

Support for all

August 2009

Dear all

I am really encouraged to see the way that our expanded local teams, working with branches and volunteers, are having such a positive impact on the lives of people living with Parkinson's.

I hope that you will be excited by what we've achieved and encouraged to think about how we can build on this success further over the next few years.

Your local manager can tell you what staff have been doing in your area.

Best regards,



Steve Ford
Chief Executive



Making life easier for people affected by Parkinson's can happen through meeting others, so 'Support for all' was designed to strengthen our branch and support group network.

The Parkinson's Disease Society (PDS) established 20 new groups in 2008 and Branch and Volunteer Support Officers (BVSOs) were there to nurture them. BVSOs carried out inductions with 267 new volunteers across the UK and also offered the same information to existing volunteers; exceeding our target to share this with 50% of existing committee members.

For the first time we offered Health and Safety training to volunteers and more than a thousand people took part. Specialist training was offered to Branch Chairs to support them in running effective committees and meetings.

Achieving our vision

Support for all was our vision and we invested in expanding and improving local services for all those living with Parkinson's wherever they are in the UK.

We have created teams of specialist staff and core PDS services to deliver the 'Support for all' objectives. We aimed to:

- **make sure one-to-one information and support was available in every locality...**
 - ✓ 120 Information and Support Workers now cover every primary care trust and health board area in the UK.
 - ✓ 13 Information and Support Managers met 19,000 people, many of whom are new to the PDS, through their expanded range of information events.
- **strengthen the existing branch and support group network...**
 - ✓ 20 Branch and Volunteer Support Officers helped to recruit more than 260 new volunteers and have expanded our network through developing new groups and branches.
- **train and educate health and social care professionals to have a greater understanding of Parkinson's...**
 - ✓ 13 Education and Training Officers delivered education and training to over 9,000 health and social care professionals in 2008.
- **push for continued development of high-quality local health and social care services...**
 - ✓ 13 Influence and Service Development Officers secured 24 new Parkinson's Disease Nurse Specialists (PDNSs) posts in 2008 and made contact with every primary care trust and health board in the UK.

Providing information and support

Through 'Support for all' we wanted to make sure that everyone living with Parkinson's in the UK had access to information and support. By the end of 2008, we had recruited 60 new staff to join our existing Information and Support Workers.

Information and Support Workers (ISWs) dealt with 34,919 enquiries including 4,164 new referrals in 2008. At the end of May 2009, ISWs had already received 27,217 enquiries including 4,064 new referrals.

A recent independent evaluation of the service showed that 86% of the users of the service rated the new, UK-wide service as excellent or good. 76% of users said that the service had made a positive difference to their life with Parkinson's.

Claire Andrew, who has Parkinson's, saw a poster for her local ISW Kay Andrews at her GP surgery. "My writing was so bad, it was nearly illegible," says Claire. "I contacted Kay, who helped me fill in forms. In particular, she helped me fill in my Disability Living Allowance application, which made sure I was paid without delay."

In 2008, the ISW service supported people affected by Parkinson's to access the £2.5million in benefits they were entitled to. This work continues, and up to the end of May, we have helped people access over £3million.



Claire Andrew (right) and her Information and Support Worker, Kay in East Berkshire



Ian and Cathy Deverall see their ISW in their Berkshire home

This means that for every £1 we spend on the ISW service, £3.50 of income is raised for families living with Parkinson's.

In their expanded role, ISWs have also stepped in to provide advocacy to people struggling to be heard. One example of this was when an ISW advocated for an older couple,

preventing them from having to make a back payment of over £2,000 to a nursing home.

The PDS telephone Helpline staff put them in touch with their local ISW, who became heavily involved in communicating between the couple, the social care team and the local NHS. She advised the couple to seek further support from other sources including their local MP, and the matter was finally concluded when the bill for fees was waived.

So far, the expanded ISW service has proved an invaluable resource – reaching people who previously didn't have access to such local support and advice. As the service continues to develop, we will be able to reach even more people affected by Parkinson's.



Jim Henry receives phone advice from his ISW in Northern Ireland

Educating and training professionals

'Support for all' set out to train and educate health and social care professionals to have a greater understanding of Parkinson's.



Resident and staff member at
Mali Jenkins Residential Home, Walsall

13 Education and Training Officer roles (ETOs) were developed to undertake this work. In the first full year ETOs were in post, Parkinson's education sessions were attended by 9,103 professionals.

This included staff from 1,595 nursing and care homes, exceeding our target of 1,320. Staff (including 466 individual GPs) from 205 general practices were also trained – almost double our target of 120.

Feedback showed that 100% of care home participants said the seminars were either 'good' or 'very good', that they would

recommend the seminars, and that their care or nursing home had benefited from the training.

The manager of a care home in Burton on Trent said: "A gentleman with Parkinson's disease regularly comes for respite in our home. I overheard, and was also told, that 'he can move when he wants to'. I was able to explain to staff that it is not a question of when he *wants* to, but more when he is *able* to."

Other staff said they are more aware of problems such as managing hallucinations, freezing, confusion, and getting medication on time.

Influence and service development

Influencing local health trusts or boards is one way 'Support for all' is making a difference through the new Influence and Service Development Officer roles.

Since coming into post, our Influence and Service Development Officers:

- have made contact with every primary care trust and health board to work to get Parkinson's on the agenda of all commissioners and planners
- are seeking the best ways to ensure people affected by Parkinson's are represented as health services go through a restructure
- are training 'local champions', to get people's experiences heard locally, and incorporated into our National Campaigns agenda
- have seen 36 new PDNS posts created. This means 10,800 more people with Parkinson's will be able to have access to a specialist nurse
- continue to work with commissioners to appoint more PDNSs
- have created steering groups and collected data around each new nurse to make sure the post is picked up after PDS funding has ended



Welsh branch members meet their local Assembly Member

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A company limited by guarantee, Registered No. 948776 (London)
Registered Office 215 Vauxhall Bridge Road, London SW1V 1EJ
Tel 020 7931 8080 Fax 020 7233 9908

PDS Helpline 0808 800 0303 (The Helpline is a confidential service. Calls are free from UK landlines and some mobile networks.)
Email enquiries@parkinsons.org.uk www.parkinsons.org.uk