

1 Title: A survey of people with Parkinson's and their carers: The management of pain
2 in Parkinson's

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4 Naisby, J.^{1,3} PhD

5 Amjad, A.² MA

6 Ratcliffe, N.² PhD

7 Yarnall, A.J.³ PhD, MBBS

8 Rochester, L.³ PhD

9 Walker, R.⁴ MD

10 Baker, K.¹ PhD

11

12 1. Department of Sport, Exercise and Rehabilitation, Northumbria University

13 2. Parkinson's UK, 215 Vauxhall Bridge Road, London, SW1V 1EJ

14 3. Institute of Neuroscience/Newcastle University Institute for Ageing, Clinical
15 Ageing Research Unit, Newcastle University, Newcastle Upon Tyne, UK

16 4. Northumbria Healthcare NHS Foundation Trust, North Tyneside General
17 Hospital, North Shields, United Kingdom

18

19 Corresponding author: Dr Jenni Naisby, Department of Sport, Exercise and
20 Rehabilitation, Northumbria University. Email: jenni.naisby@northumbria.ac.uk

21 Telephone: 0191 2156434.

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34 **Abstract**

35

36 Background: Pain in Parkinson's is problematic but under treated in clinical practice.
37 Healthcare professionals must understand the impact of pain in Parkinson's and
38 patient preferences for management.

39 Objective: To understand the impact of pain in Parkinson's and to understand current
40 management and preferences for pain management.

41 Methods: We conducted a national survey with 115 people with Parkinson's (PwP)
42 and 10 carers. Both closed and open questions were used. The questions focused
43 on how pain affected the individual, healthcare professional involvement in
44 supporting pain management, current pain management strategies and views on
45 future pain management interventions. We used descriptive statistics to summarise
46 closed responses and thematic analysis to summarise open question responses.

47 Results: 70% of participants reported pain impacted their daily life. Pain had a
48 multifactorial impact on participants, affecting movement, mood and quality of life.

49 Improved pain management was viewed to have the potential to address each of
50 these challenges. Pain affected a number of different sites, with low back pain and
51 multiple sites being most frequently reported. Exercise was the most frequently
52 noted strategy (38%) recommended by healthcare professionals for pain

53 management. PwP would value involvement from healthcare professionals for future
54 pain management, but also would like to self-manage the condition. Medication was
55 not suggested as a first line strategy.

56 Conclusions: Despite reporting engagement in some strategies to manage pain, pain
57 still has a wide-ranging impact on the daily life of PwP. Results from this survey
58 highlight the need to better support PwP to manage the impact of pain.

59

60 Pain can affect up to 85% of people with Parkinson's (PwP)^{1,2} yet is poorly
61 recognised and managed within clinical practice,³ which can have significant
62 consequences on quality of life.⁴ Pain is biopsychosocial and has a multifactorial
63 impact on individuals lives, yet this has been found to not be acknowledged by
64 healthcare professionals.⁵ Despite the problem of pain, there are limited options for
65 pain management in Parkinson's.⁶ Between 50%⁷ and 63%⁸ of those reporting pain
66 have not received any pharmacological or non-pharmacological treatment for their
67 pain, which has been attributed to an inadequate awareness of clinicians.⁹ There is a
68 need to increase education concerning pain in Parkinson's for healthcare
69 professionals and to develop options for both pharmacological and non-
70 pharmacological management of pain.¹⁰ Currently, it is unknown if pharmacological
71 therapy will relieve pain in PD due to the distinct mechanisms involved with pain
72 processing interacting with Parkinson's pathophysiology.¹¹ A small number of cross
73 sectional studies have provided some detail on how PwP manage their pain.
74 Physiotherapy and pain medication are the most frequently cited approaches.^{7,8,12}
75 However, this must be considered in the wider context of a number of individuals not
76 receiving any treatment. There is limited literature to date exploring the impact of
77 pain, current management strategies and the preferences of PwP for future
78 interventions. Understanding of these factors will help to inform the development of
79 pain management for PwP.

80

81 Currently there is only a small amount of research that focuses specifically on PwP
82 views on pain. This work aimed to enable PwP and their carers to share their
83 experiences of pain and pain management in their own words and, importantly, to

84 share their thoughts on what pain management interventions should look like. This
85 survey forms part of a wider piece of patient and public involvement to inform the
86 direction of a future research study about pain management in Parkinson's.

87

88 **Materials and Methods**

89

90 *Ethics*

91

92 The survey was approved by Northumbria University Research Ethics committee.
93 Informed consent was obtained at the start of the survey. We confirm that we have
94 read the Journal's position on issues involved in ethical publication and affirm that
95 this work is consistent with those guidelines.

96

97 *Developing the survey*

98

99 In order to ensure the survey was clear and that questions focused on aspects
100 important to PwP, we considered it vital to work with PwP to develop the survey
101 questions. JN, AA and NR drafted questions based on existing literature and the
102 research team's plans for a future study. The draft survey was then sent to five
103 people affected by Parkinson's (3 male & 2 female; time since diagnosis: ranging
104 between 2-15 years) who provided feedback on the clarity of questions and
105 recommended changes. As a result of this feedback, a number of amendments were
106 made including reducing the length of the survey, refining the focus and providing
107 more detail for certain questions.

108

109 *Recruitment and Procedures*

110

111 The survey was administered in March 2020 by Parkinson's UK on SmartSurvey, an
112 online survey software and questionnaire tool. Participants were recruited via
113 Parkinson's UK Research Support Network - an online network that brings together
114 people driven to help find a cure and better treatments for Parkinson's. The
115 Research Support Network has around 6,000 members (as of February 2020), the
116 vast majority of whom are PwP and partners, family members and carers of those
117 with the condition living in the UK. An email was sent to the network inviting people
118 to complete the survey, and the survey was also included in the Network's monthly
119 e-newsletter.

120

121 The survey gathered feedback from both PwP and partners, family members and
122 carers. The target population was those who had experience of pain. The question
123 set was the same for the two groups, aside from minor variations in wording to make
124 questions applicable. The first question required the individual to indicate if they were
125 a person with Parkinson's or a partner, family member or carer so the appropriate
126 question set could be shown (supplementary material). The survey consisted of two
127 parts. Part 1 included eight questions focused on how pain affected the individual (or
128 their partner/family member/person they cared for), their experience of healthcare
129 professional involvement in supporting pain management, current pain management
130 strategies and views on future pain management interventions. Three questions
131 collecting demographic information were also included. Part 2 consisted of a further
132 nine questions focused on feedback for the specific design of a study. Results from
133 part 2 are not reported here. The survey did not collect any identifying information.

134 Participants were able to skip any questions they did not wish to answer. The survey
135 included a mixture of closed and open-ended questions. Open ended questions were
136 deemed important to allow participants to develop responses due to the limited
137 research in this area, and also provided an opportunity for participants to highlight
138 any additional points they deemed relevant.

139

140 *Data Analysis*

141

142 We used descriptive statistics to characterise the sample. Categorical data were
143 analysed via SPSS (version 21) to generate frequencies. Open ended questions
144 were summarised using thematic coding analysis.¹² These were informed by the
145 aims of the research, whilst allowing new themes to emerge. One author (JN) read
146 through the responses, coded these and then categorised into themes. A second
147 author (KB) independently categorised the coded responses and a final presentation
148 of themes was agreed through a peer debriefing meeting between the two authors
149 and discussed with the wider team.

150

151 **Results**

152

153 We received responses from 115 PwP and 10 carers. Almost all the questions
154 (except three) were focused on the experience of the person with Parkinson's, with
155 partners, family members and carers responding on the person's behalf. Therefore,
156 the reporting of 'participants' refers to the information captured from both groups of
157 respondents (N=125), unless specified otherwise. All participants answered the
158 closed questions, and the number of responses to the open questions is indicated

159 within the tables (2-4). Participants could choose more than one answer to the
160 closed and open questions.

161

162 Closed questions

163

164 Please see table 1 for details of participant characteristics. 74% of participants were
165 aged 60 or over. 42% had been diagnosed between two and five years. A large
166 majority of participants indicated pain impacted their daily life (70%), with 49%
167 experiencing pain multiple times per week and 24% experiencing pain multiple times
168 per day. The healthcare professional (HCP) with whom the highest number of
169 participants had discussed their pain was their Parkinson's nurse (48%) followed by
170 a general practitioner (38%) and a physiotherapist (35%). 10% of PwP discussed
171 pain with their neurologist. Exercise was the most frequently noted mechanism by
172 which healthcare professionals supported individuals with their pain (38%).

173

174 Open questions

175

176 The open-ended questions provide detailed information regarding the current impact
177 of pain, it's management and future management suggestions.

178

179 *The impact and current management of pain in Parkinson's*

180

181 When asked about what pain management strategies people with Parkinson's used,
182 physical activity, paracetamol and ibuprofen were the most frequently reported.

183 Some individuals described multiple strategies, with some participants identifying a

184 wide range of strategies that had been tried to manage their pain. Other participants
185 acknowledged that no management options had been successful to date or not
186 being sure how to manage their pain. Whilst medication was cited, some participants
187 expressed reluctance at taking this. Parkinson's medication was not linked with pain.
188 Five individuals noted painful muscle spasms and cramps. Some participants had
189 tried other therapies such as massage and mindfulness. Table 2 provides a
190 description of each of the pain management strategies and examples identified by
191 participants. When asked if pain impacted their daily life, responses focused around
192 describing the location of their pain and the timing of this, alongside capturing the
193 biopsychosocial impact that this can have. Pain was reported in a number of
194 locations, with low back pain being the most frequently reported, alongside having
195 pain in multiple locations. Wearing off pain was noted by few participants. Pain made
196 movement difficult for some participants, alongside having a negative impact on
197 mood and wider daily life. Detail surrounding these open-ended responses is
198 provided in table 3.

199

200 *Pain management needs for people with Parkinson's*

201

202 Participants identified the need for pain management interventions to provide pain
203 relief. Involving healthcare professionals with pain management was deemed
204 important, with some individuals viewing it necessary to be able to self-manage their
205 pain or to have a combination of support and self-management. When asked an
206 open question about future pain management medication was not mentioned as a
207 suggestion for pain management, however some participants highlighted a non-drug
208 approach to be the preference. Table 4 provides further detail pertaining to the

209 nature of pain management interventions suggested by participants. Participants
210 indicated improved pain management would provide an overall positive impact on
211 general wellbeing, in particular improving activity and quality of life. An impact on
212 mood, sleep and daily life were often referred to alongside improved pain
213 management as having the potential to 'change the life' of some individuals. A sense
214 of being in control of pain was deemed important by some. Table 5 elaborates on
215 these findings, with specific examples provided.

216

217 **Discussion**

218

219 This survey has identified the anticipated impact improved pain management
220 strategies would have on PwP living with pain, alongside preferences on how such
221 strategies should be delivered. Studies to date present findings on strategies that
222 have been tried for PwP but have involved little dialogue with people about their
223 preferences. This survey provides a direct account of what PwP would like from
224 future pain management interventions and the potential impact they felt that this
225 would have.

226

227 Pain was highlighted as having a biopsychosocial impact, with movement, mood and
228 daily life each being cited as being impacted by pain. Despair and despondency
229 associated with living with pain in Parkinson's has been reported in a qualitative
230 study (n=4).⁵ This study reported individuals experiencing high levels of pain which
231 had psychological and social impacts. Some participants tried management
232 strategies such as exercise, whilst others felt this to not be possible. Having a sense
233 of control over pain was key. A disconnect between healthcare professionals and

234 PwP was highlighted, with individuals needs surrounding pain not addressed⁵. Whilst
235 small samples can be expected in this type of study, transferability of these findings
236 is limited as a stand-alone study. The current survey adds to these findings,
237 highlighting on a larger scale the wide-ranging impact of pain, and variation among
238 the use of strategies. A key development with the current survey is individuals
239 reporting how improved pain management would impact their daily life. A feeling of
240 overall improved wellbeing including improved activity, mood and quality of life were
241 each highlighted if pain were to be better managed. Pain can influence all aspects of
242 someone's life¹³ and be a particularly bothersome symptom.¹⁴ Individuals in this
243 survey noted the dominating effect of pain, and the overarching positive impact that
244 a reduction in pain could have on daily life.

245

246 Exercise is encouraged for PwP as a key aspect of the management of the
247 condition.^{3,15} The current survey identified that exercise is a frequently advised
248 strategy by healthcare professionals to support the management of pain. At early
249 stages of Parkinson's it has been found that activity levels are reduced compared to
250 age matched controls.¹⁶ Pain can be a barrier to exercise¹⁵ and increased physical
251 activity has been found to be associated with worse pain scores in Parkinson's.¹⁷
252 Within the literature related to chronic musculoskeletal pain, avoidance of activity
253 due to fear and reduced self-efficacy regarding managing symptoms can occur.¹⁸
254 Keeping active may not seem plausible to patients with low perceived control over
255 their pain¹⁹ and has been identified as an issue with PwP and pain.¹³ Whilst exercise
256 is also advocated for the management of pain in the general population^{20,21} this is
257 often in conjunction with other strategies including education and support.^{22,23} Given
258 that PwP in this survey highlighted exercise as a key strategy for reducing pain,

259 future work to investigate pain management strategies specific to Parkinson's is
260 necessary.

261

262 Medication was also identified as a method currently used to manage pain. The most
263 frequently cited medication was paracetamol (15% of individuals) followed by
264 ibuprofen (11% of individuals), which follows a similar pattern to cross sectional
265 studies, which have collected medication use data.^{2,12} This type of medication use
266 has been criticised as not targeting the central mechanisms of pain in Parkinson's.²
267 Alongside this, these are not large numbers of the participants reporting medication
268 use, and often individuals do not receive any support with pain management,
269 including medication.^{7,8} Some participants in the current survey identified a hesitance
270 at taking medication or suggesting a non-drug approach for future management. It is
271 important to note that in an open question about expectations for a pain
272 management intervention, medication was not suggested as a potential strategy by
273 participants.

274

275 Healthcare professional support was valued by participants for pain management,
276 appreciating the knowledge and advice healthcare professionals could provide being
277 most frequently cited. A recent systematic review of pain management for PwP⁶
278 advocates the need for further research in this area. The review demonstrated
279 promise for pharmacological therapy focusing on Safinamide, and from one study,
280 efficacy for multidisciplinary team (MDT) management. 'Miscellaneous therapies'
281 were highlighted including hydrotherapy, massage and resistance exercise, yet the
282 quality of these studies was poor. Pain is multifactorial²⁴, and individual approaches
283 like those approaches did not reflect the biopsychosocial impact of pain. The review

284 was comprehensive in its search, including allied health, behavioural therapy and
285 client centred therapy, yet identified little in these areas. Whilst MDT management
286 had shown promise for pain²⁵ this was not the primary outcome or focus of this study
287 and there was limited detail of the MDT management. A previous cross sectional
288 survey found the greatest efficacy for pain management was reported in conjunction
289 with treatment in a rehabilitation clinic or physiotherapy.¹² To date, there is limited
290 literature focusing on interventions for pain management in Parkinson's.⁶ Pain
291 management in the context of wider care, with support from healthcare professionals
292 warrants investigation given PwP identifying the wide ranging impact of pain on their
293 daily lives and a preference for support in pain management.

294

295 The participants in this study identified a number of different HCPs with whom they
296 have discussed their pain with. In previous studies an orthopaedic doctor or general
297 practitioner were the most frequently cited, with a small number citing neurologists.¹²
298 In agreement, the current survey found a small number of neurologists and
299 consultants cited. However, the Parkinson's nurse and physiotherapist were
300 frequently referred to as those who individuals had consulted. This finding is crucial
301 as it indicates that there is a need for a multidisciplinary approach to pain
302 management in Parkinson's, in support of previous work.²⁵ Healthcare professionals
303 working with individuals with chronic musculoskeletal pain have reported challenges
304 in supporting people with pain and require support themselves.²⁶ Alongside this,
305 literature exploring clinician attitudes and beliefs to chronic musculoskeletal pain has
306 found HCP attitudes and beliefs to be associated with those of their patient. A
307 biomedical orientation has a negative association with patient education, adherence
308 to treatment guideline and activity recommendations.²⁷ These results of the current

309 survey show that PwP feel HCPs have a key role to play in pain management. It is
310 therefore important for future work to understand attitudes and beliefs amongst
311 HCPs regarding pain in Parkinson's, particularly given the limited focus on pain
312 management in current Parkinson's practice.^{7,8}

313

314 70% of participants reported pain influenced their daily life, which aligns with other
315 cross sectional studies focusing on pain and Parkinson's, which report between
316 52%²⁶ and 85%² of people reporting pain. The current survey found 49% to
317 experience pain daily and 24% multiple times per day. These findings are higher
318 than previously reported of up to 21% 'often' experiencing aches and pains and 6%
319 'always' experiencing these.²⁹ Low back pain is frequently cited as problematic in
320 Parkinson's^{30,31} and was noted most frequently in this survey, followed by
321 individuals experiencing pain at multiple sites. A diagnosis of the cause of pain was
322 important to some individuals. However, given the central processes involved in
323 pain, and PwP potentially being more predisposed to pain^{32,33} a definitive diagnosis
324 may be difficult to achieve. A diagnosis can provide legitimacy to pain, and one
325 potential way to achieve this is to consider education regarding pain physiology.¹⁸
326 This captures the biopsychosocial nature of pain, supporting participants to
327 understand the multifactorial influences on a pain experience. The participants
328 focused predominantly on the location of pain within this survey. Given that there are
329 often different pain mechanisms involved with pain and Parkinson's³⁴ communicating
330 these to PwP may help with understanding.

331

332 A limitation of this study is the lack of measures of disease severity including Hoen
333 and Yahr staging, MDS UPDRS and measures of non-motor symptoms such as

334 sleep and mood. This was a non-random sample, using self-report data, which is
335 also acknowledged as a limitation of the study. Those responding are more likely to
336 have had a problem with pain in view of the nature of the study. Alongside this, as
337 individuals recruited would have expressed an interest to be contacted regarding
338 research, the population may not be entirely representative of the Parkinson's
339 population as a whole. The relationship between pain, OFF periods and anti
340 Parkinson medication was not specifically explored, however pain has been found to
341 be no different between the ON and OFF state in the largest pain and Parkinson's
342 study to date.² We did not use a validated scale to capture information regarding
343 pain in Parkinson's, for example the Kings Parkinson's pain scale.³⁵ However, the
344 survey was able to address the aim of this exploratory study, to identify current pain
345 management strategies and suggestions for the future. There were responses from
346 ten carers within this survey and it should be acknowledged they may have differing
347 views to the PwP themselves, though there were not sufficient data to investigate
348 this here. Respondents were all from the United Kingdom, which has implications for
349 the availability of services.

350

351 The key strength of this study is that it has explored preferences and needs
352 regarding pain management by directly asking PwP for their views. Feedback from a
353 small group of PwP on the draft survey questions helped ensure that the survey
354 focused on aspects important to PwP, and the use of open-ended questions allowed
355 PwP to make suggestions about what pain intervention strategies should look like.
356 Key HCPs who could be involved in pain management have also been identified,
357 which will help when providing tailored support and guidance to healthcare
358 professionals themselves. This study highlights the need to develop evidence

359 surrounding how to manage pain in Parkinson's, alongside the potential impact
360 improved management would have on PwP quality of life, movement and wellbeing.

361

362 **Author roles:**

363 1. Research project: A. Conception, B. Organization, C. Execution;

364 2. Statistical/Qualitative Analysis: A. Design, B. Execution, C. Review and

365 Critique;

366 3. Manuscript Preparation: A. Writing of the first draft, B. Review and Critique;

367 JN: 1A, 1B, 1C, 2A, 2B, 2C, 3A, 3B

368 AA: 1A, 1B, 1C, 2A, 2B, 2C, 3B

369 NR: 1A, 1B, 1C, 2C, 3B

370 AJY: 1A, 2C, 3B

371 LR: 1A, 3B

372 RW: 1A, 3B

373 KB: 1A, 1B, 2B, 2C, 3B

374

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532 **Tables**

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534 **Table 1: Participant Demographics and diagnosed questions responses**

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Demographic item from survey	Responses
<u>Age</u>	
Under 30	0
30-49	2 (2%)
50-59	30 (24%)
60-69	41(33%)
70-79	42 (34%)
80 or over	10 (8%)
<u>When diagnosed with Parkinson's</u>	
< 2 years ago	19 (15%)
2-5 years ago	53 (42%)
6-10 years ago	35 (28%)
11-20 years ago	17 (14%)
More than 20 years ago	1 (1%)
<u>Does pain impact your daily life?</u>	
Yes	88 (70%)
No	28 (22%)
Not sure	9 (7%)
<u>How frequently do you experience pain?</u>	
a. Never	9 (7%)
b. Rarely (around once per year)	7 (6%)
c. Sometimes (around once per month)	18 (14%)
d. Frequently (around once per week)	61 (49%)
e. Very frequently (most days)	30 (24%)
<u>Is pain a symptom you discuss with your healthcare professional?</u>	
a. No I haven't discussed pain with a healthcare professional	37 (30%)
b. Yes I've discussed with my GP (General Practitioner)	48 (38%)
c. Yes I've discussed with my Parkinson's nurse	60 (48%)

d. Yes I've discussed with my Physiotherapist	44 (35%)
e. Yes I've discussed with my Occupational Therapist	9 (7%)
f. Yes I've discussed with my Dietician	1 (0.8%)
g. Yes I've discussed with another healthcare professional (please detail)	33 (28%)
Consultant	14 (11%)
Neurologist	12 (10%)
Pain clinic	3 (2%)
Chiropractor	3 (2%)
Gastroenterologist	1 (0.8%)
<u>What did the healthcare professional do to support you with your pain?</u>	
a. Nothing	12 (10%)
b. Advice, education or information	36 (30%)
c. Medication	29 (25%)
d. Exercise	44 (38%)
e. Complementary therapy (e.g. massage, acupuncture)	19 (17%)
f. Other (please detail)	18 (16%)
Injections	1 (0.8%)
Botox	1 (0.8%)
Psychologist referral	1 (0.8%)
Physiotherapy referral	3 (3%)
Consultant referral	3 (3%)
Pain not related to Parkinson's	2 (2%)
Aid	1 (0.8%)
Leaflet	1 (0.8%)

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Table 2: Management strategies for pain

Category	Sub category	N	Example
Physical activity	Walking	9	Walking and trying to keep fit
	Pilates	8	If I arrive at Pilates feeling bad, I leave feeling better
	Gym	5	I try to go to the gym
	Swimming/ hydrotherapy	3	I swim when I can
	Stretching	9	Do stretching exercises
	Exercise	35	Lots of exercise
	Yoga	6	Yoga to stretch my muscles
	Dance	3	PD dancing
	Exercise class	9	Parkinson's exercise class
Cycling	1	Occasional cycle	
Medication	Paracetamol	19	Paracetamol 8 daily
	Ibuprofen	14	Taking lots of ibuprofen every day
	Co-codamol	2	Taking co-codamol 500mg 2x day
	'Painkillers'	10	I take painkillers
	Pregabalin	2	Pregabalin medication 70mg twice daily
	Gabapentin	2	Initially Gabapentin, then pregabalin, pain clinic but medication stopped working. They have not offered anything else.
	Amitriptyline	1	10mg amitriptyline daily
	Fluoxetine	1	I take fluoxetine, which really helps with the stiffness and some of the pain
	Aspirin	1	Aspirin
	Codeine	1	Codeine
	Sinemet	2	Also related to wearing off Sinemet, so next dose may relieve things
Zapain	1	Zapain capsules up to 8 in 24 hour period	
Hesitation taking medication	5	Have not tried Gabapentin...concerns about sedation	
Other therapies	Massage/ manual therapy	10	Occasional massage
	Mindfulness	5	I have tried...Bowen technique...mindfulness
	Bowden technique	2	
	Reflexology	3	Mental relaxation e.g. reflexology
	Acupuncture	1	Also undergone reflexology, acupuncture, ...mindfulness
	TENS	1	
	Cannabis oil	2	I also use cannabis oil
Support from healthcare professionals	Physiotherapy	9	Regular physiotherapy
	Chiropractor	2	Have consulted with osteopaths, chiropractors
	Osteopath	1	
	Pain clinic	1	Pain clinic (one visit)
Multiple strategies	Medication and exercise	15	Exercise, paracetamol
	Medication, exercise and other therapies	4	Regular exercise...mental relaxation e.g. reflexology, massage, very occasionally ibuprofen Private physiotherapy, directed exercise, ibuprofen

	Medication, healthcare and exercise	4	I exercise and I stretch...I often for a massage within financial constraints
	Exercise and other therapies	3	
	Healthcare, other therapies and exercise	4	
No management options have been identified or successful	Tried a range of strategies	3	I have had massage and do regular Pilates and stretches, with not a lot of benefit
	No/unsure	9	Not sure what to do
	Nothing helps	5	
No qualitative response provided		14	

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Table 3: Pain impact on day to day life

Category	Sub category	N	Example
Type and site of pain	Experience multiple symptoms	24	Long term frozen shoulder, joint and muscle pain, tendonitis
	Low back pain	32	Back is painful, probably due to posture changes
	Shoulder pain	18	Sharp pain and ache in right shoulder
	Joint pain	5	Joint pain
	Muscle pain	3	My muscles contract
	Nerve pain	3	Neurological pain is felt in my toes
	Cramps/spasms	5	Dystonia
	Tendinitis	1	
	Arthritis	3	Have arthritis in my back, not sure if the pain is this or PD
	Hip pain	5	It is permanently in the hip which radiates down the front
	Facial pain	1	Pain from tremor
	Pain linked to tremor	3	It moves and changes
	No pattern of pain	4	Abdominal pain, cant get out of bed
	Internal pain	3	Frequent back ache when wearing off
	Headache	1	
	Wearing off pain	4	
	Restless legs	1	
	Lower limb pain	12	Front of my leg from knee to ankle to top of my foot
Stiffness	10	No pain just stiffness	
Night pain	5	It wakes me up at night	
Morning pain	5	On getting up in the morning, difficulty in moving	
Biopsychosocial impact	Impacts movement	18	It makes it difficult to walk
	Pain impacts mood	5	I do get the impression healthcare professionals do not realise the extent of the pain which feedbacks into my low mood/anxiety
	Feeling overwhelmed	1	Sometimes I feel overwhelmed by pain
	Impacts sleep	2	It interrupts my sleep and makes me feel pretty miserable most of the time
	Feels frightened	2	It makes me miserable and at times frightened
	Impacts strength	2	When the pain and tightening occur they are often in association with weakness
	Impacts daily life	7	It affects me probably 75-80% of my week

	Influenced retirement	1	Daily pain was one reason I retired early
No qualitative response		34	

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628 **Table 4:** Expectations from a pain management intervention.
 629 Response to questions: 'What would you expect from a pain management
 630 intervention?' 'Would you want a healthcare professional to be involved, or would
 631 you prefer something that could self-manage?'
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Category	Sub category	N	Example
To reduce pain	To be pain free	1	To be pain free for longer periods of time
	To provide pain relief	42	Reduction of the pains
	Impact mood	2	My pain makes my mood worse
To find the cause of pain	Diagnosis	8	To find out what is causing the pain
	MRI scan	1	MRI as appropriate
Nature of the intervention	Healthcare professional supported	17	I would like to speak with professionals who have an interest in this area – explain my challenges – together see what is possible
	Self-manage	5	Would love something I can manage myself, then I don't have to go to appointments
	Healthcare professional support and self-management	6	Advice and guidance from a professional whilst getting on with it one-self
	Exercise	9	Exercises would be best
	Non drug approach	5	Non drug related relief
	To improve function	1	A reduction in pain would allow me to function better
	A holistic intervention	1	Fully holistic approach
Don't know		8	No idea
No qualitative response		17	

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Table 5: Expected impact of a better pain management strategy?
NB: In response to “What impact would a better pain management strategy have?”

Category	Sub category	N	Example
Improve wellbeing	Change life	9	It would change my life
	Improve activity	18	Make me more active
	Improve mood	9	Feel better mood wise
	Improve sleep	8	Improved sleep duration and pattern
	Improve QoL	11	A much better quality of life
	Impact hobbies	3	Freedom to enjoy daily activities
	Impact social life	2	I could socialise..without having to worry I'll have to return home
	Impact job	1	I would be able to do my job without pain
	Impact daily life	7	Make my life better
	Mental and physical improvement	3	A mental and physical impact
	Decrease symptom burden	2	It would change the outcome of everyday life
To impact management	Reassurance	3	Reassurance that the issue is being addressed
	Control	8	A feeling of being in control
	Knowledge	3	Feel I would be getting all the advice I need
Don't know		5	Not sure, I will try anything
No qualitative response		17	

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