



Winter Greetings

Newsletter:
Issue No. 7
November
2018

SERVICE DEVELOPMENT

Our Parkinson study days held in September for professionals in Health and Social Care were very successful with 50 attendees over the 2 days. The response was so good we will be holding some more sessions in the spring for the 45 people who were unable to get places. 5 people also registered to attend a "train the trainer" study day next year which will provide them with the skills to train colleagues, educating and raising awareness of Parkinson's in their place of work. These education days are presented by Parkinson's UK free of charge.

We were also looking for "Parkinson's champions" and are very pleased that 4 participants volunteered. The idea of a "champion" is to raise awareness of Parkinson's in their workplace, to be an advocate for Parkinson's patients they care for and be a point of contact for advice and liaison with our team. We very much look forward to working with our "champions" and know they will be a valuable asset to our service.

Talking of assets-our patient representatives have been a great addition to our service development group, providing a much needed patient perspective and some very good ideas and suggestions as to how we can improve our service to you.

They would very much like to hear from you and family/carers about your experiences with Parkinson's and healthcare services and would be pleased to bring any thoughts, questions or suggestions from you to our service development meeting.

Also, ideas for items you would like in the newsletter would be most welcome. They can be contacted by email at the following addresses:-

Linda and Terry Owen at Linda.Owen@manx.net

Richard Faragher at rtf@manx.net

Richard Surrey at dsurrey@manx.net

Michael Cowin at pullyman@manx.net

Val Casey at val_n_jim@manx.net

AS A TEAM WE WANT TO ENSURE YOU GET THE BEST POSSIBLE CARE

We would welcome feedback from service users and carers on how we can improve things for people with Parkinson's on the Isle of Man.

If you need help or advice there are several ways to contact us;

Susan Lawley - Specialist Nurse

Tel: **01624 642676**

Email: susan.lawley@gov.im



Graihagh Betteridge - Physiotherapist and Clare Collister - Occupational Therapist
via Community Adult Therapy Team Tel: **01624 642511**

Meet the team and join us for a coffee
on Friday 7th December 1.30 to 3.30pm at

The Independent Living centre,

Level 1, Community Health Centre
Ballakermeen Road
Douglas



A chance to see what equipment and information we can offer

RESEARCH NEWS FROM PARKINSON'S UK

24th October: The UK-wide Predict PD study, funded by Parkinson's UK, is seeking 10,000 people aged 60-80 without Parkinson's to find clues to the very earliest stages of the condition.

For further information and to register visit predictpd.com

30th October: Research points to the appendix being the source of Parkinson's

New research highlights a link between the removal of the appendix and a reduced risk of developing Parkinson's.

Commenting on the study, Claire Bale, Head of Research at Parkinson's UK, said: "The finding that removing the appendix early in life can reduce risk of Parkinson's suggests that it may play a contributing role in the loss of brain cells. This builds on previous research indicating that, for some, Parkinson's starts in the gut. "There is much still to learn about how surgical approaches, such as removing the appendix, may stop the progression of toxic proteins that cause Parkinson's. However, these approaches are unlikely to eliminate the condition, as Parkinson's may also start in other areas of the body or brain. "In most cases, the causes of Parkinson's are a mystery. But understanding how the condition starts and progresses is the first step to stopping it. If we can couple this understanding with tests that detect the earliest changes and treatments that can stop it progressing, we will have a real pathway to preventing Parkinson's."

15th November: Stopping the build-up of toxic proteins in Parkinson's

Scientists have identified a key molecule - called USP13 - which may provide a new avenue to prevent the build up of alpha-synuclein in brain cells. "This ground-breaking study highlights a previously unknown reason why the protein may be building up inside the brain cells of people with Parkinson's". Dr Beckie Port, research communications manager at Parkinson's UK

[Why not sign up for the Progress magazine, Parkinson's UK's twice yearly free magazine that keeps you up to date with all that's happening in Parkinson's research?](#)

FOR MORE INFORMATION GO TO: WWW.PARKINSONS.ORG.UK/CONTENT/RESEARCH

OR TELEPHONE 0808 800 0303

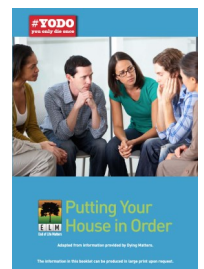


For many people, planning for the end of your life is one of those things which can always be done later, because it simply isn't something that most people like to think about. Life is unpredictable and unexpected things happen, which can deny many people the chance to discuss and plan for the end of their life.

The **End of Life Matters** initiative encourages everyone, regardless of age or health, to take simple steps to make their end of life experience better; for themselves and for their family and friends. This is why planning for the end applies to everyone, regardless of age or health.

Cruse bereavement care have produced an excellent booklet with advice called "Putting your house in order" and we have decided to add this leaflet to our newly diagnosed patient packs.

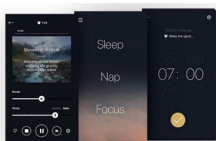
If you would like a copy or want to view the booklet on line go to www.cruseisleofman.org



Parkinson's UK is collating a library of a range of 'tried and tested' apps and devices that could be useful for people affected by Parkinson's.

For more information visit: www.parkinsons.org.uk/information-and-support/apps-and-devices-parkinsons

Pzizz :



Helps you to have better quality sleep.

Swallow Prompt :



Delivers regular and discreet prompts that remind you to swallow

Voice Analyst :



Allows you to measure the volume and pitch of your voice

Prefer the newsletter to be emailed to you? Send your email address to cats@gov.im
If you do not wish to receive future newsletters please ring **01624 642676**