

Wimbledon PSP Support Group Meeting, 9 November

The group met on Saturday, 9 November for an informal discussion session, when we were delighted to welcome several new members attending for the first time, along with a number of familiar faces.

The discussion was as wide-ranging as usual, with a particular focus on the learning process which begins with the initial diagnosis of PSP/CBD, both for the individual concerned and the family. Ideally, at the time of diagnosis it should be made clear that ongoing support will come from a range of health care professionals, such as physio/occupational/speech therapists, Parkinson's Nurse, social worker, to whom referrals can be made by the GP. It was clear from the discussion, however, that the extent to which this was always made clear at this crucial stage varied considerably and because of this it was agreed that people should contact the PSPA Helpline at an early stage.

The PSPA Helpline is an invaluable source of information and support. It is staffed by a team of Health Care Navigators who have, in addition to their knowledge of PSP/CBD, access to wide sources of information to help callers with any queries, as well as helping to coordinate the services individuals are receiving from healthcare professionals, ensuring continuity of care and being available to listen and offer support. Contact details are:

PSPA Helpline

Tel. 0300 0110 122

Email: helpline@pspassociation.org.uk

In contrast to the expert support and information available from the Helpline, the support offered by local groups like ours is more informal, based on our shared personal experience of PSP/CBD and its impact. We aim to provide a forum where people with PSP/CBD, their carers, family and friends can meet in a relaxed setting to discuss the practicalities of coping with the everyday demands of the condition and to offer mutual support. The experience of former carers is invaluable in this process as they can often suggest what helped them, whether in the form of small, practical tips or in anticipating, and planning for, major milestones in the progression of the disease. The following are examples of such points which were discussed:

Power of Attorney Although there is often reluctance to discuss this at an early stage, it was agreed that this is something which should be discussed and put in place early on, before communication is affected. Those who had done so felt a sense of relief in knowing that future decisions on, for example, potential medical interventions could be carried out in accordance with the individual's recorded wishes.

Continuity of care It was agreed that once referrals had been made to receive, for example, physiotherapy or speech therapy, it was essential that patients were not signed off after a certain time. Because the focus in such therapies is often on rehabilitation, patients can expect to be discharged when this has been achieved. In the case of progressive, neurological conditions, however, this does not apply, and a patient's needs will evolve over time and it is important to ensure that contact is maintained. Some areas have specialist neuro rehabilitation teams who will be aware of this, but where these are not available, it is recommended that at the end of each appointment the next appointment should be booked.

Care Provision It was clear from discussion that finding suitable care arrangements is one of the most complicated areas to navigate. Types of care available range from private at one extreme, to free NHS Continuing Care at the other, with many other options in between, including local council means-tested care, and several members used more than one of these. This is an area where the Helpline expertise can be particularly useful in finding a way through the system.

This was the last meeting of the year. Meeting dates for 2020 have now been confirmed (see below) and we look forward to seeing you next year.

Best wishes,

Shauna & Jeanne

2020 Meeting Dates

January 11, March 14, May 9, July 11, September 12, November 14

[All at the Mansel Road Centre, second Saturday of the month, 2.45–4.15 pm]

IF YOU NO LONGER WISH TO RECEIVE OUR EMAILS
PLEASE CONFIRM TO wimbledonpsp@gmail.com
TO BE REMOVED FROM OUR MAILING LIST