, their spouse and children, examines factors which may influence the response to a diagnosis and highlights the need for further research.

Part 2 presents the empirical paper, a mixed method study exploring the experiences of children of younger people with dementia. It considers whether these children can be

compared to other young carers, examines the impact of the

diagnosis of dementia and performance of caring tasks and describes the process of adapting to dementia.

Finally, Part 3 is a critical appraisal of the study. It explores dilemmas which arose during the course of research and discusses issues such as recruitment. It then considers the proposed model of adapting to dementia in light of previous literature, and the service implications of the study as a whole.

care and support in order that they are more creative, positive and enabling.

They aim to work collaboratively with people with dementia in all their work.

They provide advice and training to other organisations to help them develop more positive care and support services for people with dementia.

They believe that people with dementia should:

- Be able to experience all that life has to offer
- Receive appropriate and sensitive support to access opportunities and learn new skills
- Be part of opportunities and decisions that affect their lives At Innovations in Dementia they believe that with the right support and opportunities, people with dementia can communicate, engage, participate and continue to be part of relationships and communities no matter how advanced their dementia.

Some of their areas of interest:

Start Making Sense - accessible information for people with dementia Find out more about their work to make public information easier to use.

Making sure that the voice of people with dementia is heard Find out more about their projects and ideas.

The civil rights of people with dementia

They believe that people with dementia have rights that are being denied them

People with dementia making use of computers, the internet and other technology. Find out more about their projects around technology and people with dementia

Because they are a Community Interest Company. This means that any profit they make is put back into the organisation.

They do not offer services for people with dementia. Instead They work with other organisations to make sure that people with dementia can continue to take part in their communities and have active lives.

One of our PSDG members (Victoria) has been involved in making a very positive series of films about living POSITIVELY with dementia.

Nick (Victoria's husband) is a brilliant artist and loves to draw. He is one of the "stars" of the film.

The launch of these films (4x10 minute) took place at the Exeter Picturehouse Cinema. Many people were there, including professionals from all over the south west and beyond. Most importantly many stars of the films also attended. The four films can be seen on the Innovations in Dementia website. Go to : www.myid.org.uk/videos.htm

They have been made by people with dementia. They are about people who are living with dementia. But they are not just about dementia. They are about people living positively, with vitality and creativity. They are about people who are still learning and still growing. They show that dementia is life-changing, but not life-ending.

Nick's Misericords

This film follows Nick as he visits the oldest known collection of misericords, in Exeter Cathedral.

A story for Josh

We accompany Sandra as she visits the library where she spent most of her working life as a librarian. There we meet some of the cast of a story which Sandra wrote to capture the imagination of her grandson and introduce him to the world of books and reading.

Listen to Me

Peter has had a long and illustrious career as a sculptor and educator. In this film, Peter shows us round his studio, and recalls some of the events which shaped his life and career.

The Walking Group

The Walking Group is made up of members of the Forget-me-Not Centre in Swindon. Join us as we try to keep up with them as they tramp across the Wiltshire countryside.

They are available on the website www.innovationsindementia.org.uk and can be viewed by all.

If you would like to know more, Contact them:

Email: ideas@innovationsindementia.org.uk.
Telephone: 01392 420076
Innovations in Dementia CIC, PO Box 616, Exeter, EX1 9JB
Website: www.myid.org.uk
Registered as a community interest company No. 06046815

Money matters

Gift Aid

Many thanks to all of those people who have kindly sent donations to us over the past years.

If you pay tax it means that for every pound you give the charity receiving it will receive an extra 25 pence from the Inland Revenue

Cheques still need to be made payable to NHDF (PDSG)

But I have been informed by the National Hospital Development Foundation (NHDF) that the details on our Gift Aid form are a bit out of date. Apparently Her Majesty's Revenue and Customs are getting stricter!

To qualify for Gift Aid, you must pay an amount of Income Tax and/or Capital Gains Tax for each tax year (6

April one year to 5 April the next) that is at least equal to the amount of tax that the charity will reclaim on your donations for that tax year.

Carol now has the updated Gift Aid form and is happy to send a copy to you if you ever want to make a donation at any time.

Reduced Charges

Thanks to Gillian Ramsay for the following information:-

You may be entitled to reduced charges for Gas and Electricity.

All energy providers have to offer social tariffs to help their most vulnerable customers cope with the high costs of gas and electricity. According to new Ofgem rules, all social tariffs must equal the supplier's cheapest deals.

Suppliers also agreed to increase their collective spend on social tariffs by £225million between 2008 and 2011 - so if you're struggling to keep up with the rising cost of heating your home, why not talk to your provider

and see if you can be moved to a cheaper tariff?

Each supplier has its own set of rules about who qualifies for the reduced rates. For more information, contact your fuel supplier and ask for details of their social tariffs.

www.energychoices.co.uk/social-tariffs.html

provides information by supplier.

Typically there are 2 parts to the requirement, income usually excluding disability allowance and meeting the vulnerability requirements which many patients with dementia would meet.

Reductions can be as much as 20% so it is well worth enquiring.

Future Meetings

London

In the Old Boardroom of the National Hospital for Neurology & Neurosurgery, Queen Square, London. 11.30 - 15.30 Dates - 15th June, 27th September, 6th December

South West The next meeting is planned for Tuesday 11th May,

12.00 - 3.00pm For details contact Nan email: underhin@aol.com or Penelope 01297 445 488

Liverpool Neurosupport Centre, Liverpool, 13.00-15.00 13th May, 15th July, 9th September, 18th November For details contact Mary Dawber Tel: 01625 879 104

Regional Contacts

Scotland - Mrs Elaine Anderson
01292 442 273

Yorkshire - Rev. Ron Carter
01904 610 237

Northern - Mrs Jillian Ramsay
0191 421 40 m. 0770 885 74

Trent - Mrs Janet Carpenter
0116 239 2913
(Also contact for Carers of Alcohol Related Dementia)

Mersey & North West - Mrs Mary Dawber
01625 879 104

West Midlands - Sister Ann Johnson
01743 492 175

Central - Mrs Helen Beaumont
01235 200 360

London - Mrs Carole Ivey
0207 603 0550

Southern (Hants. Wilts.) Mrs Jenny Mackie
01722 336 352

Southern -(Surrey. Sussex) Mrs Val Bywater
01428 729 702
(m) 0779 272 1853

Kent - Mrs Mary Silvertown (work) 01622 694 895 (evenings & weekends) 01580 213 607

South West - Miss Penelope Roques
01297 445 488

North Wales - Mr Roy Jones
01248 351 537

South Wales - Mrs Pat Coulson
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