

Look for and try to appreciate anything that will add something of pleasure to the day....arranging flowers in a vase can become a real activity of value and worth.

I feel guilty at leaving, but have forced myself to imagine a line between my life and John's life and our life. There has to be some divide...and whilst my heart says stay...it's easier to keep going, my head knows the value that even a short break or change of scene will bring. It is similar to the days of busy motherhood...when no-one can do the job as well or as easily as you, and to hand over to anyone else seems more trouble than its worth...but it is worth it!

I have had to make a choice to do some things which make me feel better. I find it helpful to have something to look forward to. It doesn't need to be a major event, but to know it is in the diary and will happen...for me those things tend to be based around activities which keep me socially integrated, and part of a world which is not Picks!

I have learned not to chastise myself for the things I get wrong. Hindsight is a wonderful thing, but we all respond and react to the situations we are faced with in the best way we can at the time...all other things taken into account.

I try to describe the difficulties I have with John in terms of 'my' or 'me'. For example: 'that upsets me' or 'I don't like it when you speak like that'. Who knows what difference it makes, but I feel better at the end of the day, than the alternative end of a day full of 'don't do' and 'stop that'.

On a practical level, I distance myself physically when I am finding things particularly trying. Just being in a different room, albeit of the same house, I find, can help.

When trying to control my reactions and behaviour towards John, I sometimes use the analogy of having an itch. You know you will only make things worse by scratching, but the inclination to do so is hard to resist. I have to rise above my natural inclination where I can, in order not to exacerbate what is often right on the edge of bubbling over..

Nobody is able to be at their best 100% of the time. We weren't before Pick's, so why should we be now? But, speaking for myself, managing a disease like this has required a definite mental commitment and conscious approach, which I hope I have been able to share in some way through these words.

Jan Welsh, speaking to Jill Walton.



PAT MORAN MEMORIAL CONCERT

On July 9th, Bridges Community Centre, Monmouth was rocking to the beat of a concert, arranged by Mr Brien Moran, in memory of his brother Pat, who died in January 2011 from Pick's Disease. During his life, Pat had a varied and interesting career in the music industry, incorporating roles as a record engineer and producer. He enjoyed performing in his own band 'SPRING' as well as assisting others in their musical careers. In 1975 he was awarded an New Musical Express [NME] award.

The concert had been organised as a memorial and fundraising event, with proceeds being donated to the PDSG. The surprise and guest appearance of Robert Plant added to the success of the evening, and left everyone with much to talk about! As well as playing at the event, Robert Plant provided a signed t-shirt which was subsequently auctioned on e-bay and has added to the monies raised.

Our thanks to Brien for his fundraising efforts, and our thoughts and best wishes are with him and the wider family, as they come to terms with the loss of Pat, and all that Picks Disease has caused them.



We have recently been made aware of the following service and hope to establish a link on our web page directing members to it. In the meantime, we hope it will provide another means of possible support to members who wish to use the service.



What is Carers Direct?

Carers Direct is a national information, advice and support service for carers in England. Available online at www.nhs.uk/carersdirect and as a free, confidential helpline seven days a week on 0808 802 0202, it provides accurate, relevant information for carers and those who support them.

Website information

- All information on Carers Direct is Information Standard accredited and was developed in conjunction with carers and national carers organisations.
 - Since its launch in Jan 2009, Carers Direct has grown to become a substantial online resource for carers and those who support them. It now has more than 1,000 articles, 12 videos and web tools available on the site.
 - Visitors to the website are regularly surveyed to ensure Carers Direct offers the information they need.
- Carers Direct provides online blogs and forums for carers. It also has an active Facebook fan page with over 7,000 carers available at www.facebook.com/carersdirect, and a twitter account with nearly 3,000 followers at www.twitter.com/carersdirect

Helpline information

- All calls to Carers Direct are free and confidential.
 - Over 20 specially trained advisors are available to give information and advice to carers, allowing them to take decisions about their personal support needs and the needs of the person they are looking after.
 - The Carers Direct helpline advisors can put callers in touch with specialist national or local sources of help, including social care departments, respite centres, specialist charities and other carers support groups.
- Enquires can be made by phone, email, post, Type talk, Text Relay and language line*.

***Additional information on helpline contact methods**

Telephone enquiries -The Carers Direct helpline number is 0808 802 0202. Lines are open seven days a week, from 8am to 9pm on weekdays and 11am until 4pm on weekends and Bank Holidays. All calls, including mobiles, are free.

Language Line - If you need help in a language other than English, you can request a call back in the language of your choice [LINK: <http://www.carersdirectenquiry.nhs.uk/callback>]. We use Language Line, a telephone translation and interpreting service that allows a conversation in one of more than 170 languages.

Email and online enquiries - If you have a question about caring you can ask it using the Carers Direct online enquiry form at <http://www.carersdirectenquiry.nhs.uk> . A Carers Direct advisor will normally respond within 24 hours of you submitting your enquiry. Carers Direct web address is www.nhs.uk/carersdirect

Text Relay and TYPETALK - Deaf, deafblind, hard of hearing and speech-impaired people who use a textphone can contact Carers Direct by textphone/minicom, on 0800 988 8657.

Postal enquiries -You can send a written enquiry by post to Carers Direct, PO Box 4338, Manchester M6 1 0BY.

RAISING AWARENESS

The PDSG is ready to launch an initiative designed to raise awareness of fronto temporal dementia. We are piloting the scheme amongst our Regional Contact People at the moment, and look forward to seeking your involvement in the New Year. Watch this space....!

END OF LIFE ISSUES

Call it what you may, planning for the inevitable decline towards end of life is often painful and traumatic. When the person you are planning with and for has dementia, then the process can be even more complicated and painful.

In a recent Alzheimer's Society publication, [Living with Dementia June 2011] an article entitled 'Being Prepared' outlined the benefits to thinking and planning ahead. Putting people with dementia more in control of their lives, reducing stress on families and carers later down the line and increasing the chances of a 'good death' are amongst the benefits listed. Peter Ashley, a member of the Dying Matters Coalition, and himself diagnosed with Lewy Body Dementia is quoted as saying "People are scared. They don't want to talk about dying.. They think of today, not tomorrow. Thinking about what's going to happen later when you lose your capacity can be a disincentive to planning ahead. But if people can overcome these problems they might be able to see the merit in it".

As a result of several conversations over recent weeks with members of this and other support groups, we wish to bring to your attention the following publications:

www.dyingmatters.org.uk has lots of information about planning ahead

<https://www.respectourwishes.com/>

www.endoflifecareforadults.nhs.uk/publications/planningforyourfuturecare

Also, the Alzheimer's Society have just published factsheet 463: Advance Decision

The General Medical Council has written advice and policy documents with regard to Advance Planning and is apparently aware of the need to incorporate the very specific issues that arise when a person has dementia. They can be accessed via:

www.gmc-uk.org

Go to the home page and then select 'Guidance on Good Practice', then enter 'Advance Directives' into the search keywords box at the top right of the page

ON ANOTHER NOTE...the Alzheimer's Society public policy team wants to hear about your experiences of planning for end of life, end of life care itself and the emotional and ethical issues this brings up. If you would like to be involved, please contact Martina Kane via martina.kane@alzheimers.org.uk or call her on 0207 423 3580.

Dr Phillip Fletcher: New Research Assistant at the DRC

Dr Phillip Fletcher has recently joined the Dementia Research Centre at the National Hospital for Neurology and Neurosurgery. He is working alongside Dr Jason Warren, and is beginning his own research looking at the processing of emotion and sound, and the interpretation of these people with fronto temporal dementia. In a recent presentation, he explained how he was keen to investigate whether the physiologically measurable responses to sound and emotion, correlated with the perceived and reported experiences of people with FTD. He would be very happy to hear from anyone who might be interested in learning more, or indeed taking part as a volunteer in his research. Please contact him via p.fletcher@ucl.ac.uk.

PDSG ANNUAL SEMINAR: March 7th 2012, 33 QUEEN SQ, LONDON.
Details to follow or contact jill@pdsq.org.uk

PDSG Regional Contacts: For carers, there is often a sense of isolation when faced with the distress and burden that fronto-temporal dementias cause. The PDSG puts you in touch with people who understand:

Scotland- Mrs Elaine Anderson 01292 442 273

Yorkshire- Rev. Ron Carter 01904 610 237

Northern- Mrs Jillian Ramsay 01914 214 069

mob. 07708 857438

Trent- Mrs Janet Carpenter 01162 392913 [Also the contact person for Carers of Alcohol Related Dementia]

Mersey and North West- Mrs Mary Dawber 01625 879 104

West Midlands- Sister Ann Johnson 01743 492 175

Oxfordshire- Mrs Sue Smith [Young Dementia UK Mon-Thurs]
01235 522 382

Suffolk- Mrs Gillian Gubb 01502 569077

Essex - Mrs Chris Webber 01708 640443

London - Mrs Carole Ivey 0207 603 0550

Southern [Hants, Wilts] - Mrs Jenny Mackie 01722 336 352

Southern [Surrey, Sussex] - Mrs Val Bywater 01420 362 123

Mob. 07792 721853

Kent- Mrs Mary Silverton 01622 694 895[work]

01580 213607[evenings and weekends]

South West- Miss Penelope Roques 01297 445 488

North Wales-Mr Roy Jones 01248 351 537

South Wales-Mrs Pat Coulson 01792 883 684

Northern Ireland- Mr Martin McCrory 2887 753812

Lynne Ramsay: Adviser re. the medical profession and obtaining funding and services 0208 467 1462

Mob. 07760 224 396

Forthcoming Carer Support Meetings :

London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, London: dates: Dec 12th, Feb 6th, [Annual Seminar 7th March 20112], May 14th @11am-3.30pm [meetings usually include visit to local Italian Restaurant for lunch]

Liverpool: Neuro Support Centre, Norton St, Liverpool, L3 8LR
dates: 24 Nov 2011, 19 Jan 2012, 15 March, 17 May, 19 July, 20 Sept, 22 Nov [for details contact Mary Dawber on 01625 879 104. Meetings usually take place between 1pm and 3pm.]

South-West: Arundel Arms, Lifton @12.30 on October 24th [for details contact Penelope Roques 0845 458 3208]