

Parkinson's Newsletter

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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 August 2011.

WEBPAGE ON THE INTRANET

Welcome to our fourth newsletter, we hope you have found this a useful resource.

As a service we have been very keen to be able to share information and signpost you to our referral criteria and forms, useful websites, documents etc. Our webpage has received 1415 'hits' since February 2011. We have had positive feedback and would greatly appreciate your comments about our page. We are adding new information and updating the pages regularly. 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.

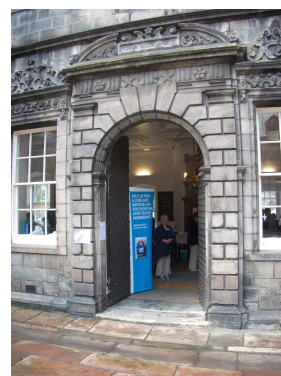
Parkinson's Information Afternoon at George Heriot's school

We hosted an information day for patients, carers and friends of anyone affected by Parkinson's on 23rd May 2011. This was a successful day with demonstrations from the Parkinson's UK Edinburgh Branch Dance and Singing groups. There was an art exhibition showing the art work by people with Parkinson's.

The Branch and support groups came along with information and Betty Thomson, Parkinson's Information Support Worker brought information on benefits and rights.

The day saw sixty people attend and a few new people identified for the nurses and Parkinson's UK, Edinburgh Branch. Feedback was positive and we will run this as a regular event.

We would like to give our thanks to George Heriot's Board of Trustees for a stunning venue.



Dr Maguire
nominated the
Parkinson's nurses
for team of the month
within the Medical
directorate.

The Parkinson's
Nurse Specialists
were awarded
"Team of the Month"
in March 2011

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.learnpro.uk.com. There have been 247 health professionals in Lothian who have passed the module.



Psychology services and Parkinson's

The psychology department based at the Royal Victoria Hospital has been developing a service for people with Parkinson's and their family. It covers all of Edinburgh.

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 multi-disciplinary team (and family if the person wishes) aims to help individuals learn different ways of coping and improve their quality of life. An anxiety pilot study is commencing in conjunction with the Parkinson's Nurse Specialists and will involve 40 patients with anxiety scored on the Hospital Anxiety and Depression Scale (HADS). The self management programme is about giving out a specially designed booklet for anxiety and a follow-up feedback session. The services are co-ordinated by Dr Elizabeth Baikie, Consultant Clinical Psychologist, and people are seen at the out-patient department, Royal Victoria Hospital.

We are excited by our joint venture with Marlene MacInnes, Psychology Trainee and we are looking forward to the pilot and evaluation. We hope it will be beneficial to people living with Parkinson's.

Alliance of Scottish Parkinson's Nurse Specialists (ASPNS) Conference 19th 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. Information and application forms are now available from the Parkinson's Nurses.

The programme will include:
Carers' perspectives
Sleep management
Power of Attorney and legal aspects
Cognitive aspects

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.

Feedback from the Community Psychiatric Nurses in East Lothian

Parkinson's Information session -Debbie Martin, Mental Health Liaison Nurse and team

"On the 14th April The East Lothian Community Team attended an information session delivered by Alison Stewart, Lead Parkinson's nurse .

"The session was well attended by all community staff working with older adults in the East Lothian area. We each had differing levels of knowledge, so the session began by Alison asking us to tell her what we knew and what we wanted to know. She then delivered a very accurately targeted talk delivering information on all aspects of Parkinson's; including signs, symptoms, treatments and strategies to support the person. This was delivered in a way which reflected our contact with the person at home and with their carer, allowing us to support the person and give information appropriate to the current evidenced approach.

"The session went on well past the planned time because the staff attending asked so many questions and were so motivated by the way the PD service has developed. So many of the ideas were innovative and things that we had thought about doing – the PD service had already done. Alison was so inspirational that we all left motivated to make changes to our practice.

"Within 24 hours three of the nurses who attended had experienced situations where the knowledge gained had in fact informed and improved their practice- nothing short of a miracle. Thank so much for the session and the inspiration, particularly at a time when so many shortages are having a negative effect on our morale , this was a real boost."

Contact Details:

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via

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or 07903 3969557

Advance Care Planning in NHS Lothian

The Advance Care Planning project is led by Jackie Whigham, Project Manager, and planned in partnership with the Marie Curie Hospice Edinburgh, St Columba's Hospice and NHS Lothian. The project aims to identify ways to help clinical staff to have an advance care planning discussion with patients identified in the palliative phase of their illness and then to ensure consistency in communicating the information to the wider health-care team using recognised tools (electronic palliative care summary (ePCS) and do not attempt cardio pulmonary resuscitation form).

In addition to work within three clinical settings (long-term care, acute medicine and primary care), the project has also worked collaboratively with the Parkinson's Nurse Specialist service. This provided an opportunity to explore current practice and investigate how their patient group would benefit from advance care planning. The Parkinson's Nurses have a vital role in providing high quality compassionate care and are often ideally placed to have an evolving advance care planning discussion with their patients.

The team are now all Advance Care Planning Champions and have a greater understanding of the anticipatory care plan process within NHS Lothian. Dissemination of this information through the team will help ensure key information is shared with the wider healthcare team using the recognised communication tools.

Jackie Whigham, Project Lead, said "Advance care planning discussions with a patient provides the opportunity for them to make their wishes known and allows time to make the right choices for themselves and their families with respect to their future plan of care".

For further information, please contact Jackie Whigham via jackie.whigham@mariecurie.org.uk or 07903 3969557

NEWS

Interesting article on Parkinson's

Lees, A.J., Hardy, J., Revesz, T.
(2009) Parkinson's Disease. *The Lancet*, **373**, pp. 2055-2066.

YPN News
Mary of the High Seas

A concert reading of the full length musical by Edinburgh Younger Parkinson's member Joel (Mason) Houck.

Mary of the High Seas is a historical action-drama set in the turbulent world of the back streets of London, the battle-fields of Flanders and the action and adventure of the high seas.

The course of the story takes Mary from a selfish young tomboy with a huge chip on her shoulder, to gregarious young war hero, to a self-reliant pirate with the heart of a lion... in the body of a woman... disguised as a man.

Directed by Joel Mason, Playwright and lyricist.

Composers Rosaleen Bans and Bruce Fraser.

The Church Hill Theatre, Edinburgh
July 22 and 23 at 7pm
July 24 at 1pm
2011
Admission £5

<http://maryofthehighseas.weebly.com/>

Parkinson's Nurse Specialists 2 years in post June 2011

**Parkinson's Nurse Specialists
Edinburgh and the Lothians**

**Alison Stewart, Lead
PNS**

Allison Darbyshire, PNS

Tina Daniels, PNS

**Suzanne Vinall,
Secretary to service**

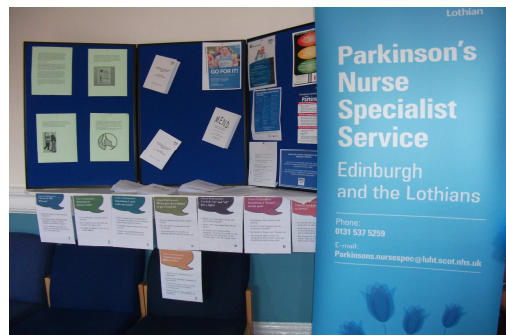
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Parkinson's UK, Edinburgh branch have been funding both Allison Darbyshire and Tina Daniels' posts for the past two years. It has been an eventful and busy time for changes and developments in the Parkinson's Nurse Specialist Service in Lothian. There have been many developments from new clinics set up in Lothian to the e-learning module on learn-Pro UK.

We are about to submit our Year Two report and look forward to the next steps as a team. We have many plans for future developments and collaborative working in the service as well as improvements to benefit people with Parkinson's.

We thank the Parkinson's UK, Edinburgh branch, West and East Lothian support groups and Younger Parkinson's Network for all their enthusiasm and support and help (when required) over the years.

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

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