The Edinburgh Parkinson's Lecture 2016

The Future of Parkinson Care

Professor Bastiaan Bloem, Consultant Neurologist, Department of Neurology, Radboud University Nijmegen Medical Centre in the Netherlands

Report on the talk prepared by Helen Harris, Edinburgh Branch Volunteer
(useful links to further information are given at the end)

Background to the Lecture

Since 2012, the Edinburgh Parkinson's Lecture has been an annual event organised jointly by the Edinburgh Branch of Parkinson's UK, the Lothian Parkinson's Service Advisory Group, the MRC Centre for Regenerative Medicine at the University of Edinburgh, and the Scotland Office of Parkinson's UK. The intention is to inform and educate by inviting an internationally renowned expert each year to review recent progress and innovations in Parkinson's in a way that members of the public, not just health care professionals, can understand. This year's lecture was held on the 11th October in the Chancellor's Lecture Theatre, Edinburgh Royal Infirmary with more than 250 attending.

It was over ten years ago that Professor Bloem and Dr. Marten Munneke established the ParkinsonNet integrated health care system for people with Parkinson's in the Netherlands. The system is now widely recognised as an example of best practice for the care of those with the condition. This fact, coupled with recent changes in strategy and focus by Parkinson's UK and the adoption by NHS Lothian of a Neurological Care Improvement Plan suggested the time was right to invite Professor Bloem to tell us about his vision for *The Future of Parkinson Care* so that we might be influenced and further inspired in our efforts to support people with the condition in NHS Lothian, Scotland and the UK.

Professor Siddharthan Chandran, MacDonald Professor of Neurology, University of Edinburgh, introduced Professor Bloem, associating him with innovation, development of a model for participatory care and an underlying aim to do the right thing in how we care for people. It proved to be a lecture delivered with much good humour, empathy and profound understanding.

The ParkinsonNet Model

For those unfamiliar with the model, Professor Bloem explained and illustrated it as a system based on five core elements:

1) **Integrated networks** starting in the patient's home through community care, general hospitals to university hospitals and back to the home.
2) **Professional experts** with specialist training.
3) The **patient as partner** (but see also later).
4) Taking care **into the home**.
5) Use of **technology** to support activities.

Over 3,000 health care professionals are involved – neurologists, physiotherapists, occupational therapists, nutritionists, speech and language therapists, multi-disciplinary

carers and others. They work collaboratively as **teams** following well researched and established **guidelines** and regularly **exchange information** via regional meetings, national conferences and online networks. By asking a limited number of health professionals to take a thorough training in the condition and attract a high caseload each week, these people build up a great deal of experience, which is further enhanced by the opportunity for information exchange. ParkinsonNet acts as the co-ordinating hub and is based at the Radboud University Nijmegen Medical Centre.

The aim is to support people with Parkinson's and their families according to the **needs of the individual** patient. By providing a web-based search engine *patients can decide* which Parkinson's specialists would best suit their needs close to their home. All this not only leads to better quality of treatments but more efficient care and containment of health care costs.

The Professional Becomes the Partner

Fundamental to the approach is the patient centred nature of care. Parkinson's is a complex disease and treatments are complex because every patient is different and requires unique solutions to their problems. As ParkinsonNet developed, Professor Bloem and his colleagues re-expressed part of the model: initially *patients* were regarded as partners in their health care. Experience suggests that the ***professional*** **should be regarded as the partner**, providing their knowledge and expertise but all the while learning from the patient. Professor Bloem showed inspiring examples of how this can lead to innovations in individual patient solutions. His examples involved the slow *shuffling gait* of patients and the *freezing of gait* problem, the situation when a patient suddenly stops despite the intention to walk forwards.

- It's known that placing lines on the floor in front of a patient with freezing of gait can act as a cueing technique to prevent the occurrence and even encourage normal stride walking. For one patient this didn't have the desired effect. He discovered for himself that what he needed were three-dimensional bars placed on the floor like the rungs of a ladder.
- Another individual uses a zimmer frame to walk exceedingly slowly and with a shuffling gait yet is able to descend and ascend stairs normally, one leg in front of the other. Placing lines in front of him didn't work – the image on the floor had to look like stairs. His Netherlands-based designer niece created a floor print to give the illusion of a staircase allowing her uncle to walk around the house with decent strides. The niece is going into business with the concept.
- A third example resulted in the development of *cue shoes* that employ a line-generating laser mounted on the toe cap of a normal shoe with a pressure-sensitive switch under the sole of each shoe to control the laser. ParkinsonNet had good results with these in-house and patients are now trialling them at home and outside. Independently, a UK based designer in London has gone into business with a laser beam shoe (Path Finder) which she developed based on experiments with her father who has Parkinson's.
- Other examples showed a patient who avoids freezing of gait by walking with a scissor-like action (crossing one leg over another), while someone else uses a skating action.

Within ParkinsonNet there are many examples of how patients themselves have been innovative in finding ways round their individual problems, demonstrating how professionals

can learn from patients. With the information exchange facilities, these lessons can be shared among the professional health care community. And these can lead to designers and manufacturers picking up on ideas.

Increased Use of Technology

Despite the success and recognition of ParkinsonNet as a best practice system, Professor Bloem and his colleagues have realised they need to bring much more of the care into the home. Advancements in information technology and cost efficiencies have allowed investment in new ways of interacting with the patient and working even better to satisfy individual needs. These include:

- establishing a small TV studio in the hospital with a talk-show involving a panel of patients and a topic chosen by them broadcast live once a month – viewers can interact or episodes can be viewed at a later date;
- the introduction of tele-health consultations between patients in their home and clinicians in the hospital, saving travelling and waiting time for patients;
- videoing patients talking about their own situation without intervention from the consultant allowing the individual to give a clearer and more genuine picture of what they want from their health care;
- an advanced innovative study just launched which will allow detailed monitoring of patients in their home and described below.

Precision Information Gathering

Professor Bloem suggests we need to change our approach to gathering information via clinical trials. Clinical trials involve people who are effectively cherry-picked because of the need to satisfy design criteria and the stipulations of the regulating bodies when a trial is being formulated. Furthermore, trials take just a snapshot in time. Together with leading researchers at the Radboud University Medical Centre and Verily Life Sciences, Parkinson-Net has just become involved in the **Parkinson Precision Project**. It will study in detail 650 Parkinson's patients in the Netherlands, initially over a two-year period.

The objective is to gain insights into the origins of the disease and disease progression. The study will use state-of-the-art techniques, advanced brain imaging and wearable devices with sensors capable of measuring various types of data in the home. It will allow the development of **fine detail patient profiles** with the intention of devising a **precision support system** for each individual. The resultant databank will also allow inexperienced doctors access to better information to support their Parkinson's patients at the local level.

Exporting the ParkinsonNet Model

The ParkinsonNet mission statement is now

Improving the lives of all those impacted by Parkinson's disease worldwide

To this end, Professor Bloem suggested the model lends itself to being exported to other countries despite the fact that every country is different in its health care system. By focusing on the approach to professional training, the establishment of guidelines, patient involvement,

and transparency, the system can still be tailored to a country's needs. Each country should look at what is good about their current approach and what is missing. Already the concepts are being taken up in Germany, Michigan, California, Norway and Luxembourg.

The future of Parkinson's care is about **participatory health** – the patient is dependent on the medic, the medic has knowledge and experience but the patient has his/her own priorities. "The patient and the professional *together* know what's best for the patient."

Closing Remarks from Steve Ford, CEO Parkinson's UK

Following a lively question and answer session chaired by Dr Conor Maguire, Consultant Physician, Medicine for the Elderly, Western General Hospital, Steve Ford gave his thoughts on the implications for Parkinson's UK. He sensed the audience had been inspired, excited and engaged by Professor Bloem's presentation but suggested there may also be an element of regret among those with Parkinson's, health care professionals and service planners when asking themselves if such inspiration and innovation exists in their own team.

There are big questions we have to answer regarding how we can take Parkinson's care forward in the UK. It's a huge challenge but on a positive note he suggested that with the establishment of the **UK Parkinson Excellence Network** 18 months ago, we have the beginnings of a system that might allow us to capture some of the ethos and approach of ParkinsonNet. The recent Parkinson's UK audit of nearly 9000 patients, their records and views about their health care, is providing useful information in identifying areas that need to be addressed, as a starting point, in integrated health care for people with Parkinson's in the UK. While money is important what we need more than anything is passion, energy and determination to move forward.

Sources of Further Information on Topics Mentioned

www.parkinsonnet.info (click the buttons under the top picture to view a variety of videos, some of which were used in the presentation)

www.parkinsons.org.uk/professionals (re the UK Parkinson Excellence Network)

tedxinnovations.ted.com/2016/01/13/spotlight-tedx-talk-simple-design-to-help-parkinsons-patients-thrive (re staircase illusion flooring)

www.youtube.com/watch?v=LnDWt10Maf8 ("From God to Guide," TEDxMaastricht, a light-hearted yet moving look at the partnership between patient and doctor, mentioned by Professor Siddharthan Chandran)

www.ru.nl/english/news-agenda/news/vm/radboudumc/healthy-brain/2016/netherlands-public-private-partnership-launch (re the Parkinson Precision Project)

blog.donders.ru.nl/?p=5094&lang=en (re laser beam-in-toe cue shoes)

http://parkinsonslife.eu/laser-guided-shoes-parkinsons-patients-path-finder-lise-pape/

(re UK Path Finder shoe)
