



Pain in Parkinson's, where do we go from here ?

Alison Stewart

Lead Parkinson's Nurse Specialist

NHS Lothian.

Pain and other motor symptoms of Parkinson's are increasingly recognised as a major cause of reduced health related quality of life.



PARKINSON'S^{UK} CHANGE ATTITUDES. FIND A CURE. JOIN US.

£35,000 research project

“Measuring pain in Parkinson’s”



One of the main barriers to understanding and treating pain in Parkinson’s is that there is no established scale to measure it.

- **There are already scales for measuring other key factors that can be linked to Parkinson’s, including sleep, depression and memory.** These tools have helped to revolutionise our understanding of the condition.

The aim of this project is to test the first ever ‘easy to use’ scale to measure pain in Parkinson’s

Have you experienced any of the following in the last month?

- | | Yes | No | | Yes | No |
|---|-------------------------------------|-------------------------------------|---|-------------------------------------|-------------------------------------|
| 1. Dribbling of saliva during the daytime | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 16. Feeling sad, 'low' or 'blue' | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 2. Loss or change in your ability to taste or smell | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 17. Feeling anxious, frightened or panicky | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 3. Difficulty swallowing food or drink or problems with choking | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 18. Feeling less interested in sex or more interested in sex | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 4. Vomiting or feelings of sickness (nausea) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 19. Finding it difficult to have sex when you try | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 5. Constipation (less than 3 bowel movements a week) or having to strain to pass a stool (faeces) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 20. Feeling light headed, dizzy or weak standing from sitting or lying | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 6. Bowel (fecal) incontinence | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 21. Falling | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 7. Feeling that your bowel emptying is incomplete after having been to the toilet | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 22. Finding it difficult to stay awake during activities such as working, driving or eating | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 8. A sense of urgency to pass urine makes you rush to the toilet | <input checked="" type="checkbox"/> | <input type="checkbox"/> | 23. Difficulty getting to sleep at night or staying asleep at night | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 9. Getting up regularly at night to pass urine | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 24. Intense, vivid dreams or frightening dreams | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 10. Unexplained pains (not due to known conditions such as arthritis) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 25. Talking or moving about in your sleep as if you are 'acting' out a dream | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 11. Unexplained change in weight (not due to change in diet) | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 26. Unpleasant sensations in your legs at night or while resting, and a feeling that you need to move ... | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 12. Problems remembering things that have happened recently or forgetting to do things | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 27. Swelling of your legs | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 13. Loss of interest in what is happening around you or doing things | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 28. Excessive sweating | <input type="checkbox"/> | <input checked="" type="checkbox"/> |
| 14. Seeing or hearing things that you know or are told are not there | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 29. Double vision | <input checked="" type="checkbox"/> | <input type="checkbox"/> |
| 15. Difficulty concentrating or staying focussed | <input type="checkbox"/> | <input checked="" type="checkbox"/> | 30. Believing things are happening to you that other people say are not true | <input type="checkbox"/> | <input checked="" type="checkbox"/> |

Thank you for completing this questionnaire. Please hand it to the doctor/nurse who sees you. They will treat it with the utmost confidence. If there are any items that you would wish to discuss with the doctor/nurse, please put a ring around them.

Questions your doctor will ask

- Where is your pain located ?
- What does your pain feel like ?
- Does the pain radiate anywhere?
- When does the pain occur ?
- Do you have pain continuously, or only at certain times?
- Does pain occur in relation to any particular activity?
- What relieves the pain ?
- What makes the pain worse ?
- Do your anti-Parkinson's medications relieve the pain ?
- Do you have arthritis ?

Pain in Parkinson's

MUSCULOSKELETAL

DYSTONIC

NEUROPATHIC

CENTRAL

AKATHESIA



There is no solution to pain but here are
some suggestion

Musculoskeletal

SYMPTOM

Common in Parkinson's
– 80%

Pain in muscles and
bones

Ache in joints

Rigidity can aggravate
pain

POSSIBLE SOLUTION

Painkillers

Regular exercise

Physiotherapy

Dystonia

SYMPTOM

Spasms / cramps

Abnormal posturing

POSSIBLE SOLUTION

Try long acting medication

Physiotherapy assessment

Botox (Botulinum toxin)

Dyskinetic pain

SYMPTOM

Drug induced
dyskinesia.

Can aggravate
underlying pain

POSSIBLE SOLUTION

Perhaps reduce
dopamine drugs

Radicular pain

SYMPTOM

POSSIBLE SOLUTION

Pins & needles

Painkillers

Numbness

Non steroidal

Possible trapped nerve

See Neurologist

Restless Leg Syndrome (Akathisia)

SYMPTOM

Difficult to describe

More discomfort than pain

Sensations in the lower legs between the knee and ankle. The feeling makes you uncomfortable unless you move your legs. These sensations:

- Usually occur at night when you lie down, or sometimes during the day when you sit for long periods of time
- May be described as creeping, crawling, aching, pulling, searing, tingling, bubbling, or crawling
- May last for 1 hour or longer
- Sometimes also occur in the upper leg, feet, or arms.

POSSIBLE SOLUTION

Low doses of pramipexole (Mirapex)
or
ropinirole (Requip)

CR Sinemet / Madopar

Gabapentin, pregabalin

Clonazepam

If iron deficiency - should receive iron supplements.

Central pain

SYMPTOM

Rare

Affects mouth, chest,
rectum and genitalia

POSSIBLE SOLUTION

Dopaminergic drugs

Painkillers

Opiates

Antidepressants.

General advice

Keep active

Pacing and rest period in
your day

Living with pain

<http://www.painassociation.com/>

