

West Lothian Branch Meeting, Parkinson's UK

24th September 2014

Introduction

Hello, I am Diane Wilsdon and I work 10 hours a week for Parkinson's UK on a project in Lothian to develop services for people living with Parkinson's. However before going off on maternity leave I worked for Parkinson's UK for 8 years as the influence and service development officer focussing mainly on negotiating for Parkinson's nurses.

Today I am going to briefly outline how the project came about, what we are trying to achieve and what we have done so far but I would like to spend most of the time Talking with you about how you can become involved and ways of you influencing health and social care services in West Lothian and Lothian generally for people living with Parkinson's. The most important aspect of the project is that it is led by people living with Parkinson's and the services that are developed or restructured are designed to meet the needs identified by people living with the condition. basically because you are the folks who know what makes a good service or not!

Transforming The Future

Last year Parkinson's UK asked people affected by Parkinson's what three things would change their life with the condition. They said:

- Finding a cure and developing better treatments – You'll have access to treatments with minimal side effects that enable you to manage your symptoms. You'll be able to see there's a clear research pathway to a cure.
- Getting the right services – at every point of your journey with Parkinson's, high quality services will be available that anticipate and meet your needs
- Taking control – You'll feel supported to take control and live life to the full in a community that understands Parkinson's

Delivering Excellence

As part of 'Getting the right services' Parkinson's UK has developed the Delivering Excellence strategy. This proposes the creation of a UK wide Parkinson's network, bringing together the strategic leadership and resources of Parkinson's UK, the passion and expertise of leading professionals and crucially the voice of people affected by Parkinson's, to drive sustainable improvement in health and social care services for people living with the condition.

On the 10th of April Professor Bas Bloem a neurologist from the Netherlands who leads the ParkinsonsNet initiative met with leading clinicians, professionals and staff from Parkinson's UK including Dr Conor Maguire and Katherine Crawford to look at how this approach could work in the UK.

ParkinsonsNet – Key concepts:

- Identified all health professionals treating people with Parkinson's.
- Selected a limited number to train as experts in Parkinson's
- Improved/ promoted communication using a secure facebook like system on the internet.
- Made these people visible to other staff and patients. Result is that they start to get increased referrals and treat a large volume of patients which improves practice.

3 day training, 1st day on Parkinson's, 2nd day on their area of work such as physiotherapy or speech and language therapy, 3rd day on working as part of a multidisciplinary team.

Started with one hospital and just physios. Now covers all of the Netherlands with 19 disciplines and 1800 professionals who meet for an annual symposium and are in regular contact through the internet forum.

Services in Lothian

Could this work in the UK and more specifically for people living with Parkinson's In East Lothian? Certainly the vision of people living with Parkinson's regularly seeing consultants, nurses, therapists, social care workers etc. who specialise in Parkinson's, receive training and ongoing support and talk to each other is one that I think we are all clear that people want.

But what are services like now?

My impression is that there are certainly pockets of good practice e.g. the Parkinson's Nurse Service gets very positive feedback but access to services appears to be random. We only have 8 full WTE neuro physios in the whole of Lothian each working in different areas each with a different line manager and different referral criteria. NHS staff often don't seem to talk to each other never mind linking in with social work or social care providers.

What is happening to address this?

NHS Lothian has set up a Neurological Improvement Group with clinicians and staff working in neurology and one patient rep. who is Patrick Mark, chairman of the Edinburgh Branch. Dr Conor Maguire and Alison Stewart, lead PNS are also on the group. It has drafted a report which I am happy to send to anyone who wished a copy setting out the issues and how they hope to address them in the coming years.

For people with Parkinson's this includes:

- Recognising that the ideal service must be a multidisciplinary one

- An ideal service would ensure it has a person centred pathway, enabling early detection of the condition and an easy and clear referral pathway. Continuity of care from diagnosis onwards should be joined up with specialists from all disciplines working together.
- Need to formalise the leadership of services for people with Parkinson's
- Ensure people with Parkinson's have access to the most appropriate treatments for their condition, including non pharmacological treatment, drug treatment and neurosurgical procedures.
- Record all diagnosis of people with Parkinson's on the NHS computer system so they know how many people have the condition and what treatments they receive.
- Need to plan provision of allied health professionals

This is all very positive stuff but there are a number of things missing and the project I am doing hopefully with yourselves is about bringing Delivering Excellence to Lothian to complement and support this work. What I think is missing and what we can provide is to ensure that people living with Parkinson's are at the heart of all decisions being made. Of course workforce development and bringing staff on board is crucial and that will also be part of the project but involving all people with Parkinson's including those with dementia and living in care homes is what will make a real difference. Other services that are missing and that we will also be working with are community health services and local authority services particularly as next year there will be the integration of health and social care at the local level. There are also numerous services provided by the voluntary sector such as ourselves but also exercise classes, home care services, information and advice services and advocacy services that all offer useful support.

What we have done so far

I have spoken with representatives from all the Parkinson's branches in Lothian and visited the East Lothian Branch and the YP group. I am going to the Edinburgh branch on the 8th of October. I have had meetings with Jane Hopton, Catriona Simpson and Jane Dalrymple who are leading on the neurological Improvement plan implementation and development relating to Parkinson's services. I am now a member of the Lothian Parkinsons services Advisory Group which includes key clinicians interested in Parkinson's from all disciplines and this project is on the agenda for discussion at the next meeting.

I have drafted a project plan including an action plan with tasks and timescales and identified key areas to work on. These include the involvement of people with Parkinson's, linking in with agencies such as the Scottish Health Council to make the project sustainable in the long term, the development of physiotherapy services, improving the knowledge of Parkinson's among GPs, mental health particularly depression and Parkinson's and getting the views of pwp living in care homes. We have just over a year to do this – no pressure.

So far I have also mapped physiotherapy services, met with the Lothian Parkinson's physiotherapy Forum. Arranged a meeting with one of the key line managers. Agreed with Fiona Barrett, Parkinsons UK head of Education that we will run two training sessions on Parkinson's for physiotherapists attached to GP surgeries and day hospitals, set up a meeting with Fiona and two senior lecturers in physiotherapy at QMU to discuss the development of a post qualifying diploma which would be the first in the UK and agreed to man a stall on Parkinsons at the first Scotland wide student physiotherapy conference.

So what do I need from you?

Lots of help! I need you to tell me your experience of Parkinson's and using services. It's the difference between what is on paper and what happens to people in reality – good and bad that highlights the need for change. We want to replicate the good practice, eliminate the bad and provide services where none exist at the moment. I have given you a handout of different ways to get involved in this work. I can't stress enough how much more powerful it is to have someone living with the condition at a meeting talking about the issues rather than just a representative such as myself. However I know that can be scary and difficult particularly with a serious fluctuating condition like Parkinson's and I will ensure you have all the support you need to be able to fill any role that seems interesting to you.

The key areas that would be great to have volunteers are for the steering group for the project both to come to meetings or to be part of a virtual email network where you would get information about what we are up to and can offer comments and suggestions. The PPF in West Lothian CHCP is another critical area, although you already have health and social care working together at the local level, at least in theory, when integration happens over the next year there are going to be changes in structure and we want to be sure that we have an in to the discussions and debates. Only someone local can join, I am on the East Lothian one and although we have not talked about Parkinson's services specifically there has been useful information on patient transport, the GP forum and influencing GPs, changes to podiatry services, changes to home care services – all of which affect people living with Parkinson's.

It also gave me an idea for a specific project that I think would be ideal to work on in West Lothian. Whenever I ask people about services someone always tells me that their GP doesn't seem to know anything about Parkinson's. Now GPs have on average 1400 patients and will only see 1 or 2 with Parkinson's so that's understandable but still not helpful for you if you are the 1 or 2! So how can you, me, clinicians and Parkinson's UK improve this situation?

Parkinson's UK have a project called 'Turn to us' which is about getting information into GP surgeries and Emma Ward who is leading on that is happy to use West Lothian as a case study and provide all the support we need such as ordering

resources. The LPSAG are writing a referral protocol which will go to GPs telling them who to refer to in their local area who specialises in Parkinson's. Alongside the Pd UK information we can also write a letter highlighting the GP module on Parkinson's available on our website and provide copies of the GP information booklet and the local services available so leaflets on the branch, Shona, ISW and the Pd nurse service. It would be great to get this into every GP surgery in West Lothian and I will definitely need volunteers to help with this!

But will it make a difference. I have a questionnaire that I would be really grateful if you could fill in about your GP service at the moment and I will send it electronically to John for other people on email and we will repeat the process in six months time. I have also met with your local officer from the Scottish Health Council and they are very keen to support patients to set up patient groups in GP surgeries. This would be an opportunity to meet with practice managers and GPs to discuss issues and to hopefully see improvements in areas such as waiting times for appointments. I hope we can get at least one patient group started in West Lothian and I am happy to also support the work initially on this.

So, that's a lot of information and again John will have an electronic copy of my presentation for anyone who is a gluten for punishment and wants to have a copy.

I would now like to just ask you some general questions as a group and then give you time to fill in the questionnaires and to talk with people individually which is often easier than as a big group.

WHO IS HAPPY WITH THE SUPPORT THEY GET FROM THEIR GP?

WHY? What do they do that you feel is good?

WHO FEELS THAT THERE COULD BE IMPROVEMENTS?

WHAT CHANGES WOULD YOU LIKE TO SEE?

HAS ANYONE GIVEN INFORMATION ON PARKINSON'S TO THEIR GP? DO YOU FEEL IT MADE A DIFFERENCE? IN WHAT WAY?

Diane Wilsdon

Influence and Service development Officer, Parkinson's UK

Tel: 0844 225 9867 Email: dwilsdon@parkinsons.org.uk

24th September 2014

West Lothian Branch Meeting, Parkinson's UK

28th May 2014

WE NEED YOU!

Involvement Opportunities

Lothian Delivering Excellence Project

1. Tell Diane your story and experience of using health and social care services, good and bad. Do you feel your consultant understands your needs? Have you been referred to the people who you felt confident could help you?
2. Join the project email network for updates and the chance to comment as the project develops.
3. Join the project steering group to meet with other people living with Parkinson's from across Lothian and have access to key clinicians and managers to guide the project and focus on the issues that matter the most.
4. Volunteer to support one of the specific projects such as physiotherapy services, GP services, mental health or research on care homes. This can be a one off meeting or chat on the phone or an ongoing commitment.
5. Volunteer for one of the opportunities outlined below and keep in touch with Diane about it.

Support and training will be provided as needed so if you are interested there are no barriers that can't be overcome to enable you to get involved .

Please contact:

Diane Wilsdon, Influence and Service Development Officer, Lothian Delivering Excellence Project, Parkinson's UK, Kings James VI Business Centre, Riverview Business Park, Friarton Road, Perth, PH2 8DY

Tel: 0844 225 9867. Email: dwilsdon@parkinsons.org.uk.

GP Practices in West Lothian and Parkinson's

1. Volunteer for the 'Turn to Us' project providing information on Parkinson's and Parkinson's UK resources to Gp surgeries in West Lothian

More information on this is available on the volunteer page of the Parkinson's UK website or by contacting Diane or Emma Ward.

Emma Ward, Turn to Us Project Manager, Parkinson's UK

Tel: 0207 932 1350 Email: eward@parkinsons.org.uk.

2. Request your GP practice sets up a patient group. The Scottish Health Council have excellent guides to enable you to do this. Their website is www.scottishhealthcouncil.org. The local officer for West Lothian is Jackie Weir and she is happy to come out to speak to the branch and/or interested people.

Jackie Weir, Local Officer, Scottish Health Council, Pentland House, 47 Robb's Loan, Edinburgh, EH14 1AB.

Tel: 0131 537 8545 Email: jackie.weir@scottishhealthcouncil.org

Influence Local Health and Social Care Services

1. Look out for consultations, workshops and meetings on health and social care services in your local papers, library and community centres. This is a period of change and they will be looking for your views on what they are planning.

Information about the CHCP and its services is available on www.westlothianchcp.org.uk

2. Join the West Lothian Public Partnership Forum. This is open to anyone living in West Lothian. Even if you don't want to attend the meetings if you would be willing to receive the papers and pass them on to Diane, that would be extremely helpful. All key proposals for changes to services should come through this Forum. You can join as a group or as an individual.

Contact: **Julie Cassidy**, WL Involving People Coordinator, West Lothian CHCP, Community Health, Strathbrock Partnership Centre, 189a West Main Street, Broxburn, EH52 5LH

Tel: 01506 771883 Email: Juliecassidy@nhs.net

Influence NHS Lothian and acute services

1. Have a look at the NHS Lothian website involvement pages. There is currently a consultation on pharmacy services. If you would like support

in responding to a consultation, I am happy to provide a written guide or go through it with you.

2. St. Johns hospital has a patient group. Unfortunately there is no co-ordinator at the moment but I will be contacting Lesley Baxter, lead involvement officer to ask about this. This might be a good place to highlight 'Get it on Time'.
3. Respond to the Neurological Improvement Plan implementation and how it affects Parkinson's services. Diane can give you further information about this as it develops or you can contact Patrick Mark, Edinburgh Brnach chair who is the Voices rep on the group.
4. Join Lothian Neurological Voices. These are the people who are being asked for their opinions as decisions are being made. Training is provided and at present there are only 4 members so new people would be very welcome. We have found it extremely useful to have Patrick on the group but it would also be good to have someone living in West Lothian to highlight issues for people living outwith Edinburgh.

Google NHS Lothian and click on the Get involved box at the top. All the information on the above issues is available but Diane can send you specific information or papers if you are interested and are not on the internet or cant find them. Its not the most user friendly website!.

Diane Wilsdon

24/09/2014

West Lothian GP Services Questionnaire

24th September 2014, WL Branch Meeting

Name:.....

Email:.....

Tel:.....

GP Practice:.....

1. Are you happy with the support you get from your GP practice?

Yes [] No []

2. Can you explain your reasons for the above answer? E.g. long waiting times for an appointment or my Gp is a good listener or he doesn't know enough about Parkinson's.

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3. Would you like to be involved in the 'Turn to Us' campaign in West Lothian?

Yes [] No []

4. Would you like to know more about setting up a patient group?

Yes [] No []

5. Would you like to tell Diane about your experiences of using GP services

Yes [] No []

If yes for any of the above questions. Please complete the details at the top of the form.

