



**Healthwatch Cornwall in
Partnership with Parkinson's
Cornwall: Report on feedback
comments about Parkinson's services
in Cornwall.**

January 7, 2015



Healthwatch Cornwall (HC) has worked in partnership with Parkinson's Cornwall to look at the health and social care services that patients with Parkinson's receive. The Parkinson's Strategy Group for Cornwall commissioned a survey that was sent to 500 Parkinson's patients in August 2014 and received 30 replies on which this report is based on.

- Lack of information and advice on medication.
- Lack of access to Parkinson's health professionals after initial diagnosis.

The main issues raised in the report include:

- Lack of empathy and poor practice by diagnostic professionals.

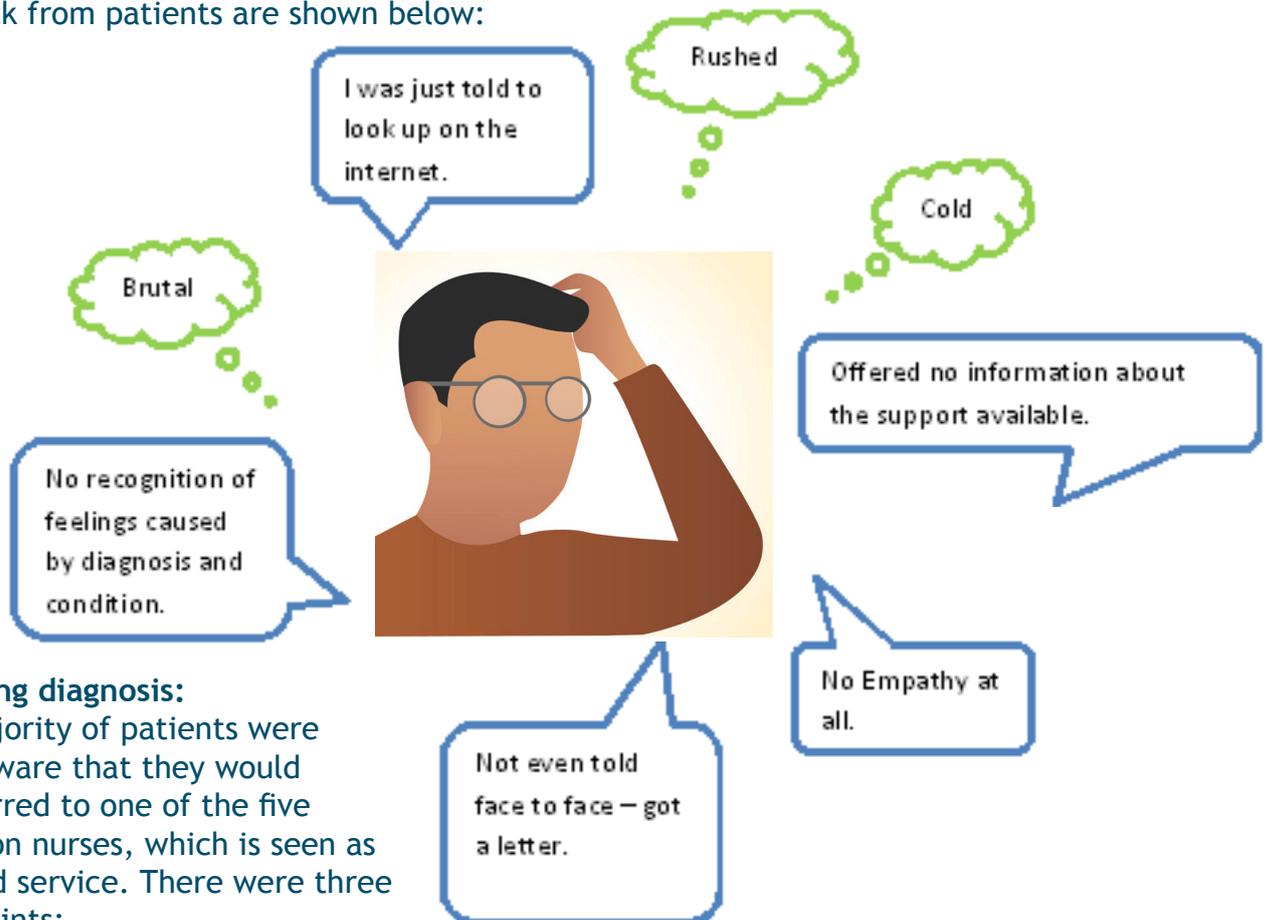
These main issues and patient feedback comments are displayed in the rest of this report.

Feedback on diagnosis and care pathway:

Diagnosis:

A Parkinson's diagnosis can be from a geriatrician, a neurologist, a GP (not NICE recommended) or from a private consultant.

The major concerns fed back relate to a diagnosis made by a neurologist. Example of feedback from patients are shown below:



Following diagnosis:

The majority of patients were made aware that they would be referred to one of the five Parkinson nurses, which is seen as a valued service. There were three main points:

1. Majority had little idea of what Parkinson's was from the information provided.
2. Had little knowledge of other therapist that could help after the diagnosis.
3. No idea of what third sector support was available.



Regarding early treatment:

Majority discussed drugs with their consultant - but many not until their second appointment, which could be a year wait.

- Patients were asked to go on the internet and find out about medication, then come back and tell the doctor what they want to do.
- Some patients were shocked by the diagnosis and therefore couldn't take any additional information in.

Hospital admissions:

These mostly concerned getting medication on time (time critical). See feedback comments below:

Wife explained the need for prompt medication from staff but wife still had to remind staff each time his meds were due, 5 times a day (RCHT Treliske).

Medication timing not adhered to, except by one shift who had been on a 'Parkinson's Course', (RCHT Treliske).

In Penrice she couldn't get them to give her the medication in advance of her meal so that she could feed herself. Her food was always cold by the time she could use the cutlery.

Agency and Weekend staff:

The comments received around this topic relate to training and awareness of Parkinson's disease. See feedback comments below:

Why go to the bother of writing about my needs in a care plan if weekend, agency and night staff do not or are not made to read it?

A few days ago after the operation his Deep Brain Simulation needed adjusting as he was dyskinetic. The weekend staff wouldn't bring him his controller and held him pinned to the bed, thinking he's have a fit, while an on call doctor came and wanted to change his drug regime.

The agency staff were no support at all in getting her to the toilet etc.

Recommendations:

1. The diagnosis of Parkinson's disease should always occur face to face with consultant and preferably a family member present.
2. The diagnosis should be followed up with an explanatory letter, containing information on Parkinson's disease and contact details for Parkinson's UK, the national charity.
3. A written record of advice given to patient in regards to medication, which could be taken and a follow up appointment with a consultant after 6 months after diagnosis rather than a year.
4. Specific training on Parkinson's care plans for all staff, including agency, which highlights need for timely medication.