

Supplementary materials

Survey

What is your association with Parkinson's?

I have Parkinson's

I am a carer/partner/family member or friend

People with Parkinson's

- What age are you?
 - a. Under 30
 - b. 30-49
 - c. 50-59
 - d. 60-69
 - e. 70-79
 - f. 80 or over

- When were you diagnosed with Parkinson's?
 - a. Less than 2 years ago
 - b. 2-5 years ago
 - c. 6-10 years ago
 - d. 11-20 years ago
 - e. More than 20 years ago

- Does pain impact your day-to-day life?
 - a. Yes
 - b. No
 - c. Not sure

Please tell us how your pain affects you:

- How frequently do you experience pain?
 - a. Never
 - b. Rarely (around once per year)
 - c. Sometimes (around once per month)
 - d. Frequently (around once per week)
 - e. Very frequently (most days)

- Is pain a symptom you discuss with your healthcare professional?
 - a. No I haven't discussed pain with a healthcare professional
 - b. Yes I've discussed with my GP (General Practitioner)
 - c. Yes I've discussed with my Parkinson's nurse
 - d. Yes I've discussed with my Physiotherapist
 - e. Yes I've discussed with my Occupational Therapist
 - f. Yes I've discussed with my Dietician
 - g. Yes I've discussed with another healthcare professional (please detail)

- What did the healthcare professional do to support you with your pain?
 - a. Nothing
 - b. Advice, education or information
 - c. Medication
 - d. Exercise
 - e. Complementary therapy (e.g. massage, acupuncture)
 - f. Other (please detail)

- Are you doing anything to help manage your pain?

- What would you expect from a pain management intervention?

- Would you want a healthcare professional to be involved, or would you prefer something that could self-manage?

- What impact would a better pain management strategy have on you?

Carers

- What age is the person with Parkinson's?
 - a. ___ Under 30
 - b. ___ 30-49
 - c. ___ 50-59
 - d. ___ 60-69
 - e. ___ 70-79
 - f. ___ 80 or over

- When were they diagnosed with Parkinson's?
 - a. ___ Less than 2 years ago
 - b. ___ 2-5 years ago
 - c. ___ 6-10 years ago
 - d. ___ 11-20 years ago
 - e. ___ More than 20 years ago

- Does pain impact their day-to-day life?
 - a. Yes
 - b. No
 - c. Not sure

Please tell us how your pain affects them:

- How frequently do they experience pain?
 - a. Never
 - b. Rarely (around once per year)
 - c. Sometimes (around once per month)
 - d. Frequently (around once per week)
 - e. Very frequently (most days)

- Is pain a symptom they discuss with their healthcare professional?
 - a. No they haven't discussed pain with a healthcare professional
 - b. Yes they've discussed with their GP (General Practitioner)
 - c. Yes they've discussed with their Parkinson's nurse
 - d. Yes they've discussed with their Physiotherapist
 - e. Yes they've discussed with their Occupational Therapist
 - f. Yes they've discussed with their Dietician
 - g. Yes they've discussed with another healthcare professional (please detail)

- What did the healthcare professional do to support them with their pain?
 - a. Nothing
 - b. Advice, education or information
 - c. Medication
 - d. Exercise
 - e. Complementary therapy (e.g. massage, acupuncture)
 - f. Other (please detail)

- Is the person with Parkinson's doing anything to manage their pain?

- What would you expect from a pain management intervention?

- Would you want a healthcare professional to be involved, or would you prefer something that the person with Parkinson's could manage themselves/with your support?

- What impact do you think a better pain management strategy would have on them?