



**APPG on Parkinson's and APPG on Diabetes joint meeting
Wednesday 19th April 2023**

Present:

Derek Thomas MP (Chair, APPG on Diabetes)
Mary Glindon MP (Chair, APPG on Parkinson's)
Ian Levy MP
Marie Rimmer MP
Virendra Sharma MP (officer, APPG on Diabetes)
Christina Rees MP (officer, APPG on Parkinson's)
Peter Dowd MP
Marion Fellows MP
Baroness Gale
Baroness Barker

Panel:

Dr Jennifer Foley (Neuropsychologist at National Hospital for Neurology and Neurosurgery and lead of Parkinson's UK Excellence Network for mental health)
Dr Amrit Sachar (consultant psychiatrist, expert in diabetes and mental health)
Liz Barnes (expert by experience)
Kayleigh Steel (expert by experience)

Staff present:

Laura Mullaney (Parkinson's UK)
Sam Freeman Carney (Parkinson's UK)
Gini Dellow (Parkinson's UK)
Jack Ashby (Diabetes UK)
Izzy Roberts (Diabetes UK)
Jack Doughty (Diabetes UK)

1. Opening Remarks

Derek Thomas opened the meeting and welcomed everyone.

Mary Glindon MP summarised some of the themes raised from the 2018 Mental Health Matters Too report and highlighted summary statistics to evidence that currently, psychological care for people with Parkinson's falls short of meeting their needs.

She stated that there had been no improvements in the five years since the report was published. In that time, the gaps in care had increased,

1. Symptoms have increased,
2. A report by Lancaster University in 2021 demonstrated that levels of anxiety and depression have increased. The study found that 7 in 10 people reported anxiety and 4 in 10 people were suffering from depression - a staggering rise from 13% in 2020 to 48% in 2021.



She emphasised that government plans for the future have to incorporate planning for the mental health needs of people with Parkinson's. Priority areas include

1. Ensuring that staff are in place through proactive recruitment and proper training
2. There is a need to integrate both physical and mental health support
3. Waiting times need to be lessened
4. Better and more data must be published

She concluded that the scale of the challenge is enormous.

2. Remarks from Dr Foley

Dr Foley remarked that mental health is something that affects most people with Parkinson's. She listed the prevalent mental health conditions including anxiety, depression, apathy, psychosis and dementia and explained how anxiety also increases the chances of psychosis. As such the neuropsychiatric burden on the health service is immense from unplanned admissions to carers that cannot cope, to people ending up in long term care settings. She cited that 86% of all hospital admissions are unplanned. Delusions can increase stays by 69 days. Annually, mental health accounts for £144 million annual spending in the NHS.

Mental health interventions and services, however, can improve this and the presence of a multidisciplinary team (MDT) can reduce unplanned admissions. As a result, the compassionate and economic argument presents a case for better MDT's, an appropriately trained workforce and equality of access across the whole country.

3. Remarks from Liz Barnes

Liz Barnes, a person with Parkinson's, shared some aspects of her own personal experience. She referenced trauma dating back to childhood abuse and complex PTSD. She was diagnosed with Parkinson's at the age of 40. Liz highlighted that she found her care fell short with little support at diagnosis. Treatment consisted of information via DVD and then an offering of drugs later. She did not feel supported, does not feel heard and does not have access to a Parkinson's nurse. Until recently she had worked as a social worker. In 2022 her mental health started "falling apart" when thoughts of her childhood trauma flooded in.

In February 2023, she admitted herself to an NHS hospital for psychiatric care. She describes her stay there as "horrific". She said she felt disempowered, abused and came out bruised. She reported this to the police but said they did not want to know and felt disregarded. Moreover, they were also unequipped to provide her Parkinson's-related care. On the back of this experience but still needing help, she lost faith in the NHS and instead went to a private trauma clinic at Kiron House in Oxfordshire. She said they were wonderful. However, the cost was prohibitive to staying longer despite a recommendation for longer support.

Liz therefore called on MPs to focus on the following areas:



1. Police not to disregard reports from people with mental health because it leaves them feeling devalued and stigmatised.
2. NHS Psychiatric ward staff to receive trauma training and training in specific mental health conditions
3. Patients to be seen, heard, known and validated.

4. Remarks from Dr Sachar

Dr Sachar remarked that mental health coexists with a number of long term conditions and Improving Access to Psychological Therapies is simply not enough. She referenced the need for cultural appropriateness and equality in care as well as the importance of self care. She said self care supported someone to feel motivated, to feel good about themselves and to feel in control. She said this also encompassed believing in the condition, that it was a long term diagnosis and also the importance of believing in the healthcare practitioner's advice. She called for mental health integration with a focus on the:

1. Workforce planning
2. Data - access to data sets and availability of data for all groups
3. Prevention through screening for common mental health problems

In reference to the need for a greater focus on prevention, she said "There comes a point where we need to stop plucking dead fish out of the river and instead go upstream and see what is happening to the healthy fish."

5. Remarks from Kayleigh Steel

Kayleigh has lived experience of diabetes and poor mental health. She spoke about her diagnosis and lack of support with her mental health which she sees as linked. She was visibly upset as she spoke about her struggle with depression and binge eating and her diagnosis with diabetes. She says her GP will not speak to her and she only sees a nurse once a year. She believes that there is a need for mental health to be supported earlier.

6. Discussion & Q&A

Following the remarks from the panel, the floor opened to a Q&A. Key points which came out of this are as follows:

- The lack of Parkinson's nurses/the postcode lottery of having access to a Parkinson's nurse are associated with increased issues for people with their mental health
- Good self care correlates with improved mental health yet there is little support people to develop improved self care
- There is a need to consider the language that healthcare professionals use and to consider patient's sensitivities
- Peer support is important and more is needed
- There is a need for upscaled mental health awareness across healthcare practice
- The importance of joined up care should not be underestimated
- In the event that there is unlikely to be a sudden surge in staffing levels, it is important to consider how improvements can be made with the current staff
- It feels that care pathways are missing and that no one is in control of the 'journey'
- It is vital that people with long term conditions are seen, heard, known and validated