Parkinson's UK

healthwatch
East Riding of Yorkshire

The Parkinson's Project

A Healthwatch investigation in partnership with Parkinson's UK

Contents

The Parkinson’s Project

Executive Summary

This report from Healthwatch East Riding of Yorkshire, with support from Parkinson’s UK, summarises an investigation into the lived experiences of people affected by Parkinson's in the East Riding. The project aimed to understand challenges and improve support for the local Parkinson's community. Feedback was gathered from people with Parkinson's and their care partners between March and July 2025 through a mix of surveys, community engagements and discussions. We actively engaged with 299 people during this project and 51 people completed a survey.

Key themes from feedback

1. The Diagnosis Journey

The experience in getting a Parkinson's diagnosis is inconsistent. Many experience delays, often due to a lack of awareness of less obvious symptoms among primary care professionals. The communication of the diagnosis varies from compassionate to unsympathetic, with many people feeling unsupported and left to find information on their own.

2. Parkinson's Nurses

Specialist Parkinson's Nurses are a highly valued service, with 92% of respondents reporting a positive experience. They are praised for their compassionate, holistic care and for being a crucial link to wider support. However, a key concern is that the six-month interval between appointments leaves many feeling the service is overstretched.

3. Managing the Condition

Parkinson's profoundly impacts daily life and independence. Beyond motor symptoms, challenges include fatigue, anxiety, and memory loss. A lack of public awareness of these "invisible" symptoms often leads to social isolation. The condition also creates a financial burden due to care costs and loss of income.

4. Accessing Support

Peer support, particularly through Parkinson's UK groups, is seen as incredibly helpful for reducing isolation. However, awareness of the full range of available support is inconsistent; nearly a third of respondents were unaware of or unsure about the support offered by Parkinson's UK. Many people anticipate needing more practical help at home as their condition progresses.

5. The Carer's Experience

The report highlights the contribution of carers, mostly spouses, whose relationships and identities are fundamentally changed by the condition. Their lives are dictated by medication schedules and fluctuating symptoms, leading to social isolation. Many carers are unaware of formal support services and express a need for respite and peer connection.

Recommendations

We are giving 13 recommendations to service providers across the East Riding to improve support for people affected by Parkinson’s. Amongst the recommendations are calls for additional training for GPs to help spot symptoms earlier, clearer consistent communication when giving a diagnosis, and making sure people know about the help available from Parkinson’s UK. There are also calls for more joined-up working between health professionals, better access to mental health support, and more carer-specific support groups.

Introduction

About Healthwatch East Riding of Yorkshire

Healthwatch provides an independent voice for the residents of the East Riding of Yorkshire. We listen to people's lived experiences of health and social care services and report these experiences back to service providers. As well as seeking the public's views ourselves, we also encourage services to involve people in decisions that affect them. Our sole purpose is to help make care better for people.

Our vision

Equitable Health and Care services that meet the needs of every person within our community.

Our mission

To give every person in East Riding of Yorkshire the opportunity to have their voices heard and empower them to play an active role in shaping services in their community.

Our values are:

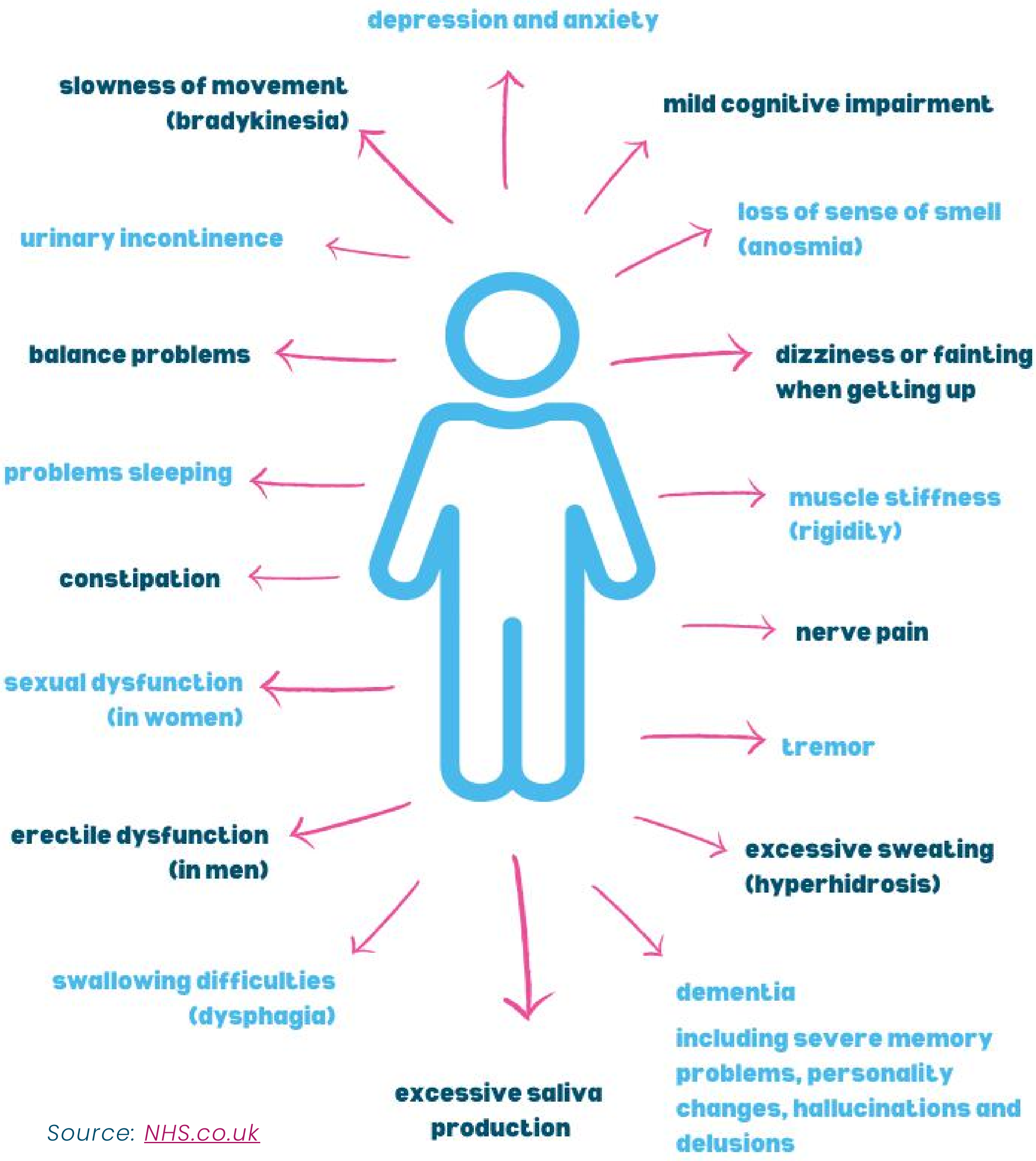
- We are proud to be **independent**, and not afraid to speak up and **challenge decisions** that do not meet the needs of our communities.
- We operate a culture of **transparency** and **openness**, ensuring we are accountable to the communities in which we serve.
- Our work is **evidence** based – led by **public voice** and need.
- We are **collaborative**, working with organisations that share our vision of **equitable health and care services** that meet the need of every person within our communities.
- **Partnering** with the Government, health and care services and the voluntary and community sector to make care better whilst retaining our independence.

What is Parkinson’s?

Parkinson’s is a progressive neurological condition. This means that it causes problems in the brain and gets worse over time. People with Parkinson's don't have enough of the chemical dopamine in their brain because some of the nerve cells that make it have stopped working.

It is not known why the loss of nerve cells associated with Parkinson's disease occurs, although research is ongoing to identify potential causes. Currently, it's believed a combination of genetic changes and environmental factors may be responsible for the condition.

Symptoms of Parkinson’s



Source: NHS.co.uk

Symptoms

There are over 40 symptoms of Parkinson's, though everyone's experience of the condition is different. The symptoms may vary in severity or progression for each person, and these may change from day to day. Typically, the symptoms are split into motor (movement and balance) and non-motor (mental health, memory, and pain). The main symptoms associated with the condition are:

- Tremor
- Muscle stiffness
- Slowness of movement

Treatment

There is no cure for Parkinson's. Treatment and therapies can help individuals manage the symptoms of Parkinson's, for example, the drug levodopa is often prescribed to improve some motor-symptoms. Other non-pharmaceutical treatments include physical activity and therapies such as physiotherapy, speech and language therapy, and occupational therapy.

About Parkinson's UK

Parkinson's UK is a national charity with one mission: to make life with Parkinson's better, today. There are many ways in which the charity supports people to live well with Parkinson's, including:

- Local support groups – these are social and/or activity-based
- Parkinson's Local Advisor's for emotional and practical support
- Online information about the condition and available treatments and therapies
- Free printed information booklets which are co-produced with healthcare professionals and people living with Parkinson's
- Online community groups and forums to connect with others
- Information packs for newly diagnosed people

In addition to the support services, Parkinson's UK regularly campaign for better care for people with Parkinson's. Their Get It On Time campaign aims to make sure people in hospitals and care homes get their Parkinson's medications on time, every time, as many of these medications are time-critical with severe consequences for missing them.

The Parkinson's UK Nurse Appeal highlights an inequality in access to health specialists for people with Parkinson's across the UK. The Nurse Appeal aims to raise £9 million over 3 years to increase the number of specialists, and it has already passed the halfway mark with £5.5 million raised. This has already resulted in 19 new Parkinson's specialists giving around 4,900 more people access to specialist care.

In addition to campaigns, Parkinson's UK lead and invest in research towards a cure for Parkinson's as well as treatments which can slow, stop, or reverse the condition. Already, the charity has invested over £130 million in vital research that has delivered groundbreaking discoveries, new medications and better care.

Why Parkinson's?

Parkinson's has been identified as an under-represented community within the Healthwatch Network. Throughout the 152 Local Healthwatch in England, there are currently only 2 which have investigated the experiences of the Parkinson's community – Healthwatch Stoke-on-Trent and Healthwatch Gloucestershire. Additionally, through general community engagements across the East Riding, we have heard of some inequalities in care delivered to people with Parkinson's which we feel should be brought to the attention of service providers.

Parkinson's affects an estimated 166,000 people in the UK, and its prevalence is rising due to the ageing population. By 2050, the global number of people living with Parkinson's is expected to double to 25 million. In East Yorkshire, this trend is particularly significant, as the proportion of residents aged 65 and over is 8.2% higher than the national average. With projections indicating that the number of older adults in East Riding will reach 122,348 by 2043, age-related conditions like Parkinson's are anticipated to become increasingly common.

"We call it Parkinson's. We don't use the word 'disease' because some people with Parkinson's have told us it sounds negative, or like an infectious illness. But unlike the flu or measles, you can't catch Parkinson's from someone." – Parkinson's UK

Aims of the Project

Amplify the voice of the Parkinson’s community

- Whether this is someone with Parkinson’s, their carer or loved one.

Highlight services and areas that are working well

- By doing this, good practice can be shared with the aim of reducing inequalities in care. We regularly hear positive feedback which we feel needs to be shared.

Understand the experiences of people affected by Parkinson’s

- We want to know what kind of support people are offered after being given their diagnosis; what did they find helpful and what else would they have liked?
- We want to know what barriers to care people with Parkinson’s experience and what can be done to reduce these.

Support the Parkinson’s community

- We will provide Healthwatch signposting and information to people affected by Parkinsons. There are many avenues of support available, e.g., the Parkinson’s UK local advisors service and support groups, and the East Riding of Yorkshire Council Carers Support Service. We will increase awareness of these to ensure people are properly supported on their Parkinson’s journey.
- Build a strong relationship with Parkinson’s UK to offer support on a long-term basis.

Methodology

A mixed-methods approach was used to gather feedback, recognising that handwriting difficulties meant surveys alone weren't suitable. Alongside online and paper surveys, insights were collected through group discussions and public engagement events. Data was gathered between March and July 2025.

Surveys

We created three surveys as a means of gathering data for this project; one for a person with Parkinson's, one for a carer/someone who supports a person with Parkinson's, and one for the Parkinson's nurses in the East Riding. As the nurses declined to take part in this project, there is no data to report.

Wish boards

Whilst at community engagements, members of the public were asked if they would like to share thoughts on the wish boards. One wish board asked "What do you wish the NHS and social services knew about what it is like to have Parkinson's?" and the other asked the same from the carer's perspective.

Community engagements

We visited the following places to collect feedback, engaging with 299 people in total:

Parkinson's UK Groups	**Leisure Centres**	**Community Centres**
Hornsea	Pocklington	The Hinge Centre
Bridlington	Beverley	Love Driffield Community Hub
Cottingham	Haltemprice	
Withernsea		
Goole		
Driffield		

Promotion of the project

Social media posts on Facebook, Instagram, TikTok, and LinkedIn promoted the project, shared condition info, and listed engagement event details. These posts received over 2,500 views across platforms.

The project featured in newsletters from Healthwatch East Riding of Yorkshire and Parkinson's UK Hull and East Yorkshire with a combined reach of over 300 recipients.

Disclaimer

All the views, opinions and statements made in this report are those of the people who participated in our surveys or contributed to group discussions. While every effort was made to gather a broad range of views, this report represents a snapshot of experiences of people affected by Parkinson's in the East Riding.

Any names of people in this report are pseudonyms given to protect the identity of the person sharing their experience.

A separate appendix with the feedback and resources used during this report can be requested via email: enquiries@healthwatcheastridingofyorkshire.co.uk

Findings

Person with Parkinson’s

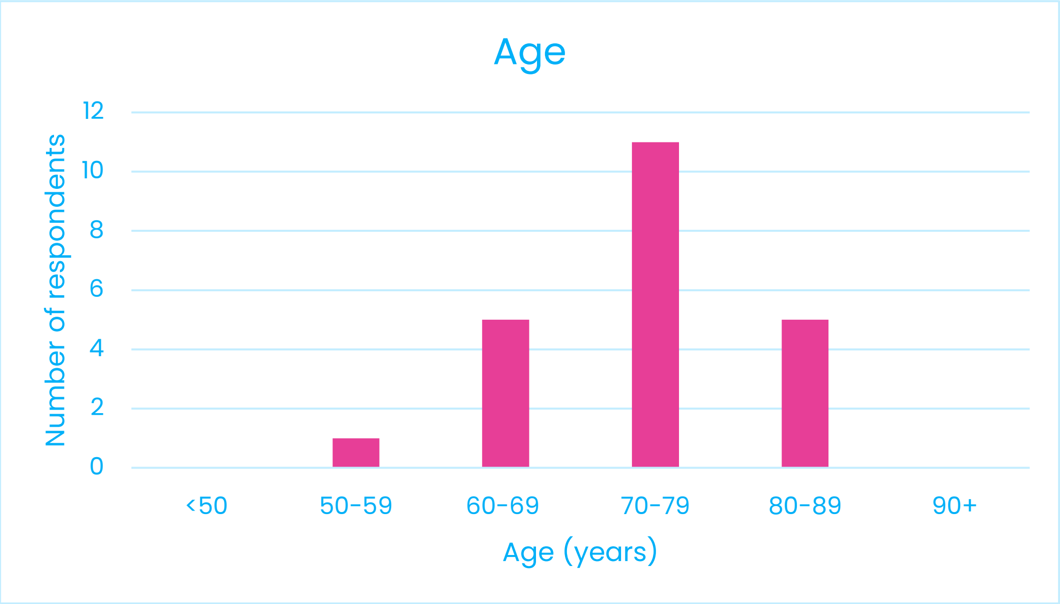
Please note: The numbers in this report come from survey responses. Comments and personal stories were gathered from both the surveys and in-person discussions.

Although there were 25 respondents to this survey, all questions were optional and some allowed multiple selections, therefore, some response numbers may not add up to total survey responses.

Demographics

Age

The most common age group was 70 – 79 years with 11 respondents. One respondent was aged between 50 – 59 years.

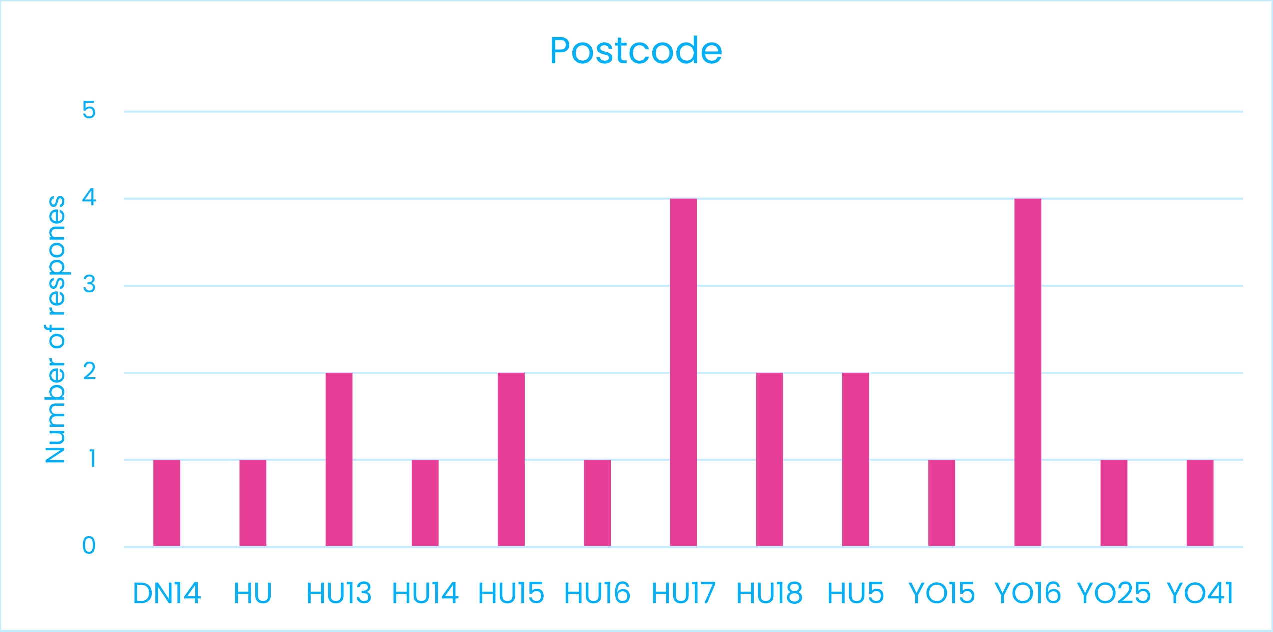


Gender

56% of respondents identified themselves as male – this is in line with males being slightly more likely to be diagnosed with Parkinson’s than females (NHS). 12% of respondents did not indicate their gender.

Postcode

The participants were asked for the first part of their postcode (e.g., YO15) which showed that there were people from 12 different postcode districts in East Yorkshire. The most common postcodes were YO16 (Bridlington area) and HU17 (Beverley area).



Who do you live with?

Most respondents (84%) live with their spouse/partner and one participant lives alone.

Diagnosis

This section of the survey focussed on the process of getting a diagnosis of Parkinson's and the immediate support and information which followed it.

Everyone who took part had been given a formal diagnosis of Parkinson's and when asked "where did you go to get this diagnosis?", 82% said they went to a GP. Of this 82%, two people said they had made an appointment for other complaints, such as backache or legs not working well, which led to the Parkinson's diagnosis.

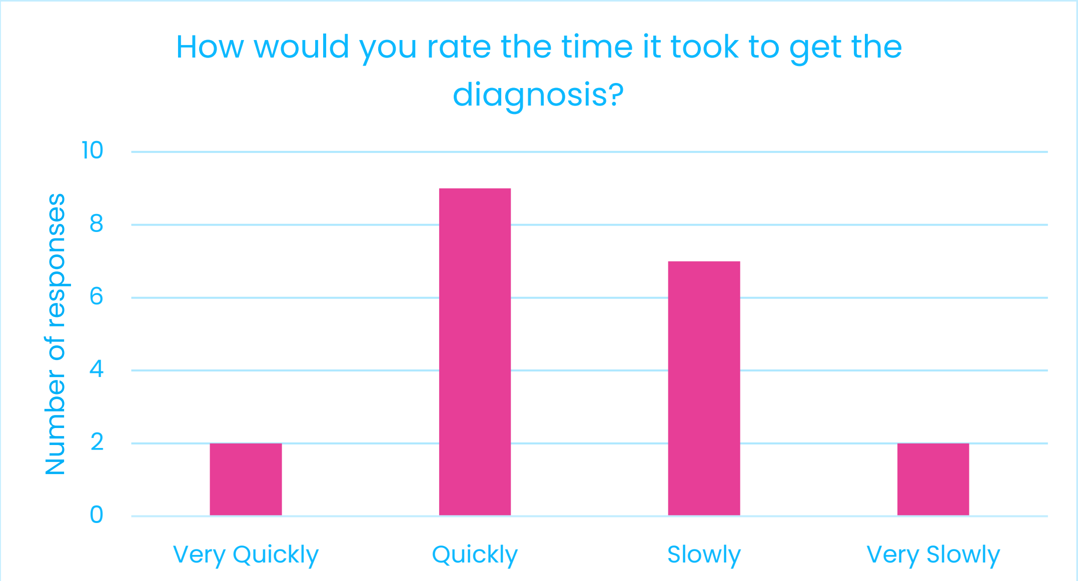
Three people paid for a private specialist consultant with one person explaining that they paid £240 at Spire, a private hospital, to confirm their suspicion of Parkinson's after three months of waiting for an appointment with an NHS consultant.

When asked "how long have you had a diagnosis of Parkinson's?", the average answer was around six years. The shortest length of time was six months and the longest was 16 years.

Delays in diagnosis

Many respondents reported a delay in getting a diagnosis of Parkinson's due to a lack of awareness of the condition by healthcare professionals.

- "Doctor said I did not have Parkinson's so I requested 2nd opinion"
- "People kept telling me I didn't have it"
- "No one recognised that I might have Parkinson's as I did not have a tremor"
- "I found most health workers reluctant to give me a definite diagnosis which delayed the start of treatment"



Although many shared concerns about delays in diagnosis, 45% said they received their Parkinson's diagnosis quickly. Experiences with appointment wait times varied—some faced "long wait for neurology appointment", while others found "reasonable waiting times and accessibility". One person praised a registrar who quickly identified the condition, later confirmed by a consultant.

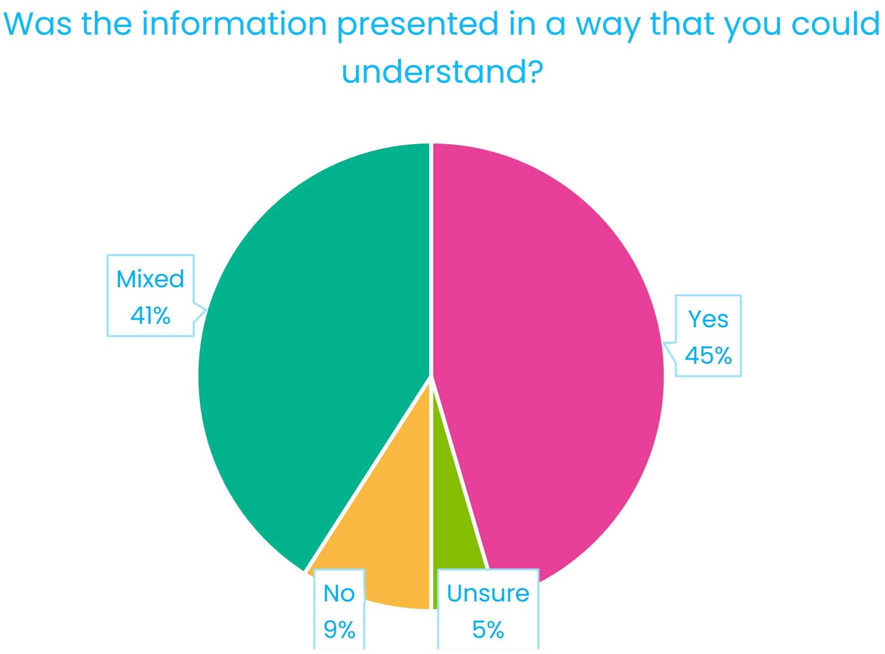
Information at the time of diagnosis

This question aimed to understand how the diagnosis was delivered to the person with Parkinson's and whether the language used was easily understood.

One person we spoke to at a leisure centre told us that her friend, Natalie, is a former nurse who has been diagnosed with Parkinson's. Natalie found out she had Parkinson's when she was picking up her prescription and recognised the drugs as being for Parkinson's patients. Her friend says that Natalie was devastated at finding out in this way.

One other respondent says he received his diagnosis via a letter, he wrote:

> "For me the experience of finding out I had Parkinson's was terrible cos I got told in the most unsympathetic way ever I was told by a letter then left."



45% of people were satisfied with how their Parkinson's diagnosis was explained, but 41% had mixed experiences. This shows a need for clearer, more consistent communication when giving a diagnosis, including easy-to-understand information and guidance from the very first appointment. It's also important to recognise how emotionally difficult receiving this diagnosis can be.

One person with Parkinson’s told us that, whilst they had a positive experience with the consultant, they were in denial about the diagnosis of Parkinson’s:

“Couldn’t fault the consultant at HRI [Hull Royal Infirmary]. It wasn’t rushed, there was space to ask questions, but I didn’t want to know any more”

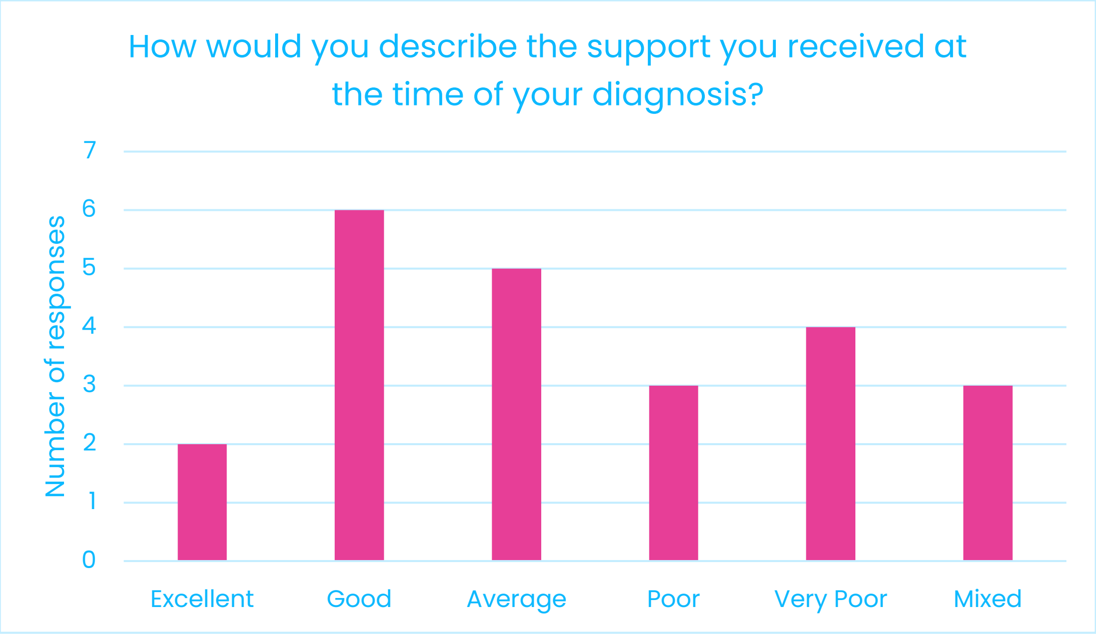
Several respondents noted that they had to seek out information or otherwise feel unprepared for what Parkinson’s would entail. With the condition getting worse over time, many people worry about what will happen when it progresses.

“I would have wanted more explanation of what will happen to me in the future. What the medication does for my condition (mild Parkinson's) and how the condition could develop. Had to ask questions myself or "bury my head in the sand".

Support at the time of diagnosis

Whilst Parkinson’s UK do provide a newly diagnosed information pack both online and at their support groups, it is not standard practice for a consultant to give these to the patient at the time of diagnosis. One respondent commented that they would have found it helpful:

“For my first hospital appointment I saw a Registrar who was pleasant enough but simply gave me a prescription and said they would see me again in 4 months. Some basic written information, e.g. a copy of the Parkinson's UK guide for people newly diagnosed would have been helpful.”



At the support groups, members commented that they felt they were left without support following the diagnosis and were not sure where to find it.

- “Felt upset, no support, given diagnosis and just sent off, see you again in a year??"
- “I feel as though I’ve been left”

People’s experiences of getting a Parkinson’s diagnosis in East Riding vary. This may be because they are referred to different hospitals depending on where they live or what they prefer. For example, some people go to Hull Royal Infirmary, while others are referred to York Hospital. Some people have asked to be referred to Leeds instead, with one person saying that talks of consultants retiring made them feel uncertain about the continuity of future care.

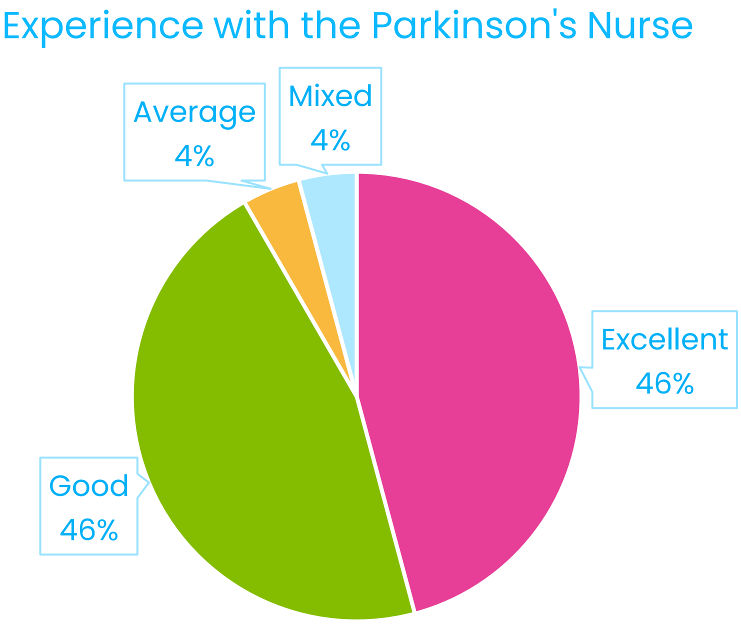
Parkinson’s Nurses

Specialist Parkinson's nurses work in hospitals, care homes and in the community. In hospitals, Parkinson's nurses run clinics and also make sure that other hospital staff understand Parkinson's. The Parkinson's nurses may also see people in their own homes, if the person can't attend clinics. Referrals are usually through a GP, consultant, physiotherapist or another health professional. Parkinson’s nurses:

- support people coming to terms with their Parkinson's diagnosis
- help people to manage their medication, so they get the best results and fewer side effects
- make referrals to other professionals such as speech and language therapists and physiotherapists
- train other health and social care professionals, for example on making sure people with Parkinson's get their medication on time in hospital.

Praise for the nurses

In both the survey responses and through discussions at support groups, the Parkinson’s nurses and the work they do have been praised thoroughly. Every person who completed the survey had been in previous contact with a Parkinson’s nurse and was then asked, “How would you describe this experience?”. The results showed overwhelmingly positive feedback with 92% answering “excellent” or “good” with the remaining two responses being “average” or “mixed”. Zero respondents described their experience as “poor” or “very poor”.



Parkinson’s Nurses Feedback

- “I have found the nurses to be very helpful and competent. They were very helpful and very kind.”
- “Extremely helpful and reassuring”
- “She goes above and beyond. Excellent.”
- “I have known the Parkinson's Nursing team for 16 years and they are superb.”
- “Nothing was too much trouble! Made me feel relaxed and important. Noticed every little thing on each visit. Very observant. Enjoy our visits to see her.”
- “Very good explanation of the disease and the treatment. Very sympathetic and efficient with the treatment.”
- “Information Prescriptions for Parkinson's medication, medication review, physical examination, help with form filling. Reassurance that available on phone”
- “A wide range of support and advice, tailored to my need”
- “Know if I have an issue I can always get an answer from the Parkinson's nurse. Got a reasonable idea of medication and why to use it regularly.”
- “The Parkinson’s nurses are good, we have a good laugh”
- “Nurses are excellent always”

More than medication

One of the themes within the feedback for Parkinson’s nurses is that patients feel listened to and understood by them. Respondents like that there’s “opportunity to discuss and ask questions” and that nurses “take note of all” that the patient says. This contrasts with previous feedback suggesting that some people with Parkinson’s do not always feel listened to by primary care physicians, such as GPs. Parkinson’s nurses were also praised for their support in coordinating care between other services.

- “I find the visits particularly good as they spend time listening to you and they always seem to find an answer to help.”
- “A wide range of support and advice, tailored to my need e.g., placement on Anxiety Management course, referral to P.D warriors at York Hospital, physiotherapy and more; all helpful!”

Many people with Parkinson’s commented that they feel other healthcare professionals do not understand the condition well enough to provide information or advice around Parkinson’s:

- “Doctors appointments are shocking when you’ve got Parkinson’s and had a fall. It’s like pass the parcel between GP – walk in centre – A&E – GP.”
- “Other complaints get put down to Parkinson’s. Doctors (GPs) don’t understand Parkinson’s enough, just because you’ve got Parkinson’s, doesn’t mean you haven’t got other things”

It is evident in this feedback that the Parkinson’s nurses are vital in not only listening to and providing information to patients, but also in ensuring that people with Parkinson’s have access to further avenues of support such as exercise and Parkinson’s support groups.

Time between appointments

Some respondents commented that, whilst the care from the Parkinson’s nurses was good, they felt as though they are waiting too long between appointments. Typically, appointments with the nurses are scheduled for every six months. It was acknowledged by multiple people both in the survey responses and at Parkinson’s UK support groups that they believe the nurses to be covering a large area with a relatively small team:

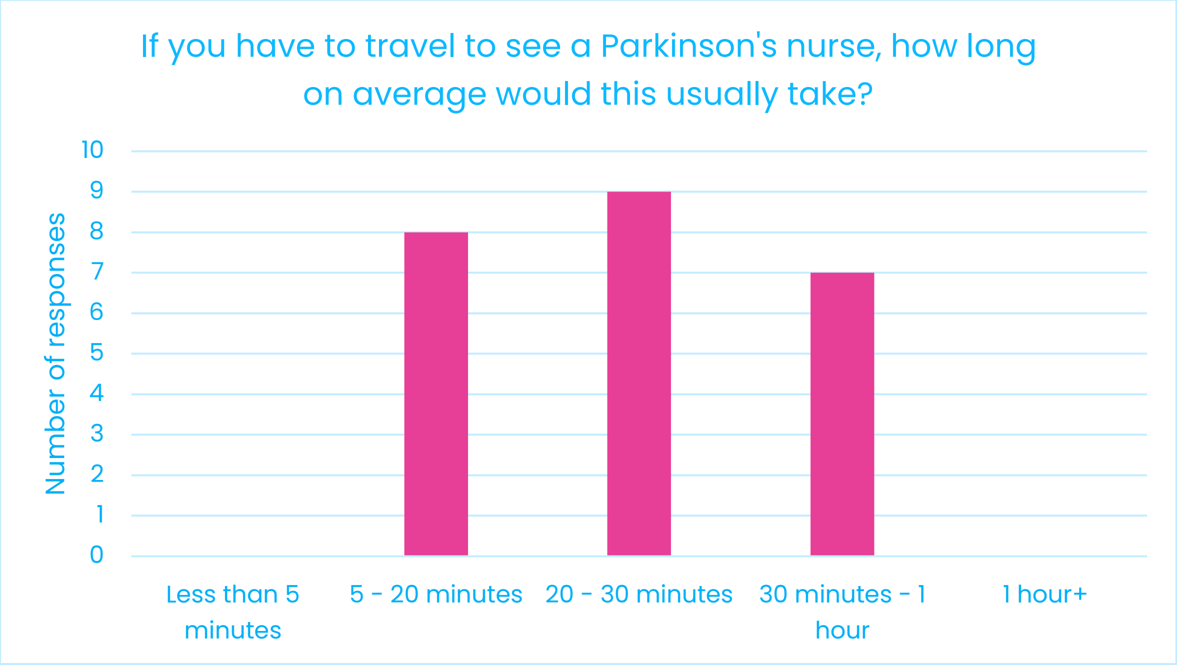
- “They are busy they cover a large area.”
- “The time between appointments is too long. Have to ring in-between.”
- “I would like to see the Parkinson's nurse more often – say every 4 months instead of 6 monthly.”
- “Have only seen one nurse since last July (now May 2025).”
- “They are spread too thinly”

Travel to healthcare appointments

Before this project began, members of the Goole support group said it was hard to travel to Parkinson’s nurse appointments, which were held in Gilberdyke. They shared this concern with the nurses and Parkinson’s UK. As a result, a new clinic was set up at Goole and District Hospital to make appointments easier to access.

Responses regarding travelling to Parkinson’s Nurse appointments are fairly evenly split between the three time categories. Travel times were not brought up as an issue at the support groups, though parking at hospitals such as Hull Royal Infirmary were highlighted as a difficulty:

"Crashed my car now I'm banned from driving. My wife takes me to the appointments now. Parking at the hospital is bad and takes a long time. Castle Hill Hospital and Hull Royal Infirmary."



When asked how about travel to Parkinson's nurse appointments, 63% of responses were either by their own car, or a lift from relative or friend.

Members of the Withernsea Parkinson's UK support group gave praise to East Yorkshire buses (EYMS) for the ease in which they can take a wheelchair on board the buses. Another member of this group promoted the use of the Holderness Area Rural Transport (HART) community bus as a way of getting to the shops and recommended this to a person who was newly diagnosed to maintain their independence.

92% of people rated their experience with Parkinson's nurse as positive

Managing the condition

Below are some of the themes in the feedback around coping with Parkinson’s:

Medication

Some of the comments made around managing Parkinson’s medication include remembering to take medication, understanding what the medication does, and changes to medication branding. Other feedback shared was that some people with Parkinson’s are taking a large quantity of medication to keep their symptoms under control – one person we spoke to said they take 24 tablets a day, some of which are to help manage the side effects of other tablets.

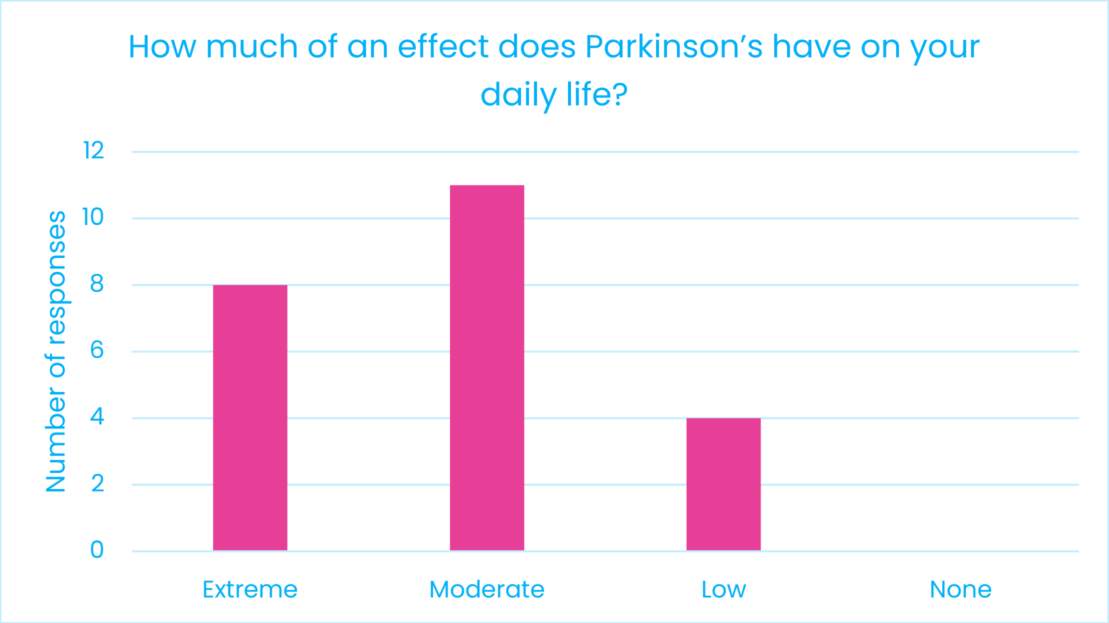
What are the challenges you experience in managing the symptoms of Parkinson's, if any?

- “Access to medication via sometimes erratic GP services (""we've run out…"")”
- “I am also inherently suspicious of medication in general and could do with greater clarity on the benefits and likely side effects of what's on offer."
- “Change of ""brand"" of medication due to cost pressures, not always properly notified or explained."
- “Keeping medication and dosage right for changing/evolving symptoms.”
- “The symptoms are so varied which means there is a large number of variations in the medication which makes understanding of the drugs and their actions difficult.”
- “It’s shocking, sometimes to get medication on time. I’ve been told it’s not a priority and it’s expensive”

Some people with Parkinson’s told us about their frustration of having to pay for prescriptions despite having a progressive condition. Parkinson’s is not currently included in the UK government’s medical exemption list for free prescriptions, though this is something that Parkinson’s UK are campaigning to change.

Effect on everyday life

One of the most prominent themes throughout the feedback is that having Parkinson’s leads to a significant loss of independence. When asked about the effect of Parkinson’s on daily life, 82.6% of people said it has a moderate or extreme effect, with many respondents commenting that they have had to give up hobbies, work, exercise, and aspects of their social life. Some people commented that they struggle with some activities of daily living (ADL) – these are the basic self-care tasks that a person does every day, such as bathing, toileting, and eating.



How much of an effect does Parkinson’s have on your daily life?

“It's not extreme but life has changed quite drastically. I can no longer drive, go to play golf, can't go to Hull City. Life is just a day to get through.”

“I was forced to retire. I cannot drive… I cannot walk anywhere, or swim, or anything active.”

“I can't drink alcohol at all anymore because of the medication, I would drink socially if I didn't have Parkinsons.”

“Movement difficult. Afraid of falling. Difficulty getting in and out of bed/car.”

“Muscle control of bowel and bladder.”

“I can't drive. I can't cook. I can't do most things I used to do without help.”

“It’s taken my independence away from me”

“It affects you in ways you wouldn’t even think about. I can’t write anything so I can’t fill out forms for things like a blue badge, I can’t carry a mug through to another room”

“I can’t cut my own toenails because of my tremor; I’d cut my own toe off.” Withernsea Hospital has taken some patients with Parkinson’s off the free NHS chiropodist service.

Some respondents highlighted that they rely on the care of a loved one (usually a spouse) to support them with ADLs and keep well at home:

- "It affects my life quite a lot I would not like to say extreme. I could not live on my own if I did not have my husband to help me."
- "Normal everyday tasks are more difficult for Peter. I (wife) am reading this questionnaire to Peter because he couldn't write because of shaking."

This emphasises the importance and value of unpaid carers who support someone with Parkinson's with every day tasks.

Non-motor symptoms

In addition to difficulties with movement and physically taking care of oneself, respondents commented on the non-motor symptoms that they manage. Whilst some barriers to ADLs come from fear of falling, many respondents said that fatigue plays a large part in their day:

"I struggle with extreme tiredness at times have to have a nap in the afternoon."

Other non-motor symptoms reported include anxiety around leaving the house and memory problems:

- "I have mental problems in going out of the house to face new people and places. I am OK if it is to a place or people I have seen before and I am comfortable with. However if the visit is new it becomes more of a challenge. Have to give myself a good talking to to get out of the front door. Not every time – just new visit/meeting."
- "Memory loss is quite upsetting."
- "Recalling names is difficult as I can forget a name or word that I have already used in the same conversation. Almost like a form of stutter. Sometimes I forget or misplace the name of the person I am talking to!"

Financial impacts

Does having Parkinson’s have a financial impact on your life?

The survey results show that 50% of respondents believe Parkinson’s does *not* have a financial impact on their life whilst 32% said yes it does and 18% were unsure. The reasoning for the responses are below:

Independence/Mobility Costs	**Changes to Income**
• Yes now need taxi for appointment and had to change dietary requirements • Many routines such as drying my hair, et cetera I am unable to do so I have to pay to have it done weekly • Acquisition of 'specialist'/adaptable fixtures, fitting and consumables. • We are trying to save to get a walk-in bath/shower as I have to help him get in and out. • Having to get help in the garden when I could manage most jobs myself. • I had to modify my house with a separate bedroom and bathroom/wet room. Also I have to pay for a carer every day. • Lots of equipment provided by NHS – but we bought a rollator and rise and recliner chair so there is financial cost. • We can't travel without big insurance or breaking the journey up in hotels.	• I had missed out on promotion and had to retire from full-time work. I do other jobs but my attendance depends on my condition on the day • It did at first, but now all finances are sorted out. Had advice from Parkinson's UK. Also had help to complete forms for benefits. PIP claim took 2 years including court tribunal. • People don’t know entitlement with benefits o It’s what you know/who o PIP Attendance Allowance and Council Tax – learnt about these from here [Goole Support Group]

Awareness of Parkinson's

Many people said there isn't enough awareness about Parkinson's, especially its symptoms, and this is something that has been reported by the Parkinson's community for many years. This includes friends, healthcare professionals, and the general public. Because of this, people with Parkinson's often feel anxious about going out and meeting others, which can lead to feeling isolated.

- "People think PD is just a tremor, they don't think it's depression, bowel and bladder problems"
- "People treat you differently when you're in a wheelchair – just because you can't walk doesn't mean you can't think"
- "People don't understand us at all"
- "Nobody listens to us, not properly"
- "Some doctors are unaware of Parkinson's symptoms"
- "Friends treat you differently with Parkinson's, it's not nice, they don't understand"

One person explained that having Parkinson's has lowered her confidence. She said:

"I worry people in the street think I'm drunk or on drugs. I feel like everyone is looking at me. I have to apologise in the shop for taking too long to pack my shopping – I tell them I've got Parkinson's but I don't like people knowing."

At one Parkinson's UK support group, everyone was asked "before the diagnosis of Parkinson's, did you know the symptoms of Parkinson's to look out for?" all 8 people said "no". One person said in hindsight they think their symptoms started a long time before the diagnosis, e.g., stiff painful legs at night. This suggests a lack of public awareness around identifying Parkinson's symptoms.

Some people wished for a greater understanding of the condition in healthcare settings and in general. Others want for more information on available treatments.

- "In general, a lot of the service need to be better educated about Parkinson's like doctors and receptionist plus pharmacist to name a few"
- "More information on brain surgery treatments"

Future concerns

At one support group in particular, the topic of mental health was discussed. One man with Parkinson's said that he "thinks about just going off into the river" to which two other men with Parkinson's agreed they felt the same. I asked if this person had talked to their doctor about these feelings, he replied that "there's no mental health support available".

In the East Riding, there is a Talking Therapies service for common mental health problems such as depression and anxiety, however, it is not an intervention specific to Parkinson's related difficulties. Also run by East Riding Talking Therapies is a treatment for people who experience depression and/or anxiety in relation to a long-term health condition. Although this treatment is open to people with any of the nine conditions (see here), Parkinson's is not one of them.

As previously mentioned, Parkinson's UK run a free hotline service for advice and information for people affected by Parkinson's. The hotline, along with the Parkinson's UK local advisor, can direct individuals to support services specific to the person's needs. It is possible that, although these avenues of support are available, the person spoken to was referring to a lack of mental health treatment, such as counselling, which is specifically for people with Parkinson's.

"I am beginning to be anxious about the long-term impact. More advice about this and how the illness might progress would have been useful. However, I can understand why this might not have been emphasised in order not to alarm [me] and I can research further myself if I want to."

Support

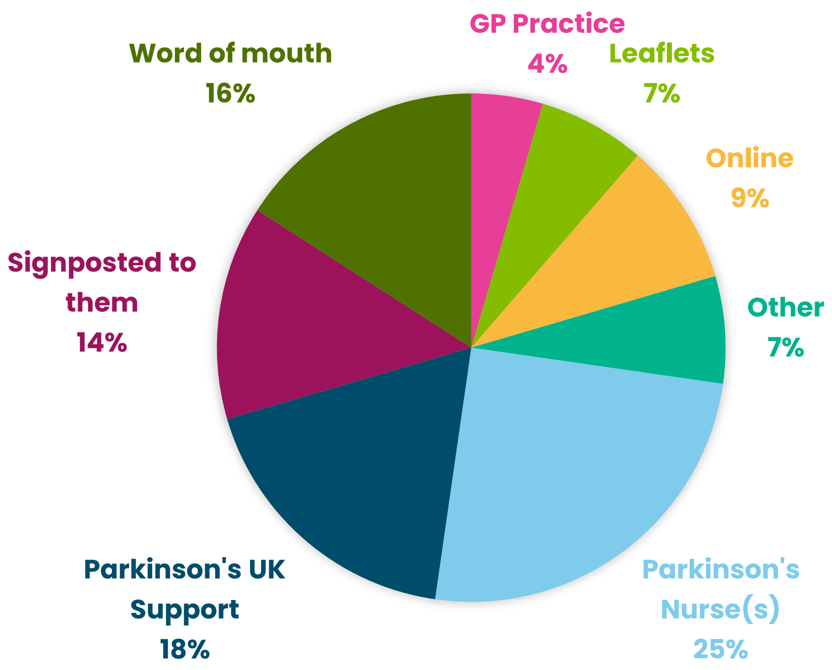
This section looks at which support services people with Parkinson's are accessing and what support they would like to have.

Services used

Which services have you found to be helpful in supporting you?

- Parkinson's UK Support/Exercise groups (18 mentions)
    - "Exercise classes, monthly support group with the local authority and local charity"
    - "Specific sessions for Parkinson's patients I.E. sports sessions at local sports centre which is also good for contact with other people in the same predicament"
- Physiotherapist (4)
- Bowel and Bladder Nurse (2)
- Speech and Language Therapist (2)
- Specialist Parkinson's Nurses and Consultants (9)
- Other mentions:
    - Internet
        - "When finding out I had Parkinson's the Internet was a great help for helping with support and who to talk to"
    - East Riding Carers Support
    - East Yorkshire Council (Blue Badge)
    - Home from Hospital
    - Dove House

How did you find out about these services?



A quarter of respondents listed the Parkinson’s Nurse(s) as a way of finding out about support services.

Parkinson’s UK

When asked “Are you aware of support available from Parkinson’s UK?”, 68% of respondents said yes. Of the remaining respondents, 16% said no and 16% were unsure. This highlights a need for some clarity on available support for people who have Parkinson’s as some people who visit the support groups may not be aware of the further support they can access.

- “Corrine [Parkinson’s UK Local Advisor] can help with anything. She came to my house and talked about money and benefits”

Ideal support

When asked about ideal support, many people responded that they feel well equipped at present, but are aware that their needs may change as the condition progresses:

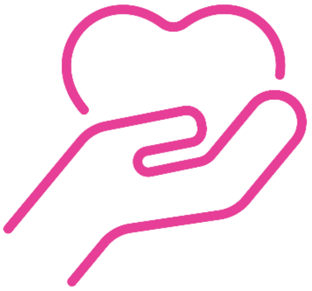
- “Nothing just now, as I am independently mobile and active. But I am anticipating needing more support as/when that changes.”
- “Bit of a "chicken + egg" problem i.e. don't know until you need/get it, as in the area of helpful equipment and home adaptation”

- “Able to manage at present”
- “So far I feel well looked after but I know others find it difficult getting to meetings and activities that would help them”

For those who said they would like help at home, some of the examples they gave were “2- 3 hours in house-sitting”, “help with gardening”, and “long-term financial & care available for lone occupiers”.

- “A day centre for 3 or 4 hours in the afternoon at a day centre for the carers benefit - postcode lottery with Hull having Jean Bishop Centre”

One respondent said that a “local group in Beverley would be good” though since the survey closed for comments, a new support group in Beverley has been established thanks to Parkinson’s UK.



Other comments

NHS services

Comments throughout the survey and engagements show an appreciation for many services within the NHS that have supported the individual. However, other responses relate to the availability and integration of NHS services, particularly the issues experienced around communications between different services.

- “The main problem appears to be lack of qualified nurses and doctors and this makes you wary of wasting their time.”
- “On the whole I am very happy with the medical treatment that I have had. The provision of a stairlift a ramp and a rollator and various domestic helps.”
- "Overall want to thanks NHS for brilliant service. Urology department at castle Hill is very supportive. “
- “Communications between doctors, specialists and pharmacists is very slow”
- “Don’t have holistic approach – give conflicting advice and meds.”
- “Occupational Therapy is a 12 week waiting list – once you get it it’s brilliant”
- Being told different information from professionals (GP/nurse/consultant) “they don’t talk to each other”
- “Constantly having to chase up information and appointments”
- “There’s not enough staff in the NHS”

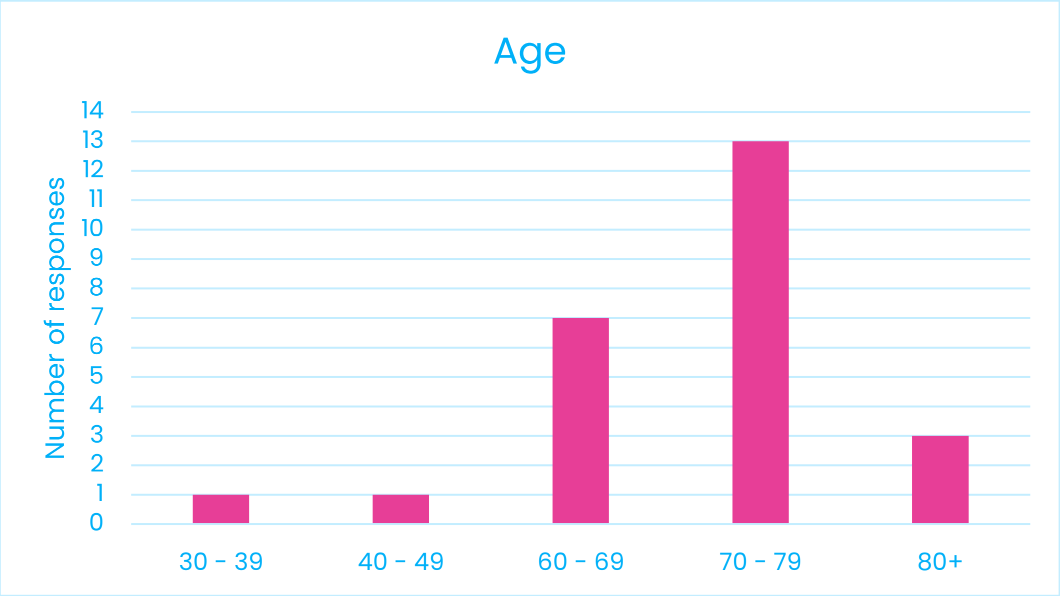
One carer of person with Parkinson’s commented that they would like to be able to talk privately with the healthcare professional to protect their loved one:

- “It would be nice to see the Dr or consultant lone, without the person with Parkinson’s as it can be upsetting saying it all in front of them”

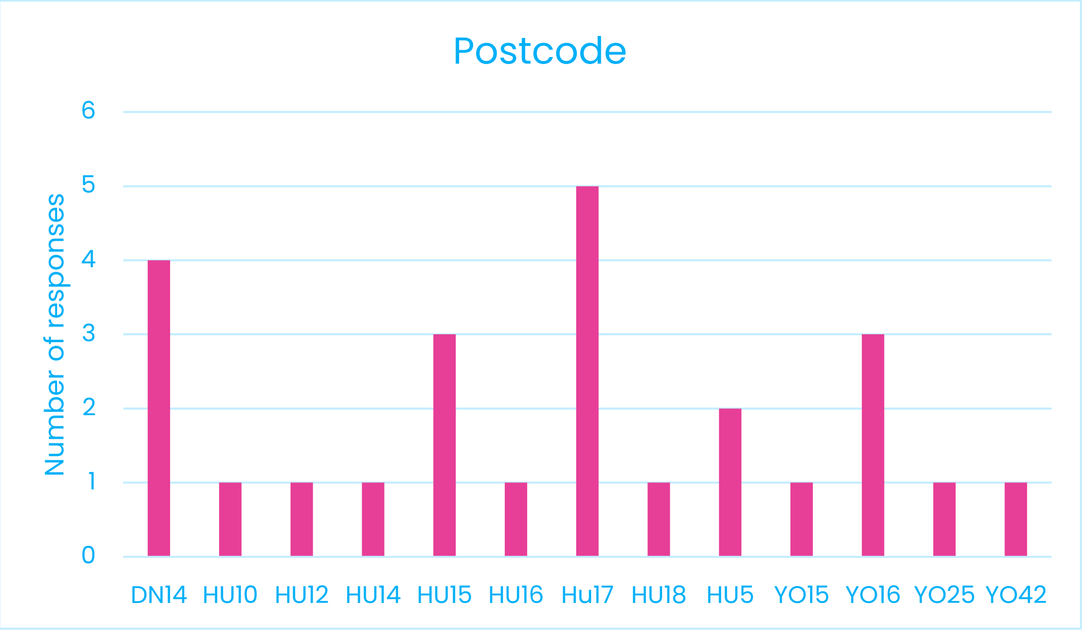
Carer's Survey

Demographics

Of the 25 people who responded to the carer's survey, 52% were aged 70-79. There were 0 respondents aged 16 – 29 or 50 – 59.



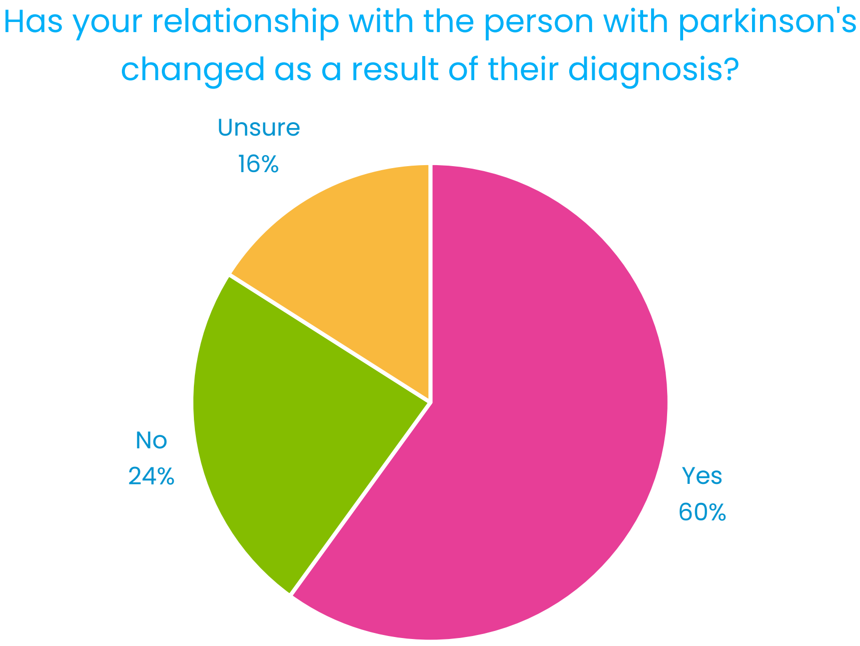
68% of respondents were female, 28% were male, and one person declined to answer. There were 13 different postcode districts highlighted with HU17 (Beverley area) making up 20% of survey respondents. One individual is the son of the person with Parkinson's and the 24 other respondents report being the spouse of the person with Parkinson's.



Relationship to the person with Parkinson’s

Relationship dynamic

When asked about their relationship to the person with Parkinson’s, 60% of respondents said it had changed due to the condition.



There were positive reasons given for the changes such as increased understanding and compassion for people with disabilities:

- “Since finding Brian has Parkinson's things have changed not in a bad way I am more understanding of his problem now, before when he did something different I'd think why is he doing that or saying that.”
- “Being a carer has made me more compassionate to people with disabilities, its also made me realise that carers need time too.”
- “The caring and sympathetic side of my personality has come to the fore much more than it ever was.”

Many of the respondents reported that their identity has changed as a result of their spouse having Parkinson’s:

- “I am now a carer, no longer a wife most of the time.”
- “We're still equals but the fact that I now do much more in household management, all the driving and I'm constantly focused on medication schedules, ensuring that my husband isn't doing too much, supporting his emotional ups and downs all mean that I've become "in charge".”

- “I feel as though I have Parkinson's because it has affected us both.”
- “My husband has Parkinson's and dementia, and some days it's like living with a 3-year-old.”

At one of the support groups we attended, a wife of a person with Parkinson’s spoke very candidly about the effect of Parkinson’s on their marriage:

“I feel as though I’ve got Parkinson’s. We’re sleeping in separate beds. Our sex life has disappeared – it wouldn’t have gone without Parkinson’s. I tell him ‘you’ve ruined my life.’”

Effect of Parkinson’s symptoms

Many respondents say that the symptoms of Parkinson’s have changed the activities that they can do with their spouse. It was reported that increased anxiety in the person with Parkinson’s has led to a decline in social activities:

- “As a couple we used to be spontaneous and go a lot of places. Now everything has to be planned to the finest detail. Also we sold our car as he was diagnosed with prostate cancer and thought he wouldn’t be able to drive again. His anxiety rises as the slightest thing and I constantly have to reassure him.”
- “We no longer go out and socialise or rarely. “
- “He is much less sociable and has lost a lot of confidence.”
- “Everything has changed, every day is a struggle for my husband and myself, every journey or outing has to be carefully planned, some friends have been very understanding others have not.”
- “Supporting a person with Parkinson's differs day to day - it is impossible to plan any outings/activities, as some days are good, others - not feeling well/tired/sleeping/unstable walking/incontinent.”

Life as a carer

Much of the feedback from carers of people with Parkinson’s echo a feeling of their own lives being taken over by their partner’s condition:

- “Parkinson's takes over your life even if you don't have it. Every thing is filled by it, from having to sort medication on time every 2 hours, when going anywhere making sure you take all medication. If the person with Parkinson's starts shaking & can't control it with meds, every thing planned to do has to change to wrap around Parkinson's.”
- “It has taken over my life. I am always "watching" to make sure he is ok - not fallen. Afraid to have any activities for myself as I need to provide 24 hour care. For richer, for poorer, in sickness and health, but the bodily fluids bits is challenging!”
- “Nothing much to say this is life now and we have to accept it!”
- “Life is hard but I have my own coping strategies. My only regret is my close friends have all passed away and other friends have drifted away because I cannot drop everything to do things   They also don’t know what to say. It can be lonely sometimes, but we have a great extended family we keep in touch with.”

Support

Current support

When asked "what support do you receive in caring for someone with Parkinson's?", 11 people said "none/nil/no support". Of these 11 people, two said "except for family" and one said, "at the moment we don't need it". One response indicates that denial about the diagnosis acts as a barrier to the carer receiving support:

"No support, he has only told a few people and doesn't want me telling anyone. He is in denial."

Two respondents said that they have paid carers, one says "I buy 2 hours a week so I can go to appointments. No other support.".

Other support includes:

- Attendance allowance – two responses
- Parkinson's UK meetings – 7 responses
- Carers groups
    - "Coffee morning is really only support, meeting other people & sharing things realising there are other people in similar position."
- "Marvellous Parkinson's Nurse"
- "Mental Health Team"

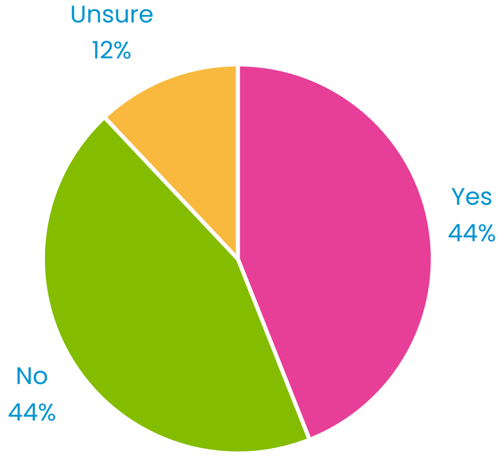
Carers Support Service

The people who support an individual with Parkinson's were asked if they are registered with East Riding Carers Support Service – this service offers emotional and practical support to unpaid adult carers looking after a family member or friend in the East Riding of Yorkshire.

From the 44% who said they are registered as a carer, the ways in which people heard about this service were:

- having carers support service visit the Parkinson's UK support groups
- word of mouth
- support groups for carers (Together We Care and Carer's Plus)
- through healthcare professionals such as at their GP Practice.

Are you registered with East Riding Carers Support Service?



Ideal support

What support would you like to receive in caring for someone with Parkinson's?
Nothing/not sure • Apart from paying for more carers, cannot think of any other support • Not sure! • Unsure. It's the fear of the unknown future. • At the minute nothing, I use the Parkinson's forum a lot - mostly to ask about symptoms and to moan. They are very good. I spoke to someone on the Parkinson's hotline and they were very supportive too • None required at present • Don't know what is available
Respite care • Someone to talk to sometimes who understands the condition. • At this point in time because my husband's Parkinson's is not severe, I don't need more support but I have friends who are often left hanging, unable for example to get respite care. • Home care, as too expensive. • Mental health

- More support for carers as life can be very difficult and lonely as people do not understand the day to day struggles that are experienced
- It would be good if there was a day centre, just in the afternoon to give me more time to re-charge.
- Apart from paying for more carers, cannot think of any other support

Community and mental health support

- A community Parkinson’s coffee group in Brough or surrounding villages.
- Community transport in west hull villages - taxis are too expensive, busses are few and far between.
- Someone to talk to sometimes who understands the condition.
- More activities where people can meet.

More regular contact with specialist

- More regular consultation with Parkinson's nurses. I know they are busy, but don't hear from them.
- Easier access to local GP’s. Better support from the Parkinson’s Nurses and Consultants.
- Access to Parkinsons Nurse? and other support services. Been waiting 6 months since moving into the area but have had no contact.

Recommendations

Based on the feedback gathered in The Parkinson's Project, the following recommendations are made to the relevant health and social care services:

East Riding Primary Care Networks

1. **Improve the Diagnosis Pathway:** Implement training for GPs and primary care professionals to increase awareness of the full range of Parkinson's symptoms, especially non-motor symptoms, to reduce diagnosis delays.

   Nominate one General Practitioner to be a Parkinson's Champion per GP Surgery. This involves undertaking at least one hour of training on identifying Parkinson's, particularly in younger people. This online training is free, provided by Parkinson's UK Excellence Network, and has been created with people with Parkinson's: https://www.parkinsons.org.uk/professionals/events-and-learning/parkinsons-gp-and-patient-perspective-supporting-initial

   The information learnt through this training must be shared to the wider primary care team, for example, to care navigators and nurse practitioners. This training must be included in all new starter inductions.

2. **Social Prescribers to Signpost to Parkinson's UK Free Resources:** Social Prescribers must have copies of Parkinson's UK information leaflets available to share with relevant patients. These should include 'A Quick Introduction to Parkinson's' and 'Our Support Services' leaflets at a minimum. Social Prescribers should be aware of support available from Parkinson's UK to be able to confidently signpost to their services, whether this is to support groups or the Local Advisor service.

3. **GP Practices to Stock Parkinson's UK Leaflets:** Information leaflets promoting Parkinson's UK support must be available throughout an individual's Parkinson's journey. This includes availability at all East Riding GP Practices.

   Order the information leaflets for free from here:
   https://shop.parkinsons.org.uk/collections/parkinsons-uk-information-1?page=1

Humber and North Yorkshire Integrated Care Board (ICB)

4. **Standardise Diagnosis Communication:** Introduce a standardised and compassionate approach for delivering a Parkinson’s diagnosis across East Riding. At the time of diagnosis, patients should be given the option to take home the ‘Newly Diagnosed Information Pack’ which explains the condition and outlines local support services available to them.
5. **Review Parkinson's Nurse Service Capacity:** Conduct an urgent review and strategy of the staffing levels and geographical coverage of the specialist Parkinson's Nurse service to ensure people get the right care at the right time. Establish a consistent and proactive system for scheduling routine appointments, so that people with Parkinson’s and their care partners receive timely notifications removing the need to chase or request updates.

Humber NHS Foundation Trust

6. **Develop Dedicated Mental Health Support:** Expand the existing Long Term Conditions Talking Therapy to include support for people with degenerative health conditions, such as Parkinson’s. This should acknowledge the unique psychological challenges associated with the condition, including anxiety and depression.

Parkinson’s UK

7. **Develop and Coordinate Community Engagement Teams:** Appoint a lead for Community Engagement across East Yorkshire and encourage Parkinson’s UK volunteers to support the lead by becoming Local Public Engagement Volunteers. Together, they should campaign to educate the public on the “invisible” non-motor symptoms of Parkinson’s with the aim of reducing stigma and misunderstanding. The lead should be the point of contact for other charities and healthcare organisations with any queries and act as a support to social prescribers, for example.
8. **Increase Awareness of Financial Support:** Support the distribution of information leaflets regarding benefits and financial support to people with Parkinson's through the specialist nurses and social prescribers. These should be a key part of the initial diagnosis information pack. Invite East Riding Council’s

Your Money Team to Parkinson's UK Support Groups to support individuals with financial concerns and questions.

9. **Encourage Organisations to be Parkinson's Aware:** Encourage organisations (local shops, hairdressers, healthcare providers etc) to become Parkinson's-aware by introducing an accreditation scheme—like the Alzheimer's Society's Dementia Friends programme. This would allow both healthcare and non-healthcare organisations to receive education about Parkinson's and demonstrate their commitment to being inclusive and supportive of people living with the condition.
10. **Sustain Community Support Groups:** Continue to explore opportunities for new peer support groups to reduce isolation for both people with Parkinson's and their care partners.

East Riding of Yorkshire Council Adult Social Services

11. **Assess Respite Care Provision:** Undertake a comprehensive review for day centre opportunities for people with Parkinson's. The findings should be used to address gaps in provision across East Yorkshire. The way day opportunities are promoted should be reviewed to ensure people with Parkinson's and their care partners are fully informed about what is available to them.

Parkinson's UK and Carer's Support Service

12. **Proactively Identify and Support Carers:** Work with healthcare providers to establish a coordinated system for identifying carers at the point of a Parkinson's diagnosis. Once identified, carers should be promptly referred to the East Riding Carers Support Service. All relevant professionals—including Parkinson's Nurses, Consultants, and GPs—must recognise the vital role of carers and actively support their access to appropriate services.

13. **Establish Dedicated Support for Carers:** Consider creating Parkinson's UK Support Groups specifically for carers of people with Parkinson's. Groups must be formed in collaboration with carers to best support their needs.

Acknowledgements

We would like to thank every person who shared their thoughts, feelings and experiences with us during this project. Thank you to the Parkinson's UK support groups for allowing us to visit and for being so welcoming.

Thank you to Josie, one of our Healthwatch volunteers, for her support in gathering feedback for this project.

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Cover Photo: World Parkinson's Day 2025 stall at St Stephens, Percy Parkinson lovingly created by Gillian.

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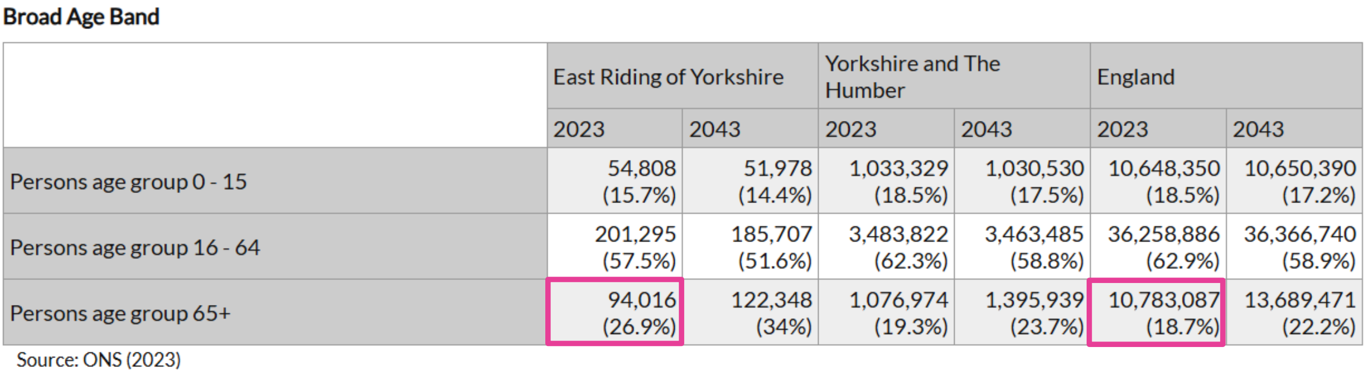
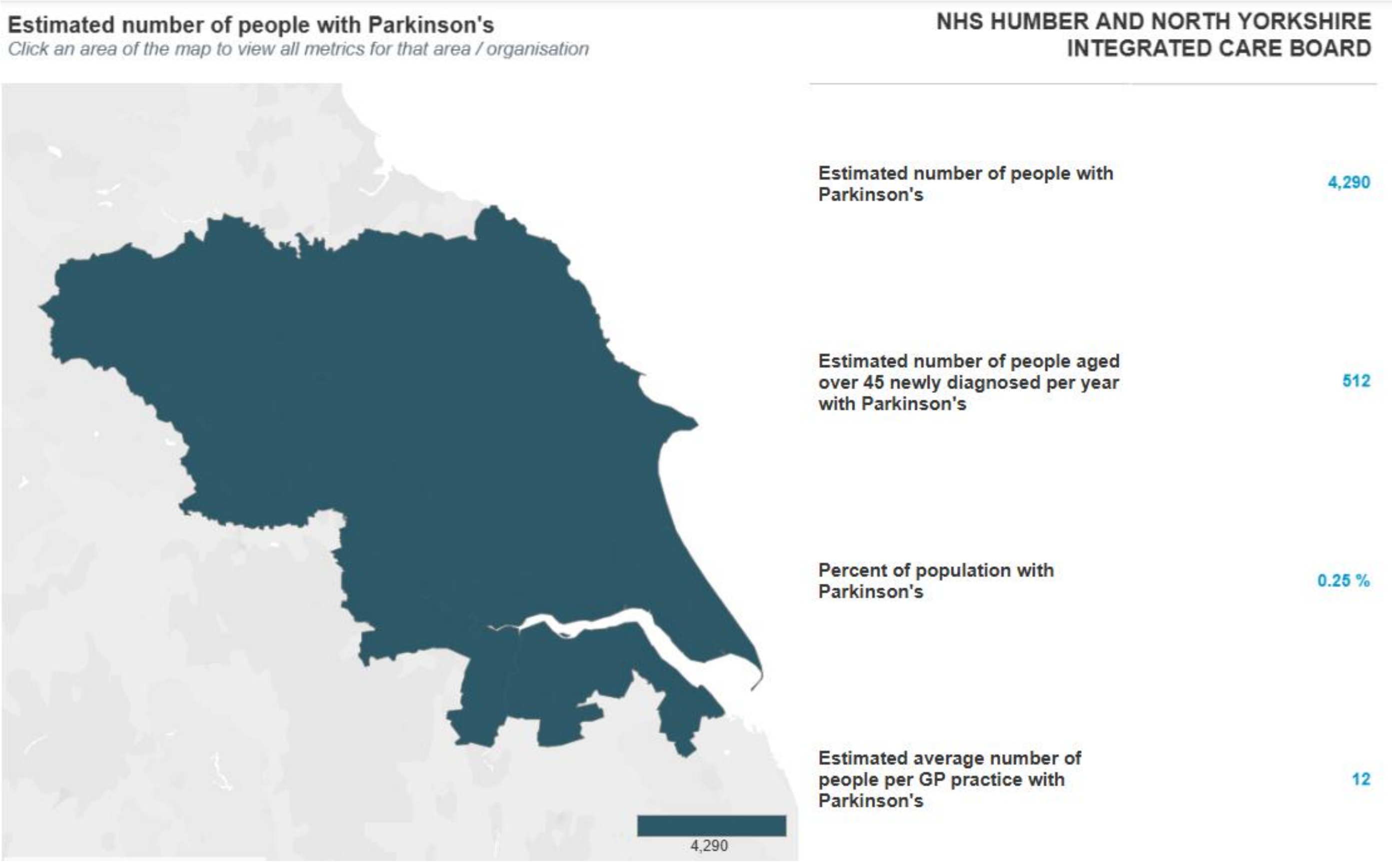


Broad Age Band

	East Riding of Yorkshire		Yorkshire and The Humber		England	
	2023	2043	2023	2043	2023	2043
Persons age group 0 - 15	54,808 (15.7%)	51,978 (14.4%)	1,033,329 (18.5%)	1,030,530 (17.5%)	10,648,350 (18.5%)	10,650,390 (17.2%)
Persons age group 16 - 64	201,295 (57.5%)	185,707 (51.6%)	3,483,822 (62.3%)	3,463,485 (58.8%)	36,258,886 (62.9%)	36,366,740 (58.9%)
Persons age group 65+	94,016 (26.9%)	122,348 (34%)	1,076,974 (19.3%)	1,395,939 (23.7%)	10,783,087 (18.7%)	13,689,471 (22.2%)

Source: ONS (2023)



Estimated number of people with Parkinson's

Click an area of the map to view all metrics for that area / organisation

NHS HUMBER AND NORTH YORKSHIRE INTEGRATED CARE BOARD

Estimated number of people with Parkinson's	4,290
Estimated number of people aged over 45 newly diagnosed per year with Parkinson's	512
Percent of population with Parkinson's	0.25 %
Estimated average number of people per GP practice with Parkinson's	12

healthwatch
East Riding of Yorkshire

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