The group met on Saturday, 14 September, when we were delighted to welcome several new members attending for the first time, along with a number of longstanding members.  We were also very fortunate to be able to welcome Liz Sturgess, from the PSPA, who is the Health Care Navigator responsible for supporting our group, who joined us for our informal discussion session.  Some of the key points discussed were:

**PSPA Helpline** Local groups like oursaim to provide an informal setting for mutual support and the exchange of practical information and personal experiences of coping with the everyday demands of PSP/CBD. For more expert information and support, however, the PSPA Helpline is an invaluable resource. Its staff, like Liz, have, in addition to their knowledge of PSP/CBD, access to vast sources of information. Liz outlined for us the wide-ranging role of the team, including providing information, helping to coordinate the services individuals are receiving from healthcare professionals, ensuring continuity of care and always, crucially, listening. There is also a comprehensive list of publications which can be downloaded, or requested as hard copies (list and details attached). The small fact card with a brief description of PSP/CBD, (which is very useful for giving to health care/social workers and others who might be encountering the condition for the first time) has now been updated (copy attached) and supplies of these can be obtained from the PSPA.

**[PSPA Helpline: 0300 0110 122]**

**Counselling** This can often be of benefit to both carers and individuals with PSP/CBD and some had positive experiences of it, while others had not felt the need to seek it. In one case, excellent counselling had been provided at a local hospice and it was noted that in recent years the scope of services offered by hospices had expanded considerably beyond end of life care and now included support in providing quality of life for those with progressive conditions.  Counselling is also provided by local Mental Health Services, Mind, or privately (when it is worth checking with the Helpline for the necessary professional accreditations to look for in private counsellors). It was also recommended that in the case of counselling for individuals with PSP/CBD this should be sought while speech is still relatively unaffected.

**Health Care Professionals** It was generally agreed that the vital support in living with PSP/CBD is provided by a network of health care professionals, including Parkinson’s Nurses and Speech/ Occupational/Physio therapists among others and this should be set up at the time of diagnosis. It is often the case that, irrespective of their specific discipline, one of these can become effectively a key worker who helps in accessing other services and maintaining continuity of care.

We finished by thanking Liz for joining our meeting, which added greatly to the depth and range of discussion.  Members also took the opportunity to ask her a number of questions, both in the group and individually, and the time she spent on these was greatly appreciated, and we are very grateful to her for this.

**The next meeting of the group will be on Saturday, November 9th.** (More details nearer the time.)