Health, Well-Being and Partnership Committee.

Parkinson's support, help and advice.

Report of Findings.

From a global perspective, with an estimated 7 billion population, evidence suggests that between 7 and 14 million people worldwide are living with Parkinson's. (Source: World Health Organisation 2004 Report)

Parkinson's disease is a chronic progressive neuro-degenerative disease affecting approximately 7 million people globally with devastating socio-economic effects on individuals, their families and society. It is the second most common age-related neuro-degenerative disorder after Alzheimer's disease.

Every hour, two people in the UK are told they have Parkinson's. In 2018 that equates to an incidence of 18,461 people to be diagnosed, leading to a prevalence of 145,519 people. That's one adult (age 18 and over) in every 350. Whilst most people are age 50+, younger people get it too. (Source: Parkinsons.org.uk)

New analysis suggests that the number of people diagnosed with and living with Parkinson's is rising; a total figure is estimated to rise to over 168,000 by 2025, with 1 in 37 people being diagnosed during their lifetime; with 1 in 20 people with the condition first experiencing symptoms when they're under 40. (Source: Parkinson's UK)

With the UK population growing and people living longer, this means that the number of people living with Parkinson's will continue to rise.

Parkinson's Disease does not directly cause people to die and, for the majority of people, does not significantly affect their life expectancy even though some of the more advanced symptoms can lead to increased disability and poor health, which can make someone more vulnerable to infection. Despite little impact on life expectancy, Parkinson's Disease patients experience progressive disability and reduced Quality of Life at all stages of the disease and at all ages. Several studies indicate that quality of life is affected not only by the motor symptoms of Parkinson's Disease, but also by the pre-motor symptoms such as depression and cognitive state.

On Wednesday 25th July 2018, I arranged a visit, for myself and Cllr Panter, to the Parkinson's Support Group in order to meet with and to hear perspectives from Parkinson's disease sufferers, caretakers and other patient representatives on the most significant effects of their disease, the help and support that was given to them, its impact on daily life, what support they wish they had been given and their experiences with currently available therapies. I have also had talks with medical practitioners and Parkinson's UK representatives.

Overview of Parkinson's Disease and meeting outcome.

Parkinson's disease is a progressive and chronic neuro-degenerative brain disorder that affects approximately 145,000 people in the UK. Parkinson's disease affects both men and women; however, men are one and a half times more likely than women to have the disease. The condition is generally characterized by primary motor symptoms of resting tremor, bradykinesia, rigidity, and postural instability. Non-motor symptoms experienced by Parkinson's disease patients may include cognitive impairment, mood disorders, and sleep disturbances. The manifestation of motor and non-motor symptoms varies among patients. The progression of Parkinson's disease may differ markedly from patient to patient following diagnosis. There is no cure for Parkinson's disease; therefore, the goals for treatment are to improve quality of life and manage the signs and symptoms of the disease. Several treatment options for Parkinson's disease are currently available and involve a wide range of administration routes including tablets, capsules, patches, subcutaneous injections, intramuscular injections and intrajejunal infusions. Carbidopa-levodopa remains the mainstay of treatment for the signs and symptoms of Parkinson's disease. Over the course of their disease, almost all patients with Parkinson's disease will take carbidopa-levodopa. In addition to carbidopa levodopa, other treatments include drugs such as dopamine agonists, COMT (catechol-O-methyltransferase) inhibitors, anticholinergics, and MAO-B (monoamine oxidase type B) inhibitors. Deep brain stimulation is also a potential therapeutic option for patients with advanced Parkinson's disease. Non-pharmacological management approaches include exercise, yoga, meditation, diet, and lifestyle modification.

Several key themes emerged from this meeting:

- Parkinson's disease is a progressive, devastating disease. Group members emphasised the difficulty of living with the unexpected onset and progression of symptoms. Many described living with daily motor symptoms which included bradykinesia, dyskinesia, tremor and dystonia. In addition to motor symptoms, participants also highlighted sleep disturbances, cognitive impairment, fatigue, and constipation.

- Parkinson's disease impacts all aspects of patients' lives. Members described severe limitations in performing at work, caring for self and family, and maintaining relationships. Participants shared the emotional toll of living with social isolation and adjusting to significant lifestyle changes to manage their Parkinson's disease.

- The meeting reiterated the complexity of Parkinson's disease management. Many of the group members described the burden of selecting the best available treatments to address their symptoms, the complexity of managing proper timing of medications in addition to pill burden (number and frequency of pills taken throughout the day), and the need for adjustment of their medication regimen because of unpredictable symptoms, changes in daily demands leading to increases in symptoms, as well as disease progression.

- Nearly all the members spoken to described using a combination of drug and non-drug treatments. They emphasised that the side effects of treatments were often as debilitating as the underlying disease symptoms. Many highlighted the benefits of incorporating non-drug therapies, such as exercise and diet modifications, with prescription regimens for optimal symptom management.

Some members stated that stress exacerbated their motor symptoms and impaired balance; this comment resonated with several others; also identified additional triggers that worsened their motor symptoms including: lack of sleep, anxiety, large crowds, stress, temperature change, and the feeling of being rushed to complete a task. Difficult environments to negotiate for a person with Parkinson's Disease.

Throughout the meeting, group members raised several other considerations that they believed were important relating to Parkinson's disease. Many commented on the need for increased awareness and education to properly diagnose, understand and treat Parkinson's disease.

The results of these conversations reveal that whilst Parkinson's patients and their supporters are in the main resourceful and stoic, the complicated nature of the condition means that they are dependent upon a myriad of different services and a need for them to be joined up. Also, professionals sometimes find Parkinson's itself difficult to understand. For example, patients found that hospital staff might not understand the importance of timely delivery of Parkinson's medication, resulting in significant problems. This spread over into primary care where over half of those with advanced Parkinson's reported that their GP didn't seem confident to offer advice about the condition. To compound this, patients reported having had their mental health impacted but only a small number had accessed services to help with this. This is particularly worrying when many of this group are more likely to be elderly and live alone, in this meeting some of the members reported not feeling part of their local community and that loneliness had influenced their health. (Source: Healthwatch Stoke-on-Trent)

Family members felt strained and let down by the medical profession, to quote one carer, *"We're left to get on with it and we have to just do our best…. But what else can we do?"* others praised the help and information from the Support Group, *"We've found out more about Parkinson's by coming here and speaking to people, than any Doctor information… but then the GP's know nothing…"*

"My GP prescribed me the wrong medication, I couldn't have it with the Parkinson's tablets. It was just as well that I had a list of what I could and couldn't have otherwise who knows what would have happened? I rang the nurses at the hospital and left a message. They rang me back three days later and said 'Oh no you can't have that, I'll send a prescription to your Doctor's now and you can go and collect it from them'…. I mean why didn't the Doctor know? He has my records in front of him that says I have Parkinson's!"

Perhaps because of the above, Parkinson's sufferers overwhelmingly report reliance upon the Parkinson's nurses. This is a vital service which should be well funded and supported. However, only a small number said that they can access services as they need to. Many members were still waiting on their follow-up appointments with the Parkinson's nurses which were now lapsed by six months from what should have been the 'regular' interval. This is not by fault of the clinic team but simply the volume of new referrals and follow-ups means that waiting times are becoming increasingly longer.

All of this means that Parkinson's patients need special consideration because they;

- are reliant upon multi-disciplinary working;
- require increasing amounts of support as the condition worsens;
- are helped by informal networks and professionals who might find the condition difficult to understand;
- are less likely to have a support network;

- are likely to have issues beyond Parkinson's;
- are more likely to have low health literacy;

With earlier diagnosis meaning that more people are being referred into Parkinson's services it seems important to consider more than the clinical when commissioning services, it needs to be patient centred in a way which acknowledges the social when delivering clinical needs. The Parkinson's Support Group in Chesterton, which is completely self-funded, is the largest active group in the county. It meets every Wednesday from 10am to 1pm and welcomes everyone with tea and biscuits. They do an enormous amount of work from building friendships; putting on a range of activities which include, but are not restricted to, BBQ's, exercise classes, trips, holistic therapy, meals together, Speech and Language therapy, education, Nordic walking. They also try and get speakers in on a regular basis with information that is pertinent to the group members and their families, such as information regarding Lasting Power of Attorney (LPA); Parkinson's Nurses have also done some 'drop-in' sessions although these have become less frequent of late, in part due to funding and the time and workload of the nurses.

There is a need for more support groups across the city; the Chesterton group has a membership of 60+ and rising and their fear is that there are many more people who need access to support groups who are not being directed to one. They also have concerns that there are many 'younger' people with Parkinson's who are not being catered for or given the information they need. Certainly, after a visit to a few local Doctors Practices, this could possibly true as when asked why they didn't have any information freely available on the public side of the desk, the response was, *"Oh, we don't do the leaflets, but (name) takes some out to the patients who are over 70…. We have quite a few patients with Parkinson's…"* When presented with the facts that people under 50 can already have symptoms and that people as young as 35 can be diagnosed with Parkinson's, there was the default, *"Oh, we don't do the leaflets…"*

Attached is a copy of a brochure that I have compiled using the 'I wish I had known/been given/knew what.......when I was diagnosed' of those from the support group, as through talking with people, these exact same issues kept cropping up, along with unable to contact the nurses due to how busy they are and a lack of suitable reading material beyond a very basic leaflet. I hope to have addressed this with this more substantial, yet still manageable, version based on what the people from the support group said that 'they wished they had been given' regarding this disease, as all too often the stock response was that there was plenty of information on the Internet. Actually... there's too much information!

Parkinson.org.uk have also had access to this brochure and their response was;

David Swindells the Area Development Manager at Parkinson's UK has had access to this brochure and his response was …. "Parkinson's UK are regularly told by people with Parkinson's that having understandable and accessible information, especially when newly diagnosed, is one of the most important ways they can start to take control of the condition. Whilst Parkinson's UK have a range of information available and specialist information and support teams, initiatives which can support our local groups in getting their contacts and information publicised can only be a good thing."

The Parkinson's Clinic Team Nurses based at the Royal Stoke and Haywood Hospitals have also had access to this brochure: They were extremely positive with the brochure and thought that *'the* *format gives enough information to help but not so much as to overwhelm.'* They would like to present it to the two Hospital Trust Boards whom they work under, with the view of getting authorisation for distribution by them (nurses) into the clinics from which they work from. This would mean that the nurses and clinic team will be able to ensure that the people most needing this information, will have access to it.

Discussion with GP practice manager regarding information available at point of entry to the surgery and the way forward, resulted in………. not very helpful. Despite Parkinson's patients, patient groups, Parkinson's Area Development Manager and Parkinson's Clinic Team staff all stating that they thought GP practices should have information on display and readily available, given that they are ultimately the first point of call after initial diagnosis and the subsequent wait until the Parkinson's Clinic Nurses are involved, it would appear that the best and only option is to 'drop a contact leaflet' off so that their elderly care facilitator will be able to hand it to the people who they think may need it when they 'go out to visit.' I hope that this will change in the not-so-distant future.

Meeting with Robin Wiles, (21.11.18) as a follow-up to a 'Wish List' that the support group had put together, was extremely productive.

A variety of potential charities were identified which could possibly help the group with costs towards conductive education, speech and language and future activities. These avenues are still being explored and will take some time due to the nature of business involving form-filling and eligibility criteria etc. However, one 'wish' on their list has already started to move forward. The group hoped that they could create a small garden area that would enable their members to access the outside to the rear of the community centre. I am pleased to report that, thanks to the generosity of B&Q Talke and the Newcastle branch of Homebase, a substantial number of plants and compost are to be donated to the group in the spring, for the garden area to be started. This will have an immediate impact on the group members as they will then be able to have the option of using an outside space, which has been shown to have a positive outcome on the physical and mental wellbeing of someone with Parkinson's.

I am also in contact with Pentagon Play, an organisation who are used to creating outdoor projects to stimulate and encourage physical development; regarding access to potential funding for seating, wheelchair adaptive tables and planters.

I will keep the committee informed with updates as this garden project progresses, along with any of the other aforementioned areas.

Parkinson's and Diabetes

The vast majority of people with diabetes will not go on to develop Parkinson's. Studies that demonstrate type 2 diabetes is linked to an increased risk of Parkinson's suggest, however, that the two conditions may affect cells in similar ways. Researchers say the exact nature of the relationship between diabetes and Parkinson's disease is unclear, but several lifestyle factors may be associated with both disorders, such as being overweight, cigarette smoking, and lack of physical activity. Although common lifestyle factors may play a role, researchers say more study is needed to fully understand the relationship between diabetes and Parkinson's disease.

That said, recent research has shown that the drug molecule, NLY01, which works in the same way as some diabetes drugs, has been found to slow the progression of Parkinson's; while activating receptors in the pancreas causes insulin to be released, researchers believe activating the same receptors in the brain may help to protect the brain cells affected by Parkinson's. (Source: Parkinsons.org.uk)

Cllr Helena Maxfield

Health, Wellbeing and Partnerships Scrutiny Committee, 30th November 2018.