



“Get on with it”

Exploring arthritis experiences of the over 50s across South Tees

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Healthwatch South Tees

There is a Healthwatch in every local authority area of England. We are the independent champion for people using local health and social care services. We listen to what people like about services and what could be improved and share these views with those with the power to make change happen. We also share views with Healthwatch England, the national body, to help improve the quality of services across the country. In addition, Healthwatch provides an Information and Signposting service to help people receive the right health and social care services locally.

In summary - local Healthwatch is here to:

- Listen to what people think of services.
- Use people's views to help shape better services.
- Provide information about health and social care services locally.

Healthwatch Middlesbrough and Healthwatch Redcar & Cleveland have been working together across Healthwatch South Tees (HWST), since 1 April 2017.

Disclaimer Note

The opinions represented in this report are those of the 58 older people living with arthritis who completed surveys and engaged in 'community conversations'. Healthwatch is not claiming these represent the views of all older people living with arthritis nor do they represent the opinions of Healthwatch South Tees.

Introduction

The prevalence of long-term health conditions for those aged over 50 is high in the UK, particularly musculoskeletal conditions, which affect one in four of the adult population¹. One of the most common musculoskeletal conditions in the UK is arthritis, experienced by more than ten million people. Other musculoskeletal conditions include:

- Osteoporosis (*summary page 10*), affecting over three million people in the UK (NHS England)
- Sarcopenia
- Back and neck pain
- Connective tissue diseases.

Statistics for Middlesbrough and Redcar and Cleveland² highlight arthritis as a local concern:

- *Almost 20% of Middlesbrough and Redcar and Cleveland's population of over 45 year olds are estimated to have knee osteoarthritis;*
- *Over 10% of Middlesbrough and Redcar and Cleveland's population of over 45 year olds are estimated to have hip osteoarthritis.*

The prominence of long-term health conditions has been recognised by the NHS Long-term Plan; the local Integrated Care System (ICS) will work with a new commitment to encouraging self-management and preventing deterioration of health. Exploring long-term health conditions, e.g. arthritis, in our consultation around the NHS Long-term Plan, 36 participants told us their experiences. Only six of these respondents noted that the support they received met their expectations with others commenting that they had been offered a “purely clinical model”, “only given pain killers” and that there is “no awareness raised of alternative therapies”.

As arthritis was recognised as a common condition among those aged over 50 across South Tees, we decided to take a closer look into arthritis care experiences.

¹ World Health Organisation

² Public Health England

Methodology - What we did

We developed a survey to explore what works well, what needs to change and what improvements could be made, asking:

- What information is received at diagnosis
- What treatment options patients are given
- What people living with arthritis have tried and tested themselves for self-care.

The survey was made available online, however the majority of responses were collected through face-to-face engagement at events, community support groups and at the James Cook University Hospital waiting room, targeting those aged over 50 with any lived experience of arthritis in the South Tees region.

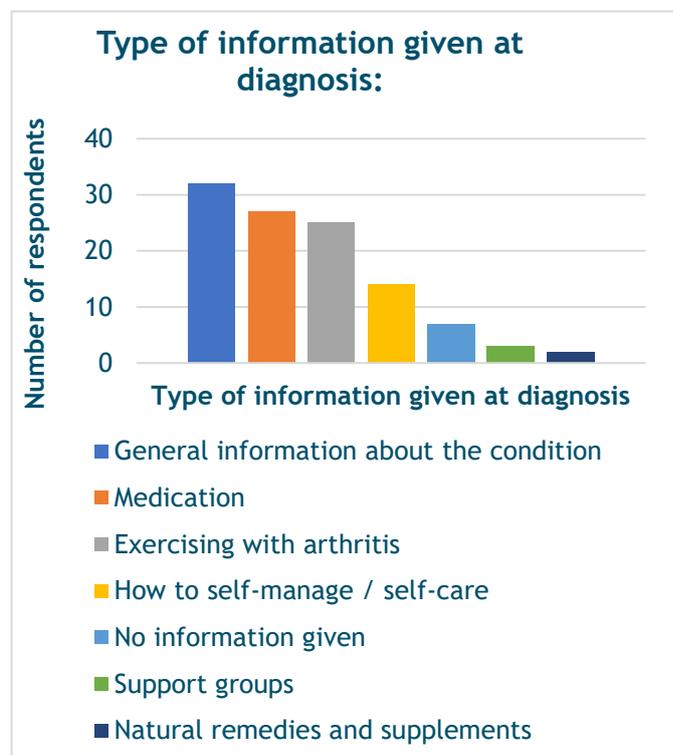
We have also taken note of ‘community conversations’; the survey wasn’t always appropriate with some questions irrelevant to the respondents’ experiences, and sometimes people liked to share their experiences with other members of the group.

Results - What we found:

Information at diagnosis

There was a mix in responses to the type and level of information received at point of diagnosis which highlights the need for some parity across services. Here’s what local people said to us;

At diagnosis, the majority of people received general information about arthritis, their prescribed medication and exercise suggestions. Only three people had been given information about local support groups, and seven people stated that they had received no information at all.



Alternatively, some people felt that they hadn't been told how to cope with their condition on a daily basis, how to improve their condition or how to lessen the pain, which they feel would have helped them with self-management. People explained how their GP hadn't offered much additional information to their diagnosis and subsequently gained most of their knowledge through their own research and searching the internet.

Some respondents expressed the need for a more holistic approach to the support and information they received, and for more alternatives to medicine:



For those who had been given information about exercising, there was an appreciation of being told of alternative ways to manage their condition, rather than medicine.

A lot of respondents did however feel they would have benefitted from:

- More time to talk through the exercises with demonstrations;
- Clearer guidance around exercises;
- Evidence of how exercise does actually help.

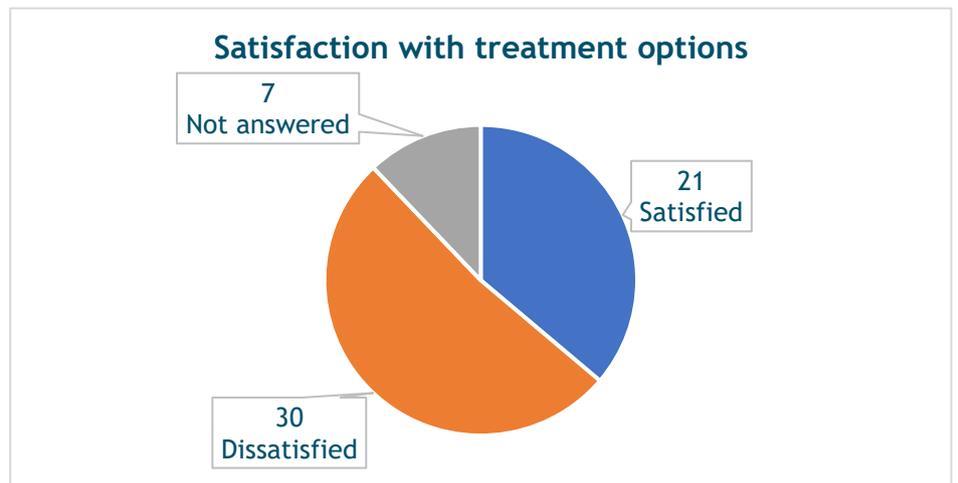
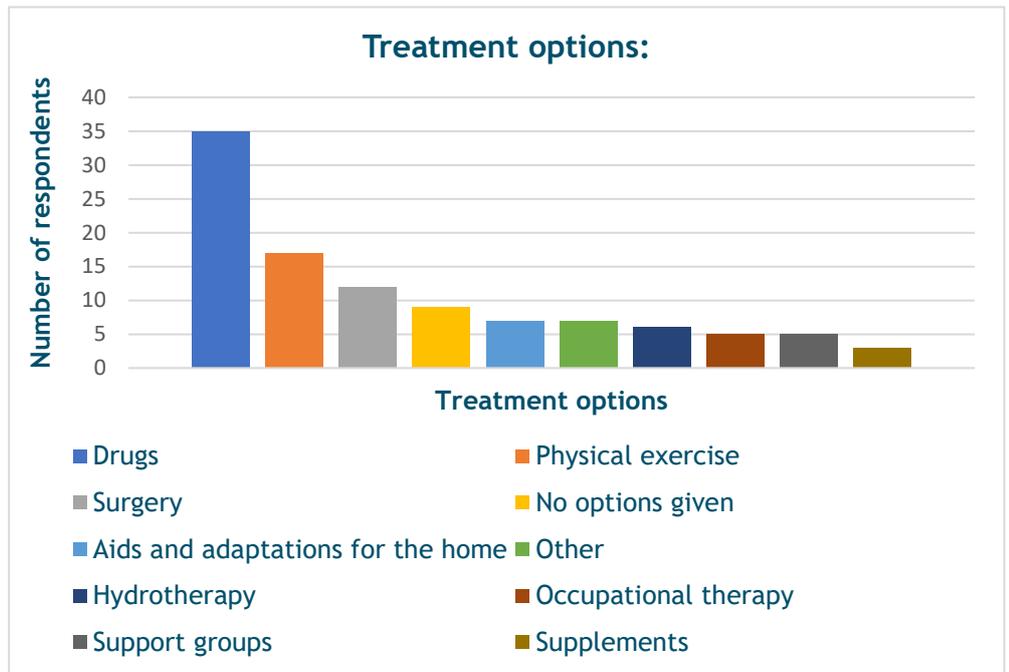
Although it is positive that patients are being told "how to self-help with exercises", there was a common fear of causing further harm by doing them incorrectly so many didn't bother to do them at all.

Some of the respondents felt they benefitted from the information they received at diagnosis, with some people describing it as "helpful" and "moderately useful" and were satisfied with the way in which they were given this; it helped them to "understand the condition" and "how to manage and live" with it.

Treatment Options

An overwhelming majority of respondents were given the treatment option of medication.

The findings show a dissatisfaction among the majority of the respondents with the treatment options they had been given; a lot of people felt these options were “minimal”, limited to painkillers and medication with other alternatives not being explored. Similarly, 50% of respondents didn't feel involved in their treatment plan:



Just told what to do then GP left me

Left to get on with it

A huge issue for a few respondents, was their ability to have surgery with a lot of respondents feeling that their age was a “huge barrier”; they expressed how their quality of life was hugely affected, but they had been told they weren't old enough or that their arthritis wasn't bad enough to warrant surgery.

Satisfaction with care and support

Overall, people were satisfied with the care and support they had received:

- **Healthcare** - People praised their GPs and hospital staff for the “really good” care they had received. More specifically, comments explained how the Rheumatology Department had “always been supportive”. Another explained how the care and support they’ve received “has helped maintain a relatively pain free life so far”.
- **Health journeys** - Respondents made positive comments about the time taken throughout the different stages of their care process; someone noted how they “can’t complain about the speed of the process” and another explained how they had experienced a “very fast referral to treatment”. One respondent stated there is “nothing to change - the system works”,

Where there was dissatisfaction, this was mostly around the need for more:

- More regular check-ups;
- More support;
- Shorter waiting times - One woman detailed how she had experienced a long waiting time for an x-ray, during which she had only been given oil and tablets. She felt her condition had severely worsened during this time which was reflected by the x-ray, which revealed arthritis in more places than was originally thought.

Experts by Experience - Self-Care Tips

When gathering arthritis experiences for those aged over 50 living in South Tees, we asked:

- What people had done themselves, alongside their prescribed medication, to manage and/or improve their condition;
- What people would recommend for others living with arthritis to try, based on their own experiences.

We understand that these may not work for all people living with arthritis, but we hope that by sharing the following tried and tested methods from our 58 respondents, that this can help to improve others' experiences of the condition:

- **Exercise** had been used by 60% of the respondents
- **Changes to diet** had been made by 45%
- **Doing further research, Losing weight and Heat and cold therapies** had been tried by 38%
- **Support groups** had been accessed by 16%
- **Massages** had been tried by 15%

When asking for more specific recommendations, respondents suggested:

- Yoga, stretching, chair-sitting exercises, lifting reasonable weights, using an exercise bike and Aquafit
- Therapies, such as physiotherapy, hydrotherapy and occupational therapy
- Natural supplements, specifically topical gels, herbal oils, vitamins and minerals
- Using a heat pad or hot water bottle on the affected area, or flexing/exercising the joint under warm water, to avoid flare ups from the cold
- Changing diet to a microbiome-friendly diet or an anti-inflammatory diet
- Resting, pacing and not overdoing it
- The JCUH Arthritis Support Group and the Redcar Versus Arthritis Support Group

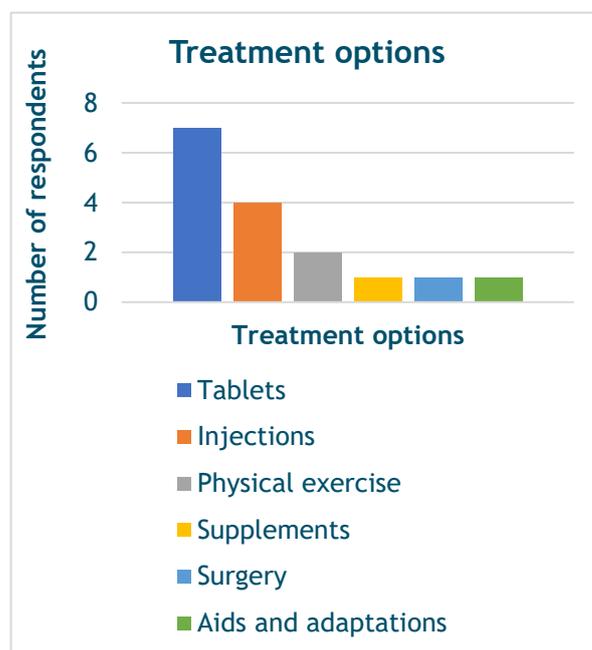
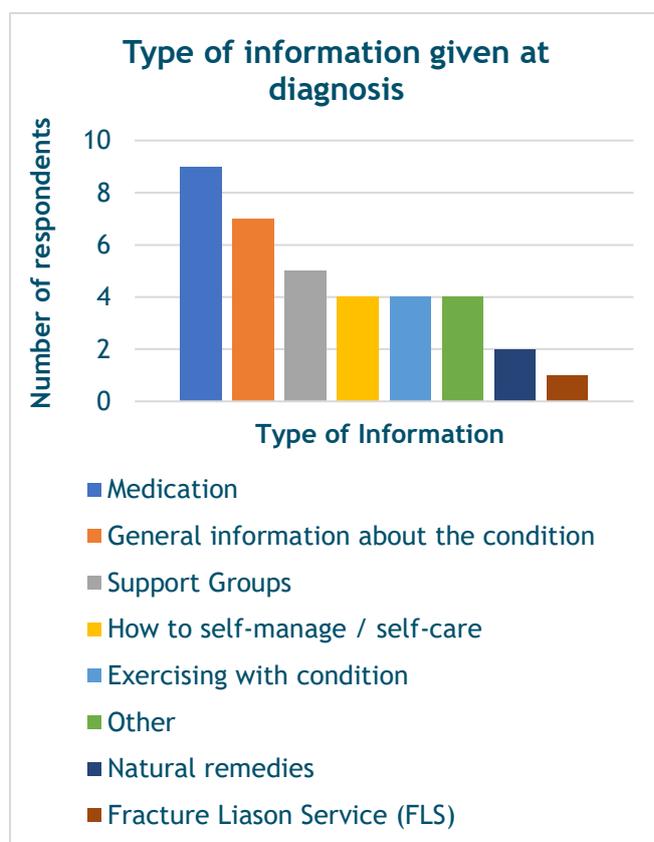
It is important that medical advice is followed by health and care professionals as Healthwatch South Tees are not medical experts.

Osteoporosis Summary

We also engaged with nine people living with osteoporosis, due to the crossover of conditions within the Bone Clinic at James Cook University Hospital. As this is another musculoskeletal condition, we have also included this intelligence in the report.

What works well

The majority of people were given general information about the condition and about the medication at diagnosis. This information was described as “excellent” and many people noted a “very useful discussion” at diagnosis.



Most people were given medication as a treatment option, which the majority of people were satisfied with.

Positive experiences were largely about the “excellent” care provided by health professionals:

GP really listened, was really thorough and tried to consider everything

GP was aware of services

What could change / be improved:

Some respondents stated they would prefer to:

- Learn about what to avoid to help their condition, e.g. types of food;
- Receive all of the information at the point of diagnosis, to know the full range of options available;
- Be signposted to useful resources, e.g. the Royal Osteoporosis Society (ROS) website

Similar to those living with arthritis, more regular check-ups and follow-ups would have also been appreciated by the respondents.

Limitations of research and next steps:

The Sample

- Overall, we collected experiences from 58 people with arthritis and nine people with osteoporosis. This is a low number in consideration to the high number of people living with these conditions, as previously highlighted by local statistics, and so findings aren't representative. However, as the data was collected through face-to-face engagement, more detailed experiences have been gathered, and patterns and trends have still emerged from the responses.
- A disproportionate amount of responses have been from white females, with only nine 'male' respondents. This obviously isn't representative of the target population of those living with arthritis; it should be understood that the research findings therefore may not be relevant to those of a different gender and/or ethnicity. This is therefore something that may be targeted in future local research about arthritis.

Answering the Survey

- Many people would mention how they had arthritis but how they didn't need to fill in a survey as they 'just got on with it'. This was a common attitude among the older people we engaged with, and it was often seen as an age-related issue.

- Some participants at the JCUH Arthritis Support Group had been diagnosed at a young age and therefore found the survey quite difficult to complete; they could no longer remember what information they had been given, or their parents had received the information.

The Younger Age Group

- It was made clear that those of a younger age also live with arthritis; and for them, it isn't something they can "just get on with". People felt that a gap existed in the care and support for young people (specifically osteoarthritis), going on to say that they are often left out of services and of considerations. As a result of this intelligence, this may be an area of future exploration for Healthwatch South Tees.

Fighting Arthritis with Exercise



When the pain in Mervyn’s hip got worse, he began to struggle with everyday tasks, and could no longer ride his bike. He began to rely on his walking stick, struggled with the inactivity and the pain - he felt miserable. This was a big change as he was used to being active.

Mervyn “**hit a really low point**” with his pain, even strong painkillers prescribed by his GP weren’t helping anymore. He discussed surgery with his doctor, where more exercise was discussed to reduce his BMI to help with his recovery post-op. He was prescribed ‘exercise through referral’, so twice a week he started attending his local Everyday Active leisure centre and received personal, tailored training from one of the instructors.

Initially, Mervyn thought “**exercise is the last thing I want to be doing with this level of pain**”. The first time he attended, he felt exhausted just from taking the stairs at the centre even with his stick, the handrail and help from his instructor.



He only managed four minutes on the walker and ten minutes on the bike and used some of the resistance bands. The pain was still a problem and he continued to need painkillers to get through it, but he persevered. Through regular attendance, he built up his fitness and strength

which reduced his pain and he can now do an hour and a half at the gym twice a week!
“I can’t believe the difference from the first session just from doing two sessions a week”.

Mervyn spoke very highly of the staff at the leisure centre, particularly his instructor, explaining how “he’ll always make time to look after you and check you’re doing it properly”.

Mervyn’s instructor tailored his exercise routine, strengthening muscles around his hip, ensuring no added pressure is applied. Mervyn has also learnt how to improve his posture and different exercises that he can do at home to help further.



Mervyn has experienced many benefits from regularly exercising:

- lost two stone
- no longer needs help getting out of chairs
- can easily take the stairs
- feels stronger and fitter
- no longer needs his stick
- has reduced his medication

This has motivated him to continue as he realises exercise has changed his life the better.

Middlesbrough GP Referral Programme
Val Jones - Exercise Referral Co-ordinator
e-mail: val_jones@middlesbrough.gov.uk
phone: 01642 515615

Redcar & Cleveland GP Referral Scheme
Ian Hall - GP Referral Co-ordinator
e-mail: ianhall@everyoneactive.com
phone: 07803019041 / 01642 771070

#HaveYourSay - Share your Arthritis Experience

1) How old were you when you were diagnosed with arthritis?

2) When first told of your diagnosis, what information were you given?

- General information about the condition How to self-manage / self-care
 Medication

- Exercising with arthritis Support groups Natural remedies and supplements

Other

No information given

b) Did you find this information useful, and can you explain why / why not?

c) How well did you understand the information given to you?

- Very well Quite well Not very well Not at all

d) How could this have been improved for you?

e) What further information would you have liked to receive?

3) How were you given information about your arthritis condition?

- Verbally Written Signposted to information on website None given

Other

b) Was this the best way for you to receive information?

- Yes, I was satisfied
 No, I would have preferred:

4) When discussing your treatment, what options were you given?

No options given Drugs Supplements Surgery

Hydrotherapy Occupational therapy Aids and adaptations for the home

Support groups Other

b) Were you satisfied with the options you were given?

Yes

No; Why not?

c) Did you feel involved in your treatment plan?

Most definitely

To an extent

Not really

Not at all

d) How could this have been improved for you?

5) Have you been satisfied with the care and support you have received?

Most definitely

To an extent

Not really

Not at all

b) Can you explain why?

**6) In comparison to when you were first diagnosed, do you now feel:
(tick those that apply)**

Better supported to live with arthritis?

More in control of your arthritis?

More informed about arthritis?

None of the above.

b) Since your diagnosis, have you tried anything that has particularly helped you to feel better supported, more in control *and/or* more informed?

Further research on self-help Anti-inflammatory diet and healthy eating

Exercise Losing weight Natural remedies and supplements

Massages Heat and cold therapies Support group

Other

Haven't tried anything Nothing has helped

7) If you can, please list three things / services that work well for you in your care that you would recommend to others living with arthritis:

8) If you could change one thing about your care and support, what would it be and why? (e.g. shorter waiting times, alternative treatments, regular check-ups, support groups, etc)

Thank you for taking the time to complete our questionnaire today.

Please answer as many of these questions as you can - this will help us better understand how people's experiences, requirements and preferences may differ depending on their personal characteristics.

Name:

Gender:

Age: Under 18 18 - 34 35 - 50 51 - 54
 55 - 60 61 - 64 65 - 69 70 +

Ethnicity:

Do you have a disability or any additional long-term health conditions?

No
 Yes



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