Parkinson's Nurse Specialists Edinburgh and the Lothians

Issue 3

March 2011

Parkinson's

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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 for professionals with an interest in Parkinson's
- 19th Aug 2011.

Welcome to our 3rd Newsletter, we hope you have found this a useful resource.

As a service we have been very keen to be able to share information about our service and signpost you to our referral criteria & forms, useful websites, documents etc. By the time you receive this Newsletter we will be LIVE.

Would greatly appreciate your comments about our page. We will be adding information and pages about other Parkinson's services. We are in the process of preparing video interviews with a patient which will give you a brief insight to how they cope on a day to day basis.

Referral to Parkinson's Services

The QIS guidelines on Neurological Health Services were launched in October 2009. There are four generic standards and five condition specific standards. Recommendations for Parkinson's disease services include:

- 17.1 Patients with suspected Parkinson's disease and related conditions are referred to a defined Parkinson's disease service delivered through a multidisciplinary team.
- 18.1 The diagnosis of Parkinson's disease is confirmed by a doctor who specialises in Parkinson's disease.
- 18.2 Patients with Parkinson's disease and their carers are provided with ongoing access to the Parkinson's disease nurse specialist.

To access to the full guidelines:

OIS:

http://www.nhshealthquality.org/nhsqis/files/LongTermConditions Neurological HealthServices OCT09.pdf

SIGN Guidelines:

http://www.sign.ac.uk/pdf/sign113.pdf

Guardian: Saturday 12 February 2011

The man of many faces
After being diagnosed
with Parkinson's, Tim
Andrews turned himself
into an art project. 128
photographers have
taken his portrait,
portraying images of how
he feels about his
Parkinson's

Guardian.co.uk

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

Remember this exciting opportunity to increase your knowledge on Parkinson's and meet your PDPP requirements.

Access the module on the LearnPro site under the CPD heading via the intranet applications box or log onto learnPro: www.nhs.learnprouk.com

We have had 223 "hits" so far which is very encouraging, please tell your colleagues about the module.



Module is being launched through NHS Learn Pro.

Development of Self Management Anxiety tool for people with Parkinson's.

The psychology department, based at the Royal Victoria Hospital, has been developing a service for people with Parkinson's and their family. People react to diagnoses and health conditions in different ways. The service is designed to help people adjust to having Parkinson's disease. Sometimes people develop depression or anxiety and cut down on their activities. Psychological intervention, in conjunction with other members of the multidisciplinary team (and family in the person wishes), aims to help individuals learn different ways of coping and improve their quality of life. So far, as well as people being seen on an individual basis, two relaxation groups have been run. The service is co-ordinated by Dr Elizabeth Baikie, Consultant Clinical Psychologist and covers all of Edinburgh. People are seen at the out-patient department, Royal Victoria Hospital.

As anxiety is a common symptom experienced by people with Parkinson's and is well recognised by clinicians, the Parkinson's Nurse Specialists wanted to develop an anxiety self-management tool. It will take the form of information booklets to empower people with Parkinson's to understand their symptoms, which may be related to anxiety and how this affects their day-to-day life. Plans are underway to pilot the tool. This has been achieved by working collaboratively with Dr Baikie and her team.

Alliance of Scottish Parkinson's Nurse Specialists (ASPNS) Conference August 2011

Put a date in your diary for the next specialist conference. It will be on 19th August 2011 and will be at the Stirling Management Centre. The programme will include:

Carers perspectives
Sleep management
Power of Attorney and legal aspects
Cognition

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It is an excellent conference at an excellent price. Details will be sent out prior to the conference, but if you want to ensure you are on the "early bird" invite please contact us on 0131 537 5259.

Rehabilitation at Astley Ainslie for Parkinson's disease R.A.AP

The RAAP group is run by the neurological rehabilitation outpatient team at the Astley Ainslie Hospital. It is a 7-week programme of exercise and education for people with Parkinson's. The aim is to run the group twice a year. Each group can be attended by up to 10 people with Parkinson's disease.

Each week there is an exercise session followed by a group discussion about different aspects of Parkinson's disease.

The exercise sessions encourage ways of maintaining general fitness and mobility. Advice is given about specific exercises and strategies for some of the physical problems of Parkinson's disease. Exercise sessions are led by a Chartered Physiotherapist.

Some of the topics covered in the group discussions are: drugs used in Parkinson's; sleep problems; pacing and activities of daily living; diet; communication and relaxation techniques. A wide range of healthcare professionals provide input to the group discussions. These include:Parkinson's Nurse Specialists, occupational therapists, nurses, psychologists, dieticians; speech and language therapists.

Referrals to the RAAP group can be made either by self-referral by the person with Parkinson's or by health care professionals.

If you would like further information about the RAAP group, please contact: katie,wilkie@lpct.scot.nhs.uk



Parkinson's Awareness Week

The Parkinson's nurses are planning for Parkinson's Awareness week this year. April seems a long time away but will creep up on us quickly. Put the date in your diary- 11th-17th April 2011.

If you have any good ideas for what we should do this year, email us at Alison Stewart.

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



Parkinson's Nurse Specialist Sleep Programme

Love and Other Drugs:

This is a mainstream film that tells the story of a drug salesman (Jake Gyllenhaal) who begins a relationship with a woman (Anne Hathaway) who has early onset Parkinson's.

There are several scenes which take place in a Parkinson's convention.

Anne Hathaway

reportedly undertook research into her role by speaking to those affected by the condition. She also researched the symptoms of Parkinson's and side effects of Parkinson's medication.

Parkinson's Nurse Specialists Edinburgh and the Lothians

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Allison Darbyshire, PNS

Tina Daniels, PNS.

PARKINSON'S^{UK}
CHANGE ATTITUDES.
FIND A CURE.
JOIN US.



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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 selfmanagement tool called "Sleep management in Parkinson's"

Patients with sleep difficulties 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.

All the Parkinson's nurses will have the opportunity to go on the training. Alison Stewart and Tina Daniels are going to the training in March 2011. The Scottish Parkinson's Nurses hope to publish the results of the findings in a joint project with Parkinson's UK.

The Parkinson's Nurse Specialist service would like to take this opportunity to thank everyone for the support to the service

Alison, Tina, Allison & Suzanne