

# RIBI Conference 2011

## REPoD (Rotarians Easing Problems of Dementia)

Transcript of Speech given by Rtn Geri Parlby, Rotary Club of Tavistock

Thank you President Jim and good morning fellow Rotarians and honoured guests.



I'd like to introduce you to my Mum. When this picture was taken she was in her early 70s and had just finished her year as President of the Babbacombe & St. Marychurch Inner Wheel club in Devon. And yet while we didn't know it at the time she was already in the very early stages of what we now know was probably vascular or multi-infarct dementia caused by a series of small almost imperceptible strokes. It took us several years to find out what was wrong with Mum and after she was finally diagnosed she suffered a long and tragic decline only ending a few years ago when she finally passed away at the age of 85 a mere shadow of the woman she had once been.



The rather handsome fella on her left is my brother. Because mum had been widowed for many years he and I joined forces to sort out the multitude of financial and practical issues that always accompany dementia, powers of attorney, financial planning, carers, house sale and ultimately nursing homes.

We shared the daily headaches and heartaches of slowly, very slowly losing someone we loved - swallowed up bit by bit by dementia.

About five years or so after this photo was taken my brother, then in his early 50s also started to develop the early signs of dementia, he was finally diagnosed as having Picks.

Disease or Fronto Temporal Dementia, a type of dementia that can affect people as young as 30. Over the difficult years that followed, his marriage fell apart, his business nearly went to the wall and his daughter ended up on antidepressants and suicide watch - she was just 15 at the time.

He is now in a nursing home - he can't speak, no longer recognizes me and looks at least 20 years older than his real age of 63 - I miss them both terribly! The repercussions that surrounded my mother and brother's battle with dementia were immense and organizing the restructuring of their lives was and still is a mind boggling task.

But I'm relatively young and used to poring over forms and certainly stroppy enough to demand my rights.

I'm a Rotarian after all!!!

But Imagine what it is like for the tens of thousands of men and women around the UK, often frail and elderly and already grieving for the loss of a much loved partner and suddenly confronted with a mass of paperwork and almost insurmountable mountains of practical issues whilst feeling alone and isolated in their battle with this dreadful disease. Imagine also what it must be like for the families of a younger dementia sufferer who may have lost both their breadwinner and a much needed parent.

Currently over 800,000 people across the UK have some form of dementia. This is a figure set to double within a generation.

Although Alzheimer's disease is the most common, there are many other conditions that can also bring about dementia, as I know to my cost. 25 million of the UK population have been in some way touched by dementia. It Costs the UK economy £23 billion a year, more than cancer and heart disease combined. 163,000 new cases of dementia occur in England and Wales each year - one every 3.2 minutes, and those are only the ones that have actually been diagnosed.

There is no doubt in my mind that we are poised on the brink of a national epidemic, one that is already presenting huge challenges to the NHS and Social Services.



So what can we as Rotarians do to help??

Well, REPoD has already made a start. Formed in the South West around five years ago by a group of like minded Rotarians from clubs across Devon and Cornwall we have been involved in a variety of projects aimed at supporting local families struggling to cope with dementia.

One of the most successful is of course the Memory Cafes. These are informal drop in sessions for people with dementia and their carers. For a couple of hours, once a fortnight or once a month, carers and the cared for get a chance to come along for a cup of tea and cake, along with fun and games. Carers can join in a carer's support group while volunteers organize and hour or so of games, singing sessions, reminiscence work, in fact all manner of entertainment where everyone gets a chance to take part. The wonderful Wadebridge Memory Café in Cornwall won the 2010 Magic of Rotary Award and those of you who were in Bournemouth last year will have heard some of the moving stories told by the café's clients.



There are now around 50 different cafes operating from the Isle of Scilly to the Dorset border with local Rotary Clubs involved in varying degrees, from setting up and running the café to volunteering or offering financial support.

And I'm delighted to say that several other clubs across the country have also followed suit – congratulations to the S. Cambridge Rotary Club who even managed to get Health Secretary Andrew Lansley to open their new café last month.

So what else can we do?

Thinking outside the box as they say our latest project is The Fifth Emergency Service, something of a return to good old fashioned Rotary with Rotarians offering their expertise to local families caring for someone with dementia.



This could be help with simple household repairs, gardening, shopping, taxi service, help with form filling, changing a light bulb, or just been a listening ear. It is often simple problems like this and the dreadful feeling of being alone that can be the final straw for elderly and overburdened carers.

Thinking inside the box, because of course we Rotarians love boxes, REPoD has come up with the idea of the Memory Box.

Longterm memory stays relatively well preserved quite late into the development of dementia. So whilst people with dementia may not remember what they did that morning they can still recall things that happened more than 40 or so years earlier.

Reminiscence is a wonderfully life enhancing opportunity for those living with dementia. And a memory box is full of a variety of different bits of memorabilia that can spark those wonderful moments of memory. Things like ration books, old comics, bubble gum cards, music CDs, photos etc., I spent a marvelous hour on Saturday at the Memory Café in Tavistock reminiscing about the creative things people used to do with war time rations - did you know you can create a pretend banana using a parsnip and banana essence - well you do now!



Being just young enough to have missed rationing I found the stories and suggestions fascinating. But what was even more inspiring was the effect that such a conversation had had on the people in the room who had some form of dementia. Unlocking those memories is one of the greatest gifts you can give to someone with dementia. We supply starter packs full of replica memorabilia so that clubs can create their own Memory Boxes to donate to their local day care centres, care homes, Memory Cafés or even libraries so local families can borrow them.

So in summing up what can your club do to help?

1. Firstly find out what support already exists in your community, don't try and re-invent the wheel, find ways to support the work that is already happening
2. If there isn't a Memory Café already in your town then think about joining forces with other community groups or neighbouring Rotary clubs and of course your Inner Wheel Club to get one started. Working in partnerships ensures sustainability.
3. Develop an emergency service ... rolling up our sleeves and getting things done is something that we Rotarians really excel at - at the risk of sounding like a party political broadcast this really is the 'Big Society' in action.
4. Memory Boxes, well the starter packs are available via our website and creating a Memory Boxes is something the whole club can join in with emptying those cupboards and digging up those long lost darning mushrooms, green shield stamp books and cigarette cards.
5. Fundraise, well REPoD operates not so much on a shoestring more of a rubber band, so we are always grateful for financial support. But even more importantly later this year we will be instigating a series of fundraising events to help raise much needed monies for research into a cure for dementia.
6. Database, Our website signposts all the main dementia advice sites around the Internet we have a award winning downloadable Carers' Pathways guide and a how to guide for setting up a memory café. We are also building the first countrywide database providing information on local support services for people with dementia, so if you have a relative with dementia living on the other side of the country you will be able to access information on the local services, but we need help from you to populate the database with localized information

These are just some of the many projects with which we need help, but most importantly we need you we need your ideas, and energies, tell us what you are doing, work with us and help to develop even more support for local families. Between us all we can really start to make a difference and become Rotarians who actually do start to ease just some of the problems of dementia.

Thank you for listening

Geri

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