



Condition Insight Report (CIR)

Parkinson's

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Completed in collaboration with
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Overview

What is the generally preferred term for someone with this condition?

A person living with Parkinson's

Brief overview of the condition

Watching the following links can help give you more context into life with Parkinson's for your claimants.

What is Parkinson's:

<https://www.youtube.com/watch?v=ODX2-C2uEAs>

Understanding Parkinson's better:

<https://www.youtube.com/watch?v=IIQNfPGt99E>

A day in the life of Janet, living with Parkinson's:

<https://www.youtube.com/watch?v=tAkN8zZFzF8>

My Parkinson's 2 years on:

https://www.youtube.com/watch?v=b10k9giHp_Y&list=PL1ixQpbHed3aA2vmbFOVGEqvUzgvzBxOs&index=34&t=0s

Early onset Parkinson's:

https://www.youtube.com/watch?v=xul_o8iJawY

Presenting symptoms

In the early course of the disease, impacts on daily activities may be mild with the disease perhaps only manifesting with minor tremor or altered appearance (facial expression becomes flat). However as the disease progresses it may cause significant impairment – requiring carer support to self-care or undertake many activities of daily life.

Can include, but not limited to:

- **Gait tends to be slow and shuffling** but festinant (increasingly hurrying) and the posture unstable, carrying a risk of falls. This becomes worse as the condition progresses.
- **Postural hypotension** (lowering of blood pressure when rising suddenly) also increases the risk of falls and causes fatigue.
- **'Freezing'** of movements.
- **Tremor and hypokinesia** impair manual and postural tasks through reduced coordination and dexterity. 75% of people with Parkinson's disease will present with tremor as the first symptom. This starts in one hand, and can be of mixed presentation and variability. Pill rolling is the term used to describe the movements involved which can occur up to six times a second.
- Movements become slower and also smaller (hypokinesia). There is also reduced dexterity and coordination.
- **Speech and swallowing** may be impaired.
- **Rigidity** gives rise to **muscle aches and/or pain**, leading to **fatigue**. Frozen shoulder can be seen in individuals with rigidity symptoms. There is a classical 'clasp knife' rigidity where the muscle resists passive movement to a point and then moves freely.
- **Loss of facial expression** and spontaneity of communication, which can be a cause of extreme misunderstanding
- Associated brain changes can **cause anxiety, apathy, sleep disorders, depression, agitation and dementia and cognitive impairment**. **Psychosis, hallucinations** can also be a result which can have a big impact on ability to function.
- **Incontinence**

Fluctuations



The functional effects may fluctuate considerably from person to person and within each day, from hour to hour, day to day and week to week. Careful history-taking is needed and the avoidance of a 'snapshot'. These effects may be unpredictable and can also be greatly affected by anxiety.

During treatment, an 'on-off phenomenon' may develop, with abrupt fluctuations in capability. Parkinson's disease can be rapidly progressive with disability progressing over a period of months, or less rapidly over some years; however it may progress more slowly, deteriorating over decades.

Think about exploring things like:

- **Does medication affect their symptoms?**
What are they like before taking it and how long before they see a difference? What is the difference for them? How long does the effect of medication last?
- **How has the condition been over the past 12 months?**
What changes have they seen, over what period of time did they experience any deterioration, what has this meant for their functional ability now compared to previous?

Where pain/fatigue are reported:

- **What level?**
Can they quantify this, do they use a scale and can they describe it? What level of severity? Can they share what a 'typical' day might be for them?
- **Triggers?**
Whilst exertion is a main trigger what amount of exertion is enough to cause further limitation? How are triggers managed?

Reliability

What specific areas should be covered to ensure a complete, reflective report?

SAFETY



Do they have any symptoms which could cause a safety consideration?

Due to the varied nature of symptoms which a person living with Parkinson's may experience safety is a critical area which needs to be explored.

Cover how risks are mitigated and if there is a history of incidents within activities 1, 2, 3, 4, 5, 9, 11 and 12 to ensure you have addressed the needs of the individual claimant.

Safety considerations can be a result from physical and psychological symptoms.

TIMELY



For any activities where restriction is reported how long does it take them to complete these activities? Has how long it takes them changed over time?

Freezing, pain, fatigue, rigidity can all affect time frames of how long it takes an individual to complete a task.

This will vary for each individual living with Parkinson's. Remember that there are no specific time frames outlined for what is reasonable.

Ensure to ask:

- How long it takes to complete tasks such as 1,4,5,6,7 and 12.
- Why they feel it takes them this long?
- Where they report having any breaks in task, how long are these breaks and how frequent?

ACCEPTABLE
STANDARD



How have they adapted to completing tasks over time – is this different to what might be considered 'normal'?

As Parkinson's progresses for the individual, how they have adapted will become their 'normal'. This may mean they do not raise these during superficial questioning.

Exploring **HOW** they complete the task in depth can help to draw out any compensation strategies which can then be explored further. E.g. using a sink to help get on/off the toilet.

Remember that not everyone is comfortable talking about their restrictions. Be sensitive and explore both their physical and psychological symptom impact.

REPEATEDLY



Are they able to repeat a task as often as required? Is this the same every day?

Treatment can significantly improve symptoms (but may also have some impairing side effects). Some will have very poor function until medication is taken so disabling symptoms may rapidly improve and normal activity can resume. However symptoms can return when medication wears off. It needs to be clear in the report whether a task is repeatable because it can change dramatically during the day. It must be explored fully and be evident how they complete a task typically and whether they can repeat it in this way as often as required.

Sensitivities

What areas might they find difficult to mention or perhaps understate the impact of?

It is more than just a movement disorder – the effects of more than 40 non-motor symptoms are often neglected.

Remember that with Parkinson's everyone is different and will respond to treatment differently. Not everyone will present with a tremor, for example.

Areas which an applicant might find difficult to talk about include:

- **Impulsive and compulsive behaviours** such as obsessive gambling, or hypersexuality that can be a side effect of some Parkinson's medication
- **Psychosis, hallucinations** and **acting out vivid dreams** that can cause injury to self and bed partner
- **Depression**
- **Incontinence**
- The **loss of cognitive functions** such as memory and slowness of thinking
- The **loss of facial expression** and spontaneity of communication can be a cause of extreme misunderstanding
- **Social issues**, isolation, anxiety and loss of dignity

As the condition fluctuates and is progressive, care and support needs will increase. This may be difficult for the person to talk about, or they may have developed coping strategies to avoid undertaking tasks or may not recognise the extent to which they do have problems. Tiredness and pain are often underestimated.

Customer care

How is it best to ask about any sensitive topics and what are the common courtesies?

In general

- Please speak to them, **don't ignore them**
- Give them plenty of time to reply to questions
- **Do not rush an answer** or attempt to finish their sentences
- Make use of open questions to allow them to bring out information they want to
- Sensitively explore further to ensure they are not overlooking something e.g. *"can you walk me through the steps of how you do that?"*
- Include the claimants companion in the assessment



During face to face interactions

- Ask if they require assistance
- Do not expect them to walk long distances
- If given a drink, it should only be half full as tremor may mean that it could be spilt
- Ensure you are close enough to hear a response so you do not need to ask them to repeat



Functional impact

A brief summary of the functional impact those living with this condition may experience

Activity 1: Preparing food

Freezing, pain, rigidity, fatigue and changes to movement can all be part of an individual's experience of living with Parkinson's. This can affect their ability to stand, prepare fresh ingredients and cook.

You can listen to testimony of an individual living with Parkinson's [here](#).

There may also be cognitive effects from the condition which mean they may not be safe to be left alone where there might be hallucinations.

Remember in PIP...

The psychological and physical aspects of this activity need to be covered where both are affecting the individual. What type of activities they can do and how they mitigate any risks, whether they could repeat any tasks done more than once in a day and the extent of any support provided.

Activity 2: Taking nutrition

Restrictions with swallowing can be a common symptom of Parkinson's. It can result in weight loss, coughing whilst eating, fear of eating and lead to conditions such as aspiration pneumonia.

It is important to explore whether this is a symptom and how this managed.

You can listen more about why Parkinson's affects swallowing [here](#).

Remember in PIP...

You need to have established the individual's ability to be nourished, either by cutting food into pieces, conveying it to the mouth and chewing and swallowing; or through the use of therapeutic sources. Spilling food, motivation to eat and risk of choking should be explored.

Activity 3: Managing therapy and monitoring a health condition

The functional level of someone living with Parkinson's can be dramatically affected by their medication. Being able to take their medication in a strict regime is important.

Due to the changes to movement that can occur physiotherapy may be a normal part of an individual's life and they may need support to complete any exercises they have been given.

Remember in PIP...

Therapy input in a domestic setting, which covers majority of weeks and where they require supervision, assistance or prompting to complete should be explored and considered.

Ensure to explore how any medication is managed including compensation strategies like alarms to combat restrictions.

Functional impact

A brief summary of the functional impact those living with this condition may experience

Activity 4: Washing and bathing

Physical changes (poor balance, spatial awareness, coordination difficulties) can affect safety in the bathroom getting in/out of an unadapted bath/shower. The range of movement can be reduced, or it can take longer to complete.

Psychological effects can impact motivation, orientation, sequencing.

Individuals may not be able to manage with aids due to the changes in their functional ability not being reliable.

Remember in PIP...

Explore what management strategies are used to manage the effects of symptoms and consider whether aids would help or whether the action would still be unreliable due to one or more aspect of STAR. Remember to consider both physical and psychological affects here and provide advice for the most affecting aspect.

Activity 5: Managing toileting needs and incontinence

Incontinence of the bladder and or bowel can be an effect of Parkinson's. Wearing incontinence pads is a usual way to manage this but as physical restrictions progress individuals may need assistance to manage their hygiene needs.

Due to rigidity, freezing and changes in movement patterns, getting on and off the toilet can be difficult. Aids or assistance may be required.

Remember in PIP...

If the claimant is incontinent, how frequent is it and is this of one or both? Can this be managed with pads independently or do they need assistance to maintain hygiene? How do they transfer on/off?

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Activity 6: Dressing and undressing

Range of movement can be reduced or affects to movement patterns mean it can take longer to complete. Dexterity may be reduced and grip strength may be diminished.

Psychological effects can impact motivation, orientation, sequencing.

Individuals may not be able to manage with aids due to the changes in their functional ability not being reliable.

Remember in PIP...

Explore what management strategies are used to manage the effects of symptoms and consider whether aids would help or whether the action would still be unreliable due to one or more aspect of STAR. Remember sitting down is not considered an aid. When they are sat does this help or would they still need support and why is this? Ensure to probe for specific detail about how they complete the task.

Functional impact

A brief summary of the functional impact those living with this condition may experience

Activity 7: Communicating verbally

Speech can be affected due to the effects on the muscle functions, which can make it difficult to control volume and clarity of speech which can lead to others misunderstanding what they are trying to express.

Loss of facial expression and spontaneity of communication, which can be a cause of extreme misunderstanding.

Remember in PIP...

That there are specific boundaries for what is considered basic and complex. How their emotions impact on their ability to manage relationships and respond to individuals is likely to be managed in A9. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 8: Reading and understanding signs and symbols

With any cognitive changes, this can affect the ability to process and understand written information and in some cases support is required.

Remember in PIP...

That there are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 9: Engaging with others face to face

Those living with Parkinson's can experience isolation.

Anxiety, agitation and apathy can also be symptoms which can affect an individuals ability to engage socially.

Loss of facial expression and spontaneity of communication can affect their ability to maintain and create relationships.

Remember in PIP...

Cover where specific restrictions are reported how they manage this. Detail of any support provided and whether this support can be provided by anyone or only specific individuals.

Functional impact

A brief summary of the functional impact those living with this condition may experience

Activity 10: Budgeting

Impulsive and compulsive behaviours such as obsessive gambling, can be a side effect of some Parkinson's medication. As any cognitive functions are affected or an individual experiences anxiety or depression this can also result in assistance being needed for this task.

Remember in PIP...

That there are specific boundaries for what is considered basic and complex. Ensure to explore for specifics where a restriction is reported to determine if simple and/or complex criteria is met.

Activity 11: Planning and following a journey

Hallucinations, anxiety, changes in cognitive function can result in restrictions for individuals going out and result in individuals needing support when they complete journeys.

Impulsive and compulsive behaviours around risk taking can also affect individuals safety and should be explored fully to determine any impact or history of incident.

Remember in PIP...

Where there are associated conditions you must explore the 4 stages to a journey 1. Frequency and type of outings 2. before a journey 3. during a journey and 4. post a journey. Any social anxiety and/or anxiety related to change? If so to what extent, how and when does this manifest, how it is managed, is it present on all journeys or just unfamiliar ones? Are there any hallucinations or cognitive changes which could affect their ability to plan and follow a route? How would they plan a route to get to an appointment at a specific time? How would they manage any changes that occurred?

Activity 12: Moving around

Postural hypotension, fatigue, dystonia, can cause falls, reduce distance that can be walked, increase timings and will affect the repeatability of ability to move around.

Listen to the lived experience of Jean [here](#) and Matt talking through walking with Parkinson's [here](#).

Remember in PIP...

Individuals may struggle to provide specific information. Try to use examples to help or things in their area they might be able to refer to. You must explore whether any journey discussed is repeatable, where possible how long it takes them, how they feel whilst doing it, and any incidents of note such as falls in the past 12 months?

Additional reading or other resources

EXTERNAL

- <https://www.parkinsons.org.uk/> has literature which can be downloaded.
- <https://www.youtube.com/user/parkinsonsUK>
- For further information see NHS Conditions and Treatments: <https://www.nhs.uk/conditions/parkinsons-disease/>
- Main learning hub for Parkinsons UK <https://www.parkinsons.org.uk/professionals/learning-hub>
- My Parkinsons interactive workbook <https://www.parkinsons.org.uk/professionals/events-and-learning/my-parkinsons-interactive-workbook>

INTERNAL

- [Parkinson's awareness session](#) - video of an awareness session delivered by Parkinson's UK

The following may be useful depending on how the claimant is affected functionally.

- Desktop Aids on Fatigue, Activity 12, Washing and Bathing, Dressing and Undressing with or without an Aid, CSE

Version control