

**All Party Parliamentary Group for Parkinson's Disease**  
**Minutes of meeting, 4pm, 28 October 2009, Room 4A, House of Lords**

**Attendees:** Baroness Gale (Chair), Baroness Masham of Ilton, Lord Brooke of Sutton Mandeville, Mark Hunter MP, Russell Brown MP, Baroness Howells, Lord Cobbold, Lord Ashley of Stoke, Michael Courtney (Office of Adam Ingram MP),

Val Buxton, Emily Cogbill, Clare Moonan, Sachin Shah, Brian Lymbery (Parkinson's Disease Society).

Mike Carr (MS Society), Catherine Mosey (Tourette's Action), Chris Randall (Stroke Association), Mary Malcolm (ASBAH), Peter Scott (Epilepsy Action), Lucy Brazg (Neurological Alliance)

**Apologies:** Tim Boswell MP, Anne Milton MP, Earl Howe, Lord Harrison, David Evennett MP, Celia Barlow MP, Ian Stewart MP, Angela Browning MP, Baroness Finlay of Llandaff, Kelvin Hopkins MP, Jim Dobbin MP, Sally Keeble MP, David Borrow MP, Eric Martlew MP, Des Turner MP, Phil Willis MP, Linda Gilroy MP, Rt Hon Hilary Armstrong MP, Albert Owen MP

**1. Welcome, introductions**

Baroness Gale welcomed members of the APPG to the meeting.

**2. Update on the Inquiry Report since it was launched in July 2009**

Baroness Gale updated Members on progress made since publication of the report of the APPG's Inquiry in July 2009. A paper summarising key results and a folder containing copies of replies, press cuttings etc was tabled for members.

**3. Discussion of how to take forward the Inquiry Report recommendations**

Baroness Gale spoke to the paper tabled, outlining parliamentary mechanisms which could be deployed in order to promote the Inquiry's report and further implementation of its recommendations. Members were in agreement to take forward the action points recommended.

Baroness Howells congratulated Baroness Gale on the achievements of the APPG in its first year of existence, in particular for the Inquiry report and the publicity received. Baroness Howells spoke of how this has helped raise the profile of the Group and the condition both internally in Parliament and externally amongst wider stakeholders.

Baroness Gale thanked Baroness Howells and extended her thanks to the Inquiry panel whose support was instrumental in enabling the Inquiry to take place.

Baroness Gale welcomed Baroness Young and Brian Lymbery to the meeting.

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4. **Guest Speaker: Brian Lymbery** spoke about living with Parkinson's disease and how the condition has affected his life. He emphasised the need to ensure that all health and social care services are available throughout the country.

**5. Guest Speaker: Baroness Young, Chair, Care Quality Commission (CQC)**

Baroness Gale introduced Baroness Young, Chair of the CQC. Baroness Young made the following points about the work and priorities of the CQC:

There is a heavy emphasis on user-involvement and there was therefore an onus on service providers and commissioners to ensure that the voice of users is meaningfully heard.

The intention is to focus on poor quality care and nip this in the bud.

Where high quality, joined up care exists, this should be celebrated and good practice spread.

With the annual assessment, the intention is to make this more of a rolling process and make assessment more 'real time'.

The issues raised in the APPG PD's report were acknowledged. In particular, with the recommendation of a CQC special review on neurology, Baroness Young suggested that clarity was needed in terms of what the review should achieve, where the blockages exist and how the CQC could help with this.

**6. Questions/discussion following Baroness Young's presentation**

Lord Ashley raised the issue of the status of the national survey of people with long term neurological conditions, which was referenced in the Healthcare Commission's submission to the APPG PD inquiry.

Baroness Young replied that the CQC will be looking into this.

Baroness Masham raised the issue of medicines management in hospitals for people with Parkinson's.

Baroness Young replied that specialist nurses are crucial in facilitating high quality care in these situations.

Lord Brooke asked what work the CQC has undertaken on how service-users and stakeholders can be in dialogue with them.

Baroness Young emphasised that many representative bodies exist. The point was also made that external organisations need to demonstrate how a CQC special review of neurology could make a difference. This also needs to address the existence of local determination in terms of the way health and social care are delivered.

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Mark Hunter MP raised a point about the importance of specialist nurses in the care of people with Parkinson's.

Baroness Young acknowledged this.

Baroness Young agreed that the APPG PD can submit any further questions to her office and these will be answered.

Baroness Gale invited external organisations present to submit questions.

Val Buxton (Parkinson's Disease Society) VB highlighted the potential use of the Quality Neurology tool and asked about ways to work with the CQC to get this embedded as an approach to auditing the NSF for Long Term Conditions.

Baroness Young highlighted the following ways in which interested stakeholders could work with the CQC in this regard:

- Mobilise the service user voice as this continues to be a key PCT/Trust requirement at a local level.
- Work to influence the Healthcare Quality Improvement Partnership's National Audit Programme. The CQC has a role in setting these priorities.
- Facilitate more local audit work
- Work to influence the new annual assessment process which is being developed (to replace the annual health check) and focus on strengthening the voice the user through this process

Chris Randell (Stroke Association) asked how the CQC could take on board lessons gained from the recent Stroke review.

Baroness Young commented that Stroke had a higher prevalence than other neurological conditions.

Lucy Bragz (Neurological Alliance) responded by explaining that neurological conditions were not just another patient group and that there are approximately 8 million people living with long term neurological conditions in the UK. She also stated that neurological conditions had been neglected and that a Special Review would help to address this.

Lucy Bragz raised the point that the CQC has a unique ability to carry out the work of a neurological review, partly because it spans both health and social care. In this respect, it has the ability to see where joint commissioning is not happening.

Baroness Young responded that the CQC does have some 'teeth' in the shape of the regulatory system and its role in driving forward the implementation of minimum standards. Baroness Young acknowledged that the APPG PD report is a good wake-up call to local health and social care decision-makers.

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Baroness Gale thanked Baroness Young for attending the meeting. Baroness Gale said that the APPG PD would send the CQC further questions which there had not been time to answer.

## **7. Future Meetings**

Baroness Gale said that the next meeting would be held in the new year. Notification of dates would be provided by email.

## **8. AOB**

There was no any other business.