

PDSG

PICK'S Disease Support Group

The Pick's Disease Support Group Newsletter

OCTOBER 2010

For carers of frontotemporal dementia: Pick's Disease, Frontal Lobe Degeneration, Dementia with Lewy Bodies, Corticobasal Degeneration and Alcohol Related Dementia

Inside this issue:

• *The second of a two part series written by Dr Sebastian Crutch of the Dementia Research Centre, focusing on the role of the neuropsychologist in diagnosis of dementia. The full article can be viewed at WWW.pdsg.org.uk and will appear in a forthcoming information booklet*

• *RADAR keys explained*

• *Fundraising Update*

• *AGM Diary Date*

NATIONAL KEY SCHEME FOR TOILETS FOR DISABLED PEOPLE



One of the practical, social problems facing carers of people with dementia is managing the use of public toilets. These are rarely unisex thereby making it difficult for a partner to assist with any practical help required during toileting activities. Access to a toilet designed for disabled people, providing more room and provision to assist can be of enormous benefit to those caring for a person with dementia.

RADAR believes that everyone who experiences ill-health, injury or disability should have the same freedom and independence as all other citizens.

One important part of freedom is having the confidence to go out, knowing that public toilets will be available that are accessible and meet your requirements..

If accessible toilets for disabled people do have to be locked, providers are asked to join the NKS, which involves fitting standard locks to their toilets and making keys available to disabled people. This has now been adopted by over 400 local authorities Almost 8000 toilets have been fitted with the NKS lock . The scheme is also used by a number of other organisations including the National Trust, transport undertakings, shopping centres and some pub companies. Purchasing a NKS key, therefore allows access to NKS public toilets throughout the country.

For those who are unable to obtain an NKS key in their own locality, RADAR supplies keys at a charge of £3.00 (if collected and on declaration of a disability), £3.50 (if supplied by post and on declaration of a disability) or £4.11 (if the declaration is omitted)

The required declaration is simply a stated reason outlining why you are requesting a key...for example: 'I would like a key for my wife who suffers from dementia' .

REMITTANCE can be sent to: RADAR, 12 City Forum, 250 City Road, London EC1V 8AF.

Alternatively contact RADAR via: Tel: 0207 250 3222

Fax: 0207 250 0212

Minicom: 0207 250 4119

You can help the PDSG.....

We are trying to reduce the number of hard copy newsletters that we post each quarter. Please visit us at www.pdsg.org.uk and sign up to receive email notification that the newsletter is available to download [and print if you wish!]

From July 2011 we will only continue to post newsletters to people who have positively requested that we do so by contacting Jill Walton at 22 Brushwood Drive, Chorleywood, Herts, WD3 5RT . Alternatively, email jillpdsg@virginmedia.com or telephone **0845 458 3208**. Many thanks in advance for your assistance in this venture!



QUESTIONS NEUROPSYCHOLOGISTS ASK (AND WHY THEY ASK THEM)

Dr Sebastian Crutch, Dementia Research Centre, Department of Neurodegeneration, UCL Institute of Neurology, University College London, UK. In this, the second of a two part series, he unravels some of the reasons behind the extensive neuropsychological testing that patients undergo.

Neuropsychology is the branch of psychology that deals with the relationship between the nervous system, especially the brain, and cerebral or mental functions such as language, memory, and perception. In other words, neuropsychologists are interested in how aspects of our behaviour and mental abilities alter following damage to or degeneration of the brain. By testing and measuring our behaviour and abilities, neuropsychologists try to make inferences about the nature, extent and location of the underlying brain cell loss or dysfunction. In this article we explore the motivation for the questions which neuropsychologists ask, and in particular consider the characteristic symptoms associated with damage to different parts of the brain.

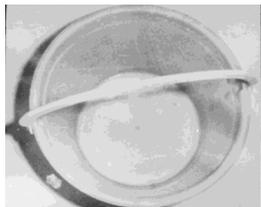
PART 2

[Part 1 of this article is available in the July 2010 newsletter and can be accessed via pdsg.org.uk]

The parietal lobes

The functions of the parietal lobe are somewhat more diverse, and there is a significant difference between the dominant side (the left in most people) and the non-dominant side. The dominant parietal lobe can be thought of as being concerned with things we have to put together into an order or structure. So tasks such as writing and spelling (which require putting letters and words together) and calculation (which involves ordering and combining numbers) are critically dependent on the dominant parietal lobe. This side of the parietal lobe has also been heavily implicated in a condition known as apraxia, an impairment of learned purposive movements, which is tested for by asking people to imitate or pantomime gestures and movements. The non-dominant parietal lobe could be thought of as our '3D centre'. One function of this area is to combine visual information from the occipital lobes into a 3D representation of the object being viewed. Damage to this area leads to a symptom known as visual agnosia, an inability to recognise objects, faces or surroundings. This is the reason the neuropsychologists often ask people to try to identify pictures and degraded or distorted images. The parietal lobes also contribute to our understanding of space, both in terms of our sense of body and personal space (e.g. knowing where our hand is relative to our body), and in terms of calculating the location of objects in external space (e.g. when we are reaching to pick something up). Spatial skills are often tested by asking people to count dots, arrange blocks in a particular order or to perceive which of two squares has a dot exactly in the centre.

Figure 2. Example tests of parietal function.

Calculation: "what is..."	Perception: "what is this object?"	Praxis: "Copy this gesture..."
$4 + 5 =$ $19 - 12 =$ $152 + 79 =$ $189 - 98 =$		

The temporal lobes

The temporal lobes deal primarily with memory and language functions. Neuropsychologists test for the status of at least two types of memory. Episodic memory which, as its name suggests, is our memory of events or episodes which are recorded with a reference to the time when they occurred (for example: 'I ate eggs for breakfast this morning'). Tests for episodic memory include asking someone to remember as many words as they can from a word list read aloud, or showing someone a series of photos of unfamiliar faces and then asking them to identify those same faces from among a larger sample. By contrast, semantic memory can be thought of as our encyclopaedia for facts and figures about the world (for example: 'Eggs have a shell, are laid by hens, and can be eaten boiled, scrambled or fried'). Episodic memory is compromised to some extent in most forms of dementia but perhaps most profoundly in Alzheimer's disease. Semantic memory is most selectively and seriously affected in individuals with semantic dementia.

The frontal lobes

The frontal lobes perform multiple different functions yet work in unison to form our executive or management centre. The lateral or outer surfaces of the frontal lobe appear to be critical for organising and planning our actions and learning new tasks. In learning to drive, for example, these brain areas help us put together a very complex sequence of movements, which at first seem difficult and clumsy but gradually become more smooth and automatic. For someone with damage to this area, it is like being a learner all over again with many multi-stage tasks such as cooking and shopping becoming very difficult because the pattern or plan of action has been lost. Damage to these lateral areas can also cause people to get stuck on what they are doing (known as 'perseveration'). The middle portion of the frontal lobe generates our motivation and general impetus. If this part of the brain is affected, people can lose their 'get-up-and-go', becoming lethargic and reluctant to get out of bed or perform a particular activity.

Again, it is important to realise that what might be perceived as laziness by some could be a direct consequence of the loss of cells in this area of the brain. The regulation of our behaviour appears to be governed by a third area of the frontal lobes, the orbitofrontal area, located in the curvature at the very front of the brain. In healthy people these parts of the brain help to monitor, control and moderate our behaviour: for example, preventing us from saying something rude when someone has really annoyed us. Neuropsychologists probe the integrity of frontal lobe functions with a range of tasks which require attention, decision-making, persistence and inhibition. These include sorting items into categories (e.g. colours and shapes), alternating rapidly between two tasks (e.g. finding numbers and letters), and suppressing pre-potent responses (e.g. naming the colour of the ink a word is printed in rather than reading the word itself). These tasks eventually become difficult for most people with a progressive degenerative condition, but are particularly affected in FTD in the early stages of the disease.

Challenges facing neuropsychologists

Unfortunately of course it's not quite that simple. Although different parts of the brain are undoubtedly specialised for different tasks, the brain works as a network. Some parts are particularly important for individual skills, but most tests at the neuropsychologist's disposal in fact require the person being tested to use more than one skill at a time. Take for instance picture naming, a common test used for assessing language abilities and in particular word retrieval skills. In showing someone a picture of a dog and asking them to name it, the neuropsychologist is in fact requiring the person to perceive the picture clearly (its shape, colour, features, etc.), know what it is (i.e. access correct semantic knowledge about dogs), retrieve the correct name, and then to say the name aloud (requiring appropriate pronunciation and coordination of speech muscles to create the correct sound). So many stages underlying such an apparently simple task.

This is one of the reasons why neuropsychologists often ask a lot of questions; they need to assess as many different skills as possible in order to derive the most accurate cognitive profile of the person being tested. Numerous other factors also have to be taken into account, such as the previous abilities of the person being tested, their education, age, mood, tiredness, how long they have had the disease for, whether they have tried the test before, and also how difficult the test is for other people of a similar age and background.

Conclusions

Overall neuropsychology offers a non-invasive window into the brain, providing information which, in coordination with clinical interviews, brain scans and blood tests, can help health professionals to reach a prompt and accurate diagnosis. At its best, neuropsychological assessments can also be used to inform patients and carers about the condition they are facing, and to guide coping strategies and care planning.

Fundamentally, neuropsychologists should be asking questions which increase understanding of how and why challenging behaviours occur, and thus enable carers in particular to focus more upon the person with dementia than the dementia itself. Or, as the Canadian physician William Osler (1849-1919) put it, "Ask not what disease the person has, but rather what person the disease has."

DIARY DATE.....PICKS DISEASE SUPPORT GROUP AGM: MARCH 9TH 2011

Venue: 33 Queen Square, London.

Speakers to include: Professor Nick Fox [Consultant Neurologist] and Dr Colin Mahoney [Research Fellow] at The National Hospital For Neurology ,Dementia Research Unit, Selina Wray [Research Fellow at the Institute of Neurology] 'Cell Models in Picks Disease/FLD' ,Mark Easter [Clinical Effectiveness Manager @ Milton Keynes PCT] 'Mental Capacity Issues', Representative from Care Aware ' Planning for Later Life and Paying for Long Term Care', Caren Mathiause [Carer] 'My Family'

COST: £35 FOR CARERS £50 FOR PROFESSIONALS

TO BOOK YOUR PLACE EMAIL JILL WALTON AT jillpdsg@virginmedia.com OR TELEPHONE PENELOPE ROQUES ON 0845 458 3208

PLEASE SEND CHEQUE [WITH YOUR NAME PRINTED ON THE REVERSE SIDE] PAYABLE TO P.D.S.G TO JILL WALTON, 22 BRUSHWOOD DRIVE, CHORLEYWOOD, HERTS, WD3 5RT

Raising Awareness – and Money!

As you know we don't charge a membership fee or for the information we provide. So many people are impoverished by this illness that a joining fee could be the last straw when we just want to help. Over the years many people have donated money and services to the PDSG and we are very grateful indeed. It has enabled us to function without having to spend effort in fund raising.

Recently there have been some outstanding achievements and I particularly want to mention two. Ollie and Claire Hallam and team set out to raise £10,000 to be shared between the AS and the PDSG. Ollie's father had Pick's Disease. The eqipe "Rosbif" entered a triathlon in Mimizan in South-West France.

Not only did they complete the triathlon but the French were most hospitable, loved having a GB entry and have invited them back next year. The equipe" rosbig" has raised £21,332.10 to be shared between the PDSG and AS. We are most grateful.

Another brave soul Megan Owen attempted and nearly completed the Bob Graham round which involves 42 peaks and 65 miles of running in the Lake District over 3 days. Unfortunately the weather was not kind to Megan but she still raised £2,000.

We would also like to thank Peter Moore, the charity committee and nine hosts from his local pub 'The Volley' who have raised £700 again.

These wonderful fundraisers follow a great tradition – our first fundraiser was Professor Martin Rossor who ran the London Marathon when the PDSG was founded. Many thanks to all those who have raised money and awareness for the PDSG.



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

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 01428 729 702

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

Forthcoming Carer Support Meetings :

London: The Old Boardroom of the National Hospital for Neurology and Neurosurgery, Queen Square, London: dates: 6th December @11.30-am-3.30pm [meetings usually include visit to local Italian Restaurant for lunch]

Liverpool: Neuro Support, Norton St, Liverpool, L3 8LR dates 18 Nov, 20 Jan 2011, 17 March, 19 May [for details contact Mary Dawber on 01625 879 104. Meetings usually take place between 3pm and 5pm.]