

# PCA SUPPORT GROUP

## Newsletter

Welcome to the PCA Support Group Newsletter

Issue 5 June 2009

Welcome to the latest edition of the PCA Support Group Newsletter. Despite the last meeting being held on Friday the 13<sup>th</sup> (of March), nearly 50 people made it safely to central London to hear Riitta Kukkastenvehmas deliver a very helpful talk about financial benefits and allowances which may be available to people with PCA. A summary of the main points raised is provided on pages 2-4.

Professor Nick Fox, Consultant Neurologist at the National Hospital and a familiar face to many group members, then led a group Question and Answer session, examining issues such as the nature and progression of PCA, current research and future prospects, diagnosis, treatment and public awareness, to name but a few topics. The main talking points are described starting on page 5.



**Next PCA Meeting: Friday 10 July 2009 (RSVP to Jane or Seb)**

**Coffee from 10.30am and lunch from 1pm**

**Royal London Homeopathic Hospital, 60 Great Ormond Street, London, WC1N 3HR**

*This meeting will be dedicated to small group discussions about the experience of living with PCA. There will be opportunities for both joint and separate conversations for those with PCA and for the relatives and friends of people with the condition.*

-----  
Future meeting dates for your diaries: Friday 13 November 2009

Contact Us:

**Jane Douglas** 08451 555 000 x 723560 or email [jdouglas@drc.ion.ucl.ac.uk](mailto:jdouglas@drc.ion.ucl.ac.uk)  
**Sebastian Crutch** 08451 555 000 x 723113 or email [s.crutch@drc.ion.ucl.ac.uk](mailto:s.crutch@drc.ion.ucl.ac.uk)

# PCA SUPPORT GROUP

## Newsletter

---

### FINANCIAL BENEFITS

The world of benefits is confusing and applying for assistance is often a difficult and frustrating process. Luckily we were able to welcome Riitta Kukkastenvemas back for the meeting to give an introduction to the main benefits and support services that people with PCA should be eligible to claim. The five major benefits discussed included Disability allowance, Attendance Allowance, Incapacity Allowance, Carers Allowance and Council tax benefit.

#### Disability Living Allowance

- Has two separate components
  - (1) Care component
  - (2) Mobility component
- For physical or mental disability (or both) severe enough that the person claiming needs help caring for themselves and/or assistance walking.
- Patients must be under 65 years when claiming.
- The weekly allowance is based on the amount of care needed on a daily basis.
- Worth applying for both components as people with PCA have

successfully claimed the mobility allowance due to visual difficulties affecting moving around unaided

#### Attendance Allowance

- Same criteria as Disability Living Allowance, however, patients must be over 65 years when claiming.
- Two rates: High (if care needed day AND night) or Low (if care needed day OR night).

These previous two allowances are assessed on capacity and are not means tested, so everyone should apply. The following three allowances are means tested and rate of payment will depend on individual financial circumstances.

#### Incapacity Benefit

- Eligible if a person is unable to continue or take up work because of illness or disability
- Three different rates depending on how long they have been unable to attend work

#### Carers Allowance

Carers are eligible to apply if they are:

- Over 16 years old and spend at least 35 hours per week caring for someone receiving Attendance

# **PCA SUPPORT GROUP**

## **Newsletter**

---

Allowance or Disability Living Allowance (at the middle or highest rate).

- Earn no more than £95.00 a week
- Important to note that the weekly rate of £50.55 may be reduced depending on certain other benefits, including State pension
- Also if the carer is receiving other benefits at or over £50.55, Carer's Allowance cannot be paid, but worth being registered as eligible as it may help with other applications in the future.

### **Council Tax Benefit**

- Useful to contact an advisor about your particular circumstances to see what percentage discount is applicable.

There are also helpful community support agencies and related assessments. A Social Services Needs Assessment is required to gain access to services and is in three parts: community care assessment, carer's assessment and financial assessments. The financial assessment is optional, but if not taken up will result in full financial responsibility for services.

### **Community Care Assessment**

This assessment is carried out by a social worker, occupational therapist or physiotherapist. They assess the amount of assistance the person requires in the areas of:

- Physical difficulties
- Health/housing needs
- How easily the person can access help (i.e. proximity of family, friends or carers)
- The person's and primary carer's wishes for types of care and services

### **Carer's Assessment**

- Assessment of the carer's individual circumstances and needs aiming to support the person in their caring role. This can be prior to the assessment of needs of the person they are caring for.

These assessments result in Social Services providing appropriate services to meet the needs assessed or Direct Payments for the person or carer to purchase services that cater to their needs themselves. Services may include:

- Equipments or adaptations at home like safety railings

# PCA SUPPORT GROUP

## Newsletter

---

- Help with housework or personal care
- Meals on Wheels
- Emotional support

Also useful to get a GP or optician referral to a consultant ophthalmologist to check eligibility for registration as partially sighted. This can lead to reduced TV licence cost, travel costs and may involve support benefits.

Finally, financial and social support aim is to help people to continue living as independently as possible. It is highly recommended to contact benefits advisors as they are very helpful in assisting in applications for benefits and are not there to catch you out. Some important points discussed at the PCA meeting included:

- It may be useful to include a letter from your consulting neurologist who understands PCA with applications forms due to the limited experience most GPs have of it.
- Don't let the complexity of the forms put you off applying as Benefits Officers have been very helpful, particularly from Age Concern and Citizen's Advice.

- Stress the difficulties experienced in daily living are because of the condition.
- Despite being difficult to do, really worth putting down the worst case you need to be prepared for or the worst day you have experienced.
- Reapply immediately as soon as your situation and/or the needs of those involved changes.
- Benefits are paid from the first date of contact but will not be backdated, start enquiries as soon as possible.

### Important contacts:

Age Concern: (tel) 0800 009 966

Citizen's Advice Bureau:

(tel) 0207 833 2181

AD Society: (tel) 0845 300 0336

Disability Benefits Enquiry Line:

(tel) 0800 88 22 00

[www.direct.gov.uk](http://www.direct.gov.uk)

# PCA SUPPORT GROUP

## Newsletter

---

### Q&A WITH NICK FOX

#### The nature of the condition

- In PCA it is known that the brain cells at the back of the brain are affected. These cells are particularly responsible for processing vision, hence the reason why many people with PCA are often first sent to see opticians a few times before a doctor is consulted for their problems. In PCA, the light enters the eyes normally, but the processing of this information within the brain is abnormal. However, vision is not the only ability affected. Other brain regions near those specialising in vision are responsible for complicated hand movements, calculation and spelling, and so these skills may also be affected. What would be expected with typical Alzheimer's disease is memory problems, however with PCA memory problems are not generally one of the early signs hence why diagnosis is difficult and delayed.
- With regard to the cells which are affected, it is known that some are lost, but the majority are present but not functioning well. This gives hope for future therapies, which may be able to improve the functioning of those cells.
- PCA (Posterior cortical atrophy) simply means that there is a problem with the cells at the back of the brain. It doesn't necessarily imply that it is a form of Alzheimer's disease, although that is the cause

in the majority of cases. PCA can also be caused by conditions such as Dementia with Lewy Bodies. Thus some people use descriptive terms such as 'posterior presentation of Alzheimer's disease', 'biparietal Alzheimer's disease' (referring to the brain regions adjacent to the back of the brain) or Benson's syndrome (named after the clinician who first described the condition).

#### Causes

- A mixture of genes seem to give a greater susceptibility. However, there is no value in testing family members for these genes because there isn't an inheritance issue, and many people with these genes do not go on to get PCA whilst others without the gene may develop the condition.
- From birth, certain brain cells produce waste products. One root of Alzheimer's disease is that for reasons yet to be understood, some individuals experience a build up of these waste products which have a damaging effect on cells' normal functioning. So far we do not fully understand why this process affects some people and not others, or why certain parts of the brain are affected while others are not.

#### Diagnosis

- Diagnosis is not known with 100% certainty unless you examine brain tissue directly, but other

# **PCA SUPPORT GROUP**

## **Newsletter**

---

investigations (clinical interview, brain scans, psychology tests, lumbar puncture) give a near definitive diagnosis. Gaining a complete history of the person with PCA (including insights from those close to them) is very important.

- It is quite common for diagnosis to take a long time, and for initial misdiagnoses to be made, such as depression, stroke, eye problems etc.
- All medical professionals need to be aware of PCA. There is a need for more courses for GPs, occupational therapists etc. PCA is not always recognised, even within the AD community. Our understanding of PCA is evolving constantly. Every person with PCA is quite different, and the aim of some work at the Dementia Research Centre is to determine whether PCA is one disease or whether there are different expressions. Establishing this will help determine the progression and course of the disease.
- The PCA Support Group is incredibly important in raising awareness and being a force for good in driving research for this disease. In the past, advocates for many rare disorders have brought about changes leading to greater awareness and ultimately research into the conditions.

### **Treatment**

- One group member asked about the use of statins in treating dementia. Statins are very good for treating raised cholesterol, and thereby reducing heart disease and stroke. Large studies have shown that raised cholesterol is also a risk factor for Alzheimer's disease, perhaps as much as 20 years before the disease becomes apparent. Studies so far have not shown that having statins helps those who already have Alzheimer's disease. It maybe that early administration of statins has an effect.

### **Research**

- The process of showing that a treatment works is very slow and painstaking. At present there are approximately 10 different strategies aiming to slow down Alzheimer's disease. Immunotherapy looks very promising, certainly in cell and mice studies. Human studies are yet to report, but look promising. It is speculated that future treatments for Alzheimer's will involve a mixture of medications (a cocktail of tablets) in order to tackle different aspects of this very complicated disease.