

# Parkinson's Newsletter

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## Welcome

The Parkinson's Nurse Specialist service (PNS) provides a range of services for people with Parkinson's, their family and carers. The nurses are based at the Royal Victoria Hospital but cover the Lothian area.

They have both combined and nurse-led clinics in the Royal Victoria, Liberton, Roodlands, Western General and St John's Hospitals.

Current services are:

- Advocacy
- Support for the individual, carer and family
- Information and advice
- Complex assessments
- Symptom management
- Referral to, and liaison with, other services
- Support and advice
- Nurse-led Parkinson's clinics
- Self-management programmes.
- Educational groups for people with Parkinson's and their families.



*Parkinson's Nurse Specialists Allison Darbyshire, Alison Stewart and Tina Daniels.*

Contact us on 0131 537 5259 or Secretary Suzanne Vinall on 0131 537 5256.

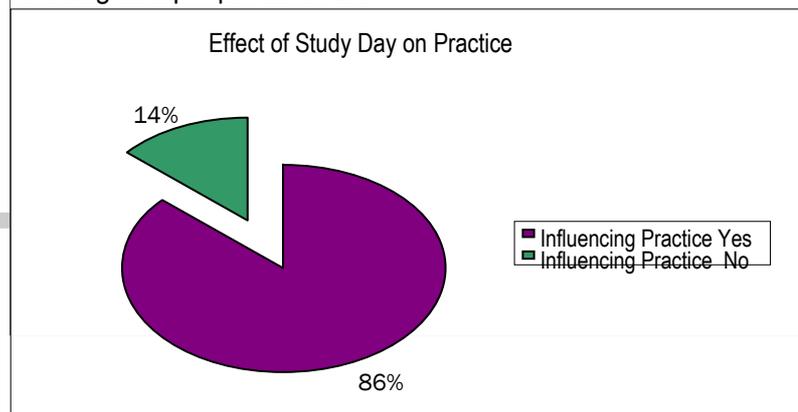
## Special points of interest:

- Parkinson's Disease Society has changed its name, rebranding in April 2010 to Parkinson's UK.
- Alliance of Scottish Parkinson's Nurse Specialists conference on Parkinson's - Next year August 2011.

## Alliance of Scottish Parkinson's Nurse Specialists (ASPNS) Conference August 2010

In 1999 the PDNS in Scotland decided to host a Multi disciplinary Conference. The aim was to share knowledge about Parkinson's, influence practice and offer a networking opportunity to individuals from throughout Scotland. In 2010 the conference hosted 104 delegates and was oversubscribed by 25. The delegates are asked to complete an evaluation form which helps plan the programme for the next year.

Have you heard anything today that will change or influence your practice when working with people with PD?



## Alliance of Scottish Parkinson's Nurses Specialists Conference

SOME COMMENTS FROM DELEGATES:

- "Practical solutions to help people with swallowing difficulties"
- "More aware of PD medication"
- "I have a greater understanding of pain and PD"
- "I have more knowledge on PSP and MSA"
- "Utilise palliative care earlier than I thought"
- "Have a better understanding of the whole spectrum of Parkinson's"
- "More aware of atypical symptoms-will pass my knowledge on to colleagues"
- "Improved knowledge of on/off"
- "Greater understanding of the many issues involved and how they relate to the bigger picture in anticipating future care needs"
- "More aware of side effects of drugs"
- "Consideration of palliative approach as a longer term approach not just end of life"

## Parkinson's UK

Parkinson's Disease Society has changed its name and logo. The rebranding was launched in April 2010 to coincide with Parkinson's awareness week.

Parkinson's UK is the biggest Parkinson's support and research charity. It is committed to finding a cure and improving life for everyone affected by Parkinson's.

For more information on Parkinson's, see the website at [www.parkinsons.org.uk](http://www.parkinsons.org.uk)

Scotland's manager for Parkinson's UK is Katherine Crawford,

## e-learning module on "Caring for a Parkinson's patient in hospital" goes live

The Parkinson's nurse team have been working with Marion Wilson in NHS Lothian to develop an e-learning module - Caring for a Parkinson's patient in hospital. The module was piloted by staff at the Royal Victoria hospital and ward 51 at the Western General .

Available on learnPro NHS, the e-module includes a lot of practical information relating to the particular problems experienced by people with Parkinson's and is aimed at improving the patient's experience in hospital. This will compliment the

'Get it on time' campaign by Parkinson's UK which also aims to make sure that people with Parkinson's in hospitals and care homes get their medication on time – every time.

Katherine Crawford from Parkinson's UK states:

"People with Parkinson's tell us that being treated and cared for by health care professionals who have some knowledge of Parkinson's greatly improves their hospital experience. We at Parkinson's UK- [www.parkinsons.org.uk](http://www.parkinsons.org.uk) - welcome this exciting new learning opportunity and would encourage every health care professional across the Lothian's to take advantage of this opportunity. "

LearnPro™

Module is being launched through NHS Learn Pro.

To access the module it will be available under the CPD heading on the LearnPro site via the intranet applications box or for more information log onto learnPro: [www.nhs.learnprouk.com](http://www.nhs.learnprouk.com)

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## The Lothian Parkinson's Congress

One of the aims of the Lothian Parkinson's Forum is to provide an educational platform for all members of multidisciplinary teams caring for people with Parkinson's in the area. We achieve this through an annual congress. Last year, we had a very successful meeting in the Royal College of Physicians & we hosted this again on November 12th at the Marriot Hotel, Edinburgh. The programme was comprehensive and we will feedback evaluations in our next Newsletter.

### PROGRAMME:

**12.30 - 13.30: Registration / (Soup & sandwiches) in Foyer :  
Viewing Pharmaceutical exhibition stands**

### SESSION 1:

**1.30pm - 2.30pm: Sleep Disorders in Parkinson's Disease:**

**Professor Kevin Morgan** (Professor of Gerontology, at Loughborough University)  
Website -

<http://www.lboro.ac.uk/departments/ssehs/staff/academic/kevin-morgan.html>

**2.30pm - 3pm: Quality of Life in Parkinson's : A study:**  
**Alastair Faulkner, Medical Student, University of Edinburgh**

**3.00 - 3.30pm: Coffee & Networking opportunity**

### SESSION 2:

**3.30pm - 4.15pm: Setting up a Multidisciplinary Parkinson's**

**Service: The Sheffield Experience: Dr Jane Liddle,**  
Consultant Geriatrician, Sheffield.

**4.15pm - 5pm:**

**The implications for Lothian of the NHS QIS Neurology Standards - Parkinson's disease.**

**Panel Discussion and Questions:**

**Guest Speakers:**

Prof Alex McMahon, Deputy Director, Strategic Planning & Modernisation, NHS Lothian  
Sally Wilson, Programme Manager, Neurological Services, Implementation & Improvement Support, NHS QIS

Dr Conor Maguire, Chairman, Lothian Parkinson's Forum.

**5pm: Close of meeting**

**Weblink:**

<http://www.nhshealthquality.org/nhsqis/files/LongTermConditionsNeurologicalHealthServicesOCT09.pdf>



## World Parkinson's Congress Glasgow 2010 201010octobe2010

The second world Parkinson's congress took place in Glasgow for 4 days this Autumn.

It was a fantastic gathering of people who all have an interest in Parkinson's. Three thousand delegates descended on the SECC in Glasgow.

Delegates included international experts in the field of Parkinson's. There were physicians, therapists, nurses and people with Parkinson's and their carers. Many interesting seminars and lectures as well as a quilting exhibition and international information stands.

It was a source of great encouragement to the Lothian Parkinson's nurses generating new ideas to improve the service provided in the area.

## Parkinson's Nurse Specialist Sleep Programme

Parkinson's Nurse  
Specialists Edinburgh  
and the Lothians

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Sleep disturbances are common in people with Parkinson's affecting up to 96% of patients.

In response to requests from the Scottish Parkinson's Nurses , Parkinson's UK has funded a 3 day education programme aimed at equipping Parkinson's nurses with a tool-box of strategies to help those experiencing sleep difficulties.

Lothian nurses are piloting the use of a 6 week self-management tool called "Sleep management in Parkinson's"

Patients with problems can opt into the programme and are supported through each of the six booklets. Initial response from those taking part has been very positive with most of respondents reporting an increase in sleep efficiency.

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The Parkinson's Nurse Specialist service would like to take this opportunity to wish you all a Merry Christmas and a Happy New Year

Best Wishes

*Alison, Tina Allison & Suzanne*