



ARTHRITIS CARE

*Empowering
people with arthritis.*

ARTHRITIS HURTS

The hidden pain of arthritis

Summary of the findings of Arthritis Care's pain survey 2010

ABOUT ARTHRITIS CARE

Arthritis Care is the UK's leading charity working with and for people with all forms of arthritis. We offer people with arthritis the information and support they need to make informed choices about managing their arthritis, to reach their potential in society and to fully participate in their communities.

We believe that people with arthritis are entitled to receive the best available treatment and medication, and to have their voice heard in decisions affecting their health.

One quarter of a million people are actively engaged with Arthritis Care throughout the UK. Our free and confidential helpline service reaches 12,500 people every year¹, while our homepage has approximately 60,000 visitors a month, our online forum has 14,303 members², and our Facebook and Twitter accounts have 1,318³ and 203⁴ followers respectively.

BACKGROUND TO THE SURVEY

The present survey is the most comprehensive survey of people with all forms of arthritis in the UK focusing on their pain.

Arthritis is the biggest cause of physical disability in the UK⁵, affecting up to 10 million people⁶, including 12,000 children⁷, and accounting for 30% of GP visits⁸. It carries a huge economic as well as human and social cost, estimated at £7 billion annually in terms of lost labour in 2007⁹. It is the most common cause of chronic pain in the UK¹⁰ with pain being the most common symptom of living with arthritis¹¹.

An average of 85% of contacts to the Arthritis Care helpline are about pain¹². Around 5,150 people per year receive information about pain management via the helpline¹³.

While we know pain affects the majority of people living with arthritis in the UK¹⁴, Arthritis Care wanted to ask people how their pain affects them in their everyday life in order to raise public awareness of this during Arthritis Care Week 2010. The results will be used to provide more information to people with arthritis who live with pain everyday, and to help those treating people living with pain to better understand the issues people with arthritis face in their daily lives.

METHODOLOGY

The online survey was promoted from 24 March to 5 April 2010 to Arthritis Care supporters via the charity's website home page, social networking outlets and via its online discussion forum. An email was sent directly to 14,776 Arthritis Care supporters living with arthritis inviting them to take part in the survey.

A total of 2,263 surveys were analysed.

KEY FINDINGS

The survey shows that a majority of respondents are putting up with severe levels of pain on a regular basis.

The survey indicates that many people feel unable to consult their GP or specialist to discuss how to lessen the pain they experience on a day to day basis. This means that when pain is at its most severe:

- 65% of respondents have difficulty making a cup of tea
- 58% of respondents have difficulty making the bed
- 63% of respondents have difficulty having sex
- 65% of respondents have difficulty having a hug
- 77% of respondents are unable to sleep through the night.

These figures indicate that people are having to endure significant limitations on everyday life due to unmanaged pain.

RESULTS

Profile of respondents

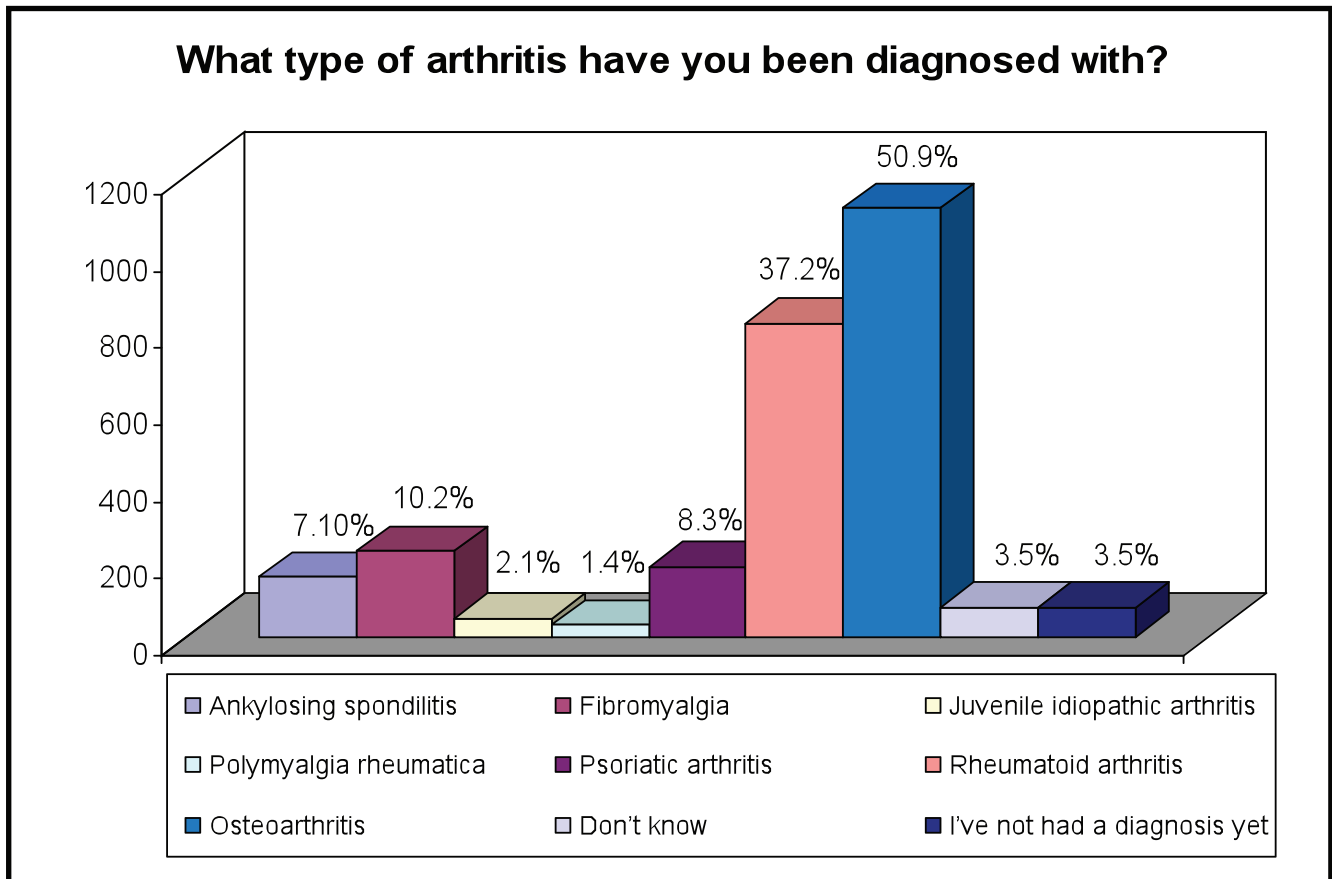
Out of the 2,263 responses collected:

- 78.7% were female and 21.3% male
- most of the participants were White British (89.3%)
- the greatest age range was 45-64, equating to 59.7%
- most were of working age (82%)
- there were more male participants in the 65+ age range (26.61%) than female (14.37%)
- there were more females in the 35-44 age range (15.71%) than male (10.6%)
- 80% of participants were English, 9.86% Scottish, 5.08% Welsh and 3.14% from Northern Ireland.

Type of arthritis

- Just over half (50.9%) of the participants had osteoarthritis (OA) and 37.2% rheumatoid arthritis (RA) (graph 1).
- Of those, 174 stated they had both conditions (7.92%).
- There were fewer female participants with ankylosing spondylitis (AS) than male (6% and 10.2% respectively).
- There were more people over the age of 65 years living with OA.

Graph 1



Diagnosis

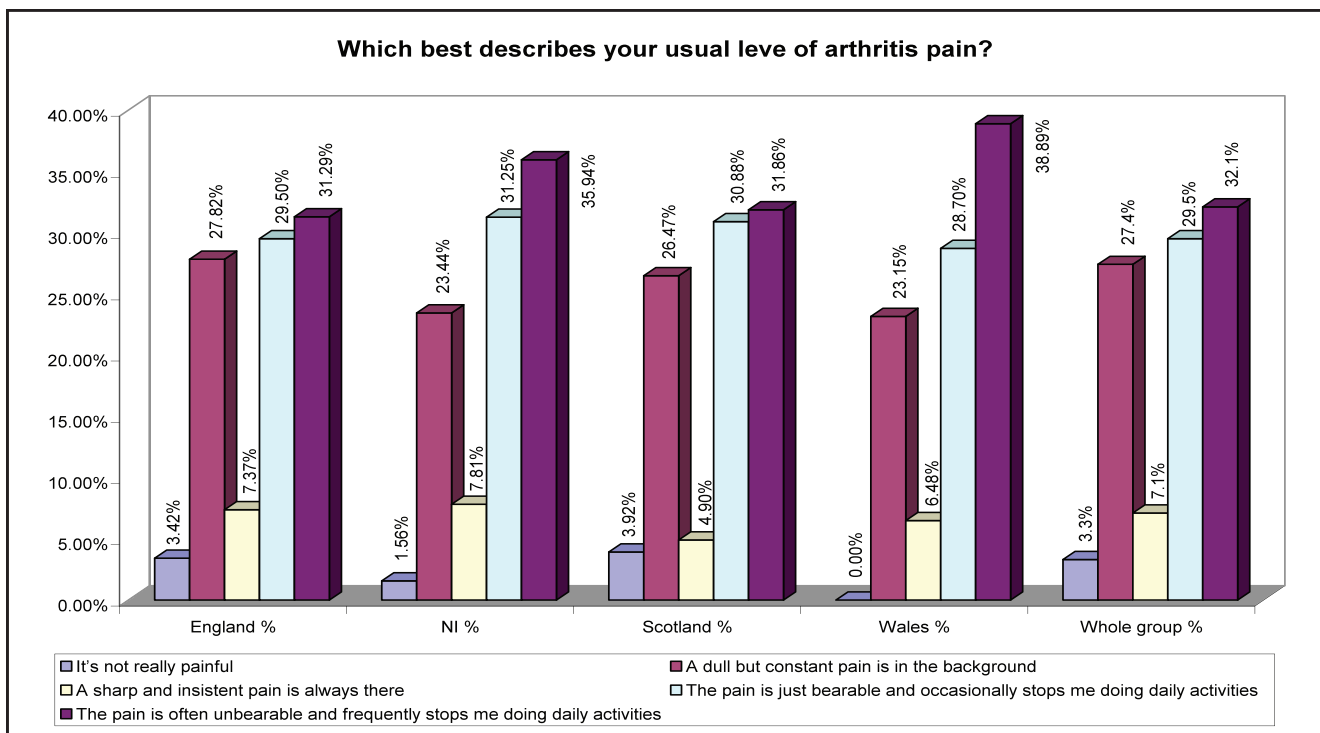
Participants were asked how long ago they experienced their first symptom of arthritis and how long ago they were diagnosed. A large number of respondents (63.45%) had their first symptom 6 years or more ago, with 12.8% experiencing this more than 25 years ago.

Our analysis showed a 4.07 year delay in diagnosis on average. The length of time it took the person to visit a healthcare professional must be taken into consideration when looking at this result.

Arthritis pain

A large amount of respondents (32.1%) described their everyday pain to be often unbearable (graph 2) which frequently stops them from doing daily activities. There was no significant difference across the UK in terms of the most common level of arthritis pain.

Graph 2

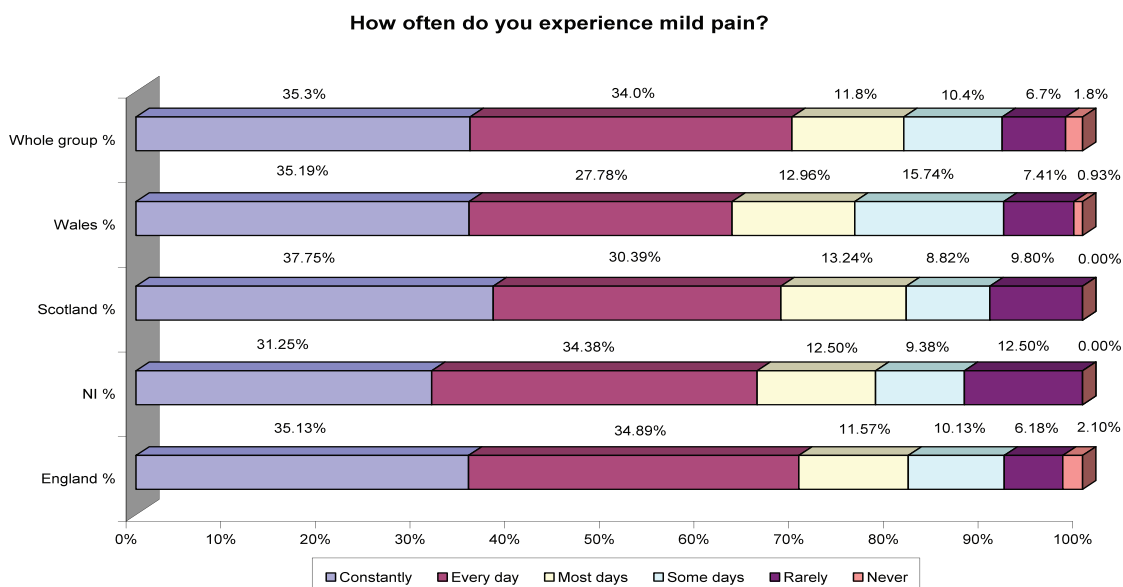


The respondents were asked how often they experience mild, moderate and severe pain. 69.3% said they lived with mild pain every day, 42.8% with moderate pain every day and 19.6% with severe pain every day.

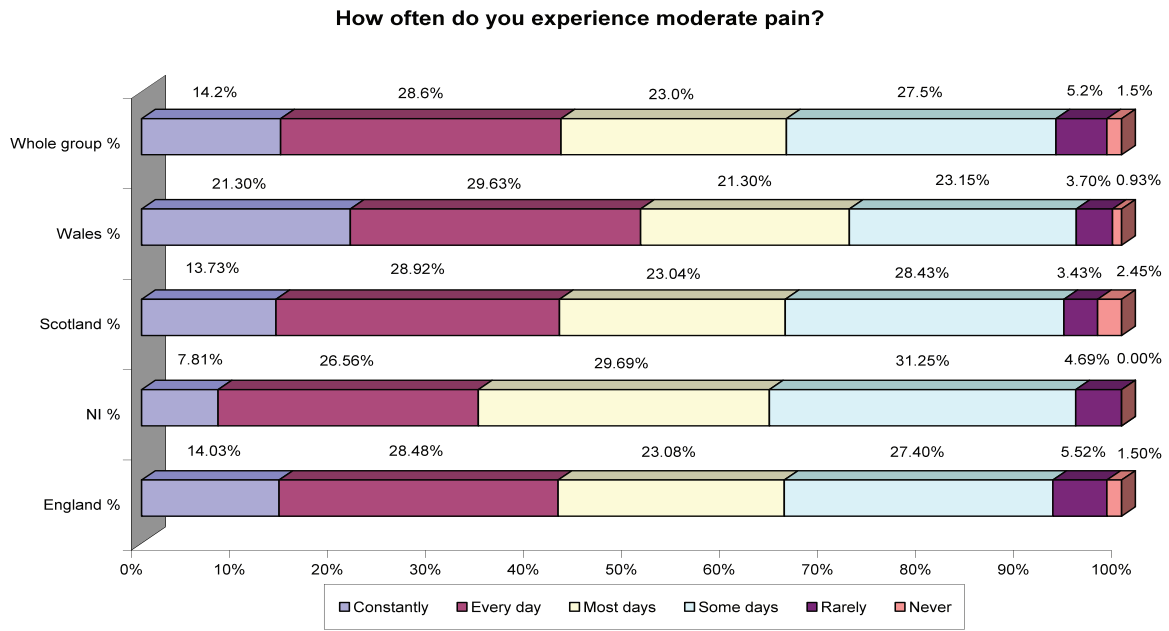
“ It has made me an old woman prematurely and I feel very dependent on others, when previously I was a very capable person.”

There was no significant difference between male and female or which country you live in when asked about mild, moderate and severe pain, although more respondents from Wales experienced severe pain constantly and every day than in other parts of the UK. More people with OA stated they experience severe pain every day than those with RA.

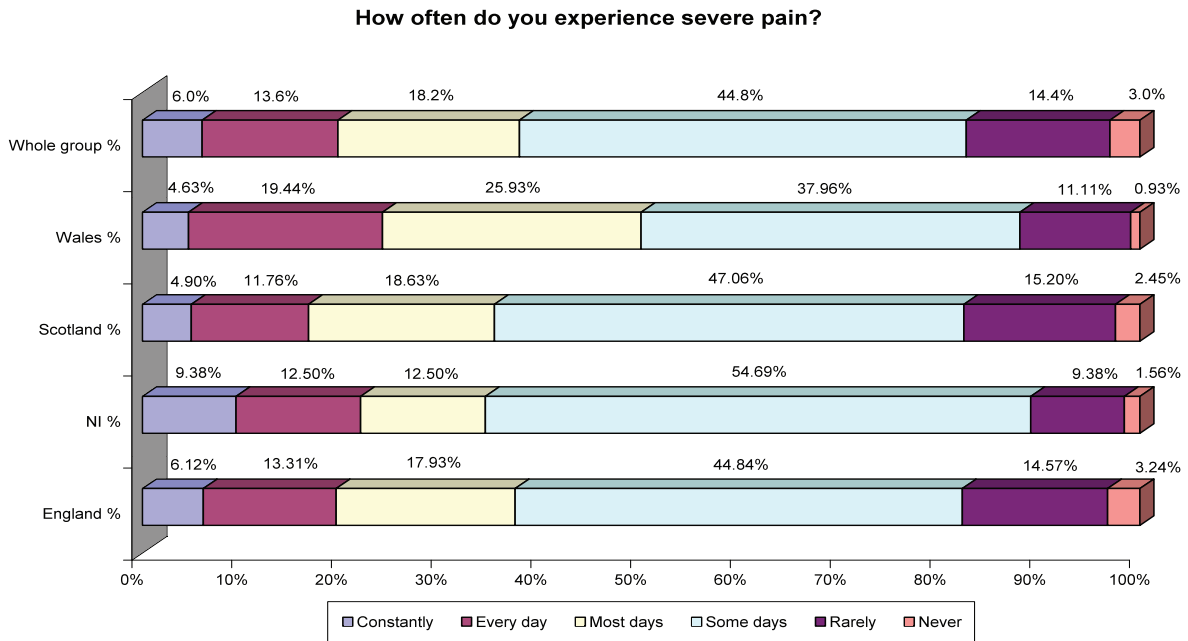
Graph 3



Graph 4



Graph 5



**The respondents were asked to answer all three questions*

Over half the group (56.7%) stated they would not visit their doctor or specialist about pain until it was ‘unbearable and frequently stopped them from doing daily activities’.

This indicates that people are suffering in silence with their pain by not seeing a doctor until they reach crisis point.

We asked all the participants a number of questions about how arthritis pain affects their lives. In line with how they described their everyday pain, a large amount had difficulty carrying out the simplest but important daily activities (Graph 6, table 1). These questions were multiple choice.

Graph 6

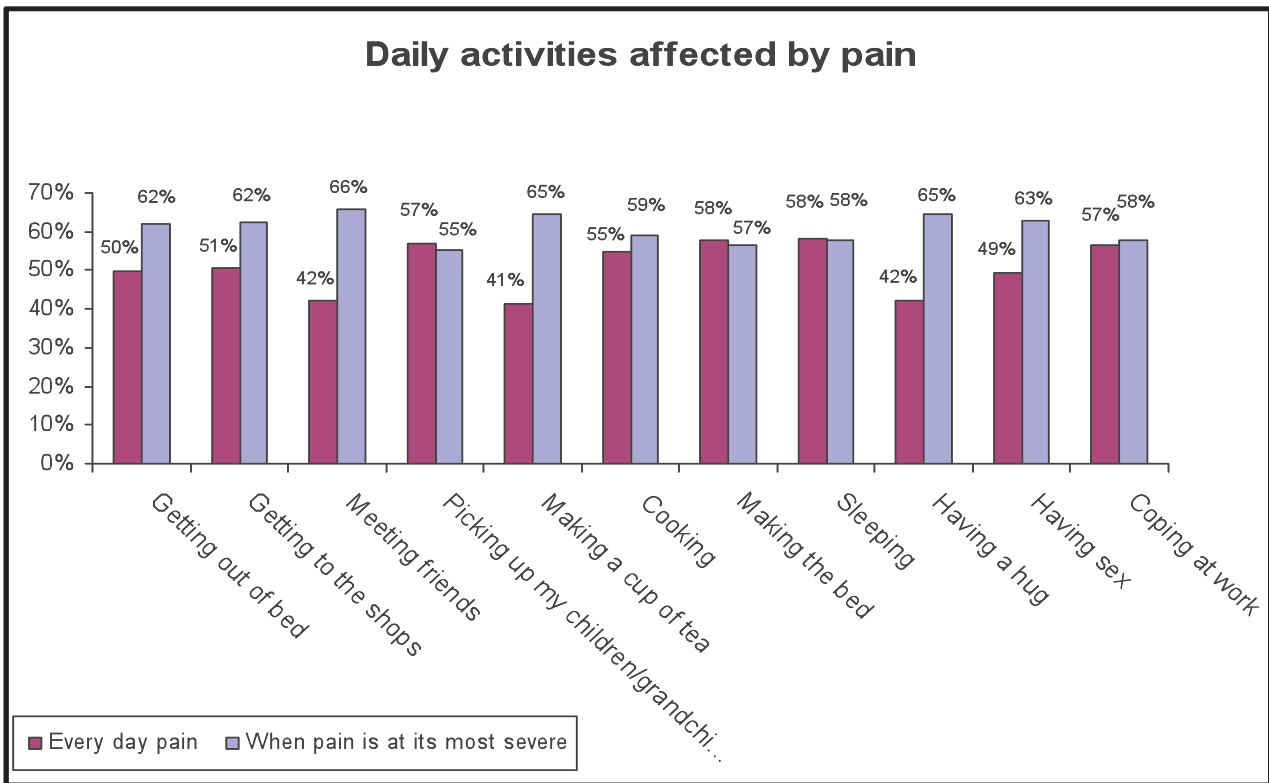


Table 1

Does your every day or most severe pain cause you difficulty carrying out any of the following activities? [Please tick all that apply] (All age ranges)	Everyday pain	When pain is at its most severe
Getting out of bed	723	903
Getting to the shops	780	962
Meeting friends	536	840
Picking up my children/grandchildren/cat	642	623
Making a cup of tea	436	682
Cooking	747	801
Making the bed	864	847
Sleeping	964	954
Having a hug	395	604
Having sex	562	715
Coping at work	611	625
None of the above	105	64
Other	137	122

When the whole group was asked about what pain prevents them from doing, a large number said sleeping through the night (70%), and nearly 50% said it prevents them from working (graph 7- whole group).

“ My life has been taken away from me, it dominates my everyday thoughts and makes me feel so unwell all the time. There is hardly ever a good day, only bad days. ”

Graph 7

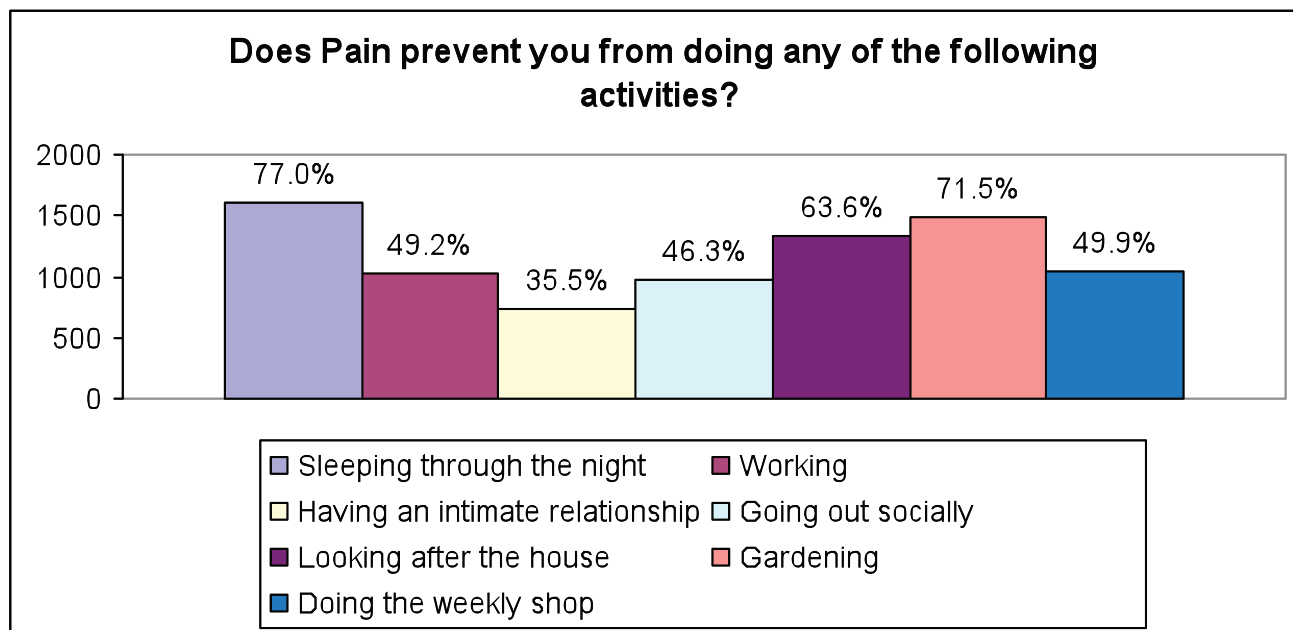


Table 2

Does pain prevent you from doing any of the following activities [please tick all that apply]	Count	%
Sleeping through the night	1609	77.0%
Working	1028	49.2%
Having an intimate relationship	741	35.5%
Going out socially	967	46.3%
Looking after the house	1328	63.6%
Gardening	1494	71.5%
Doing the weekly shop	1043	49.9%
Other	238	11.4%
Skipped question	174	7.70%
TOTAL	2263	100%

Table 3

Does pain prevent you from doing any of the following activities [please tick all that apply]	England %	NI %	Scotland %	Wales %	Whole group %
Sleeping through the night	44.9%	52.1%	45.29%	50.43%	77.0%
Working	32.1%	40.8%	32.29%	39.13%	49.2%
Having an intimate relationship	41.2%	54.9%	45.74%	50.43%	35.5%
Going out socially	58.3%	67.6%	57.85%	66.09%	46.3%
Looking after the house	67.1%	62.0%	61.43%	70.43%	63.6%
Gardening	45.5%	49.3%	48.43%	54.78%	71.5%
Doing the weekly shop	10.5%	8.5%	9.42%	11.30%	49.9%
Other	13.4%	11.3%	13.45%	15.65%	11.4%
TOTAL that answered the question	313.0%	346.5%	313.90%	358.26%	404.4%
TOTAL	100%	100%	100.00%	100.00%	100.00%

A high percentage of respondents had problems looking after the house (63.6%) and over 70% stated their arthritis pain prevents them from being able to do gardening. A large number reported that pain prevented them from doing more than one activity.

“ Some days putting my feet to the ground takes a lot of courage as I know the pain in my feet will be unbearable. ”

“ I feel exhausted, down, forgotten, guilty, missing out on life. ”

24.3% of respondents said that people close to them do not understand what they are going through, and 57.9% said they regularly hide their pain from them.

Graph 8

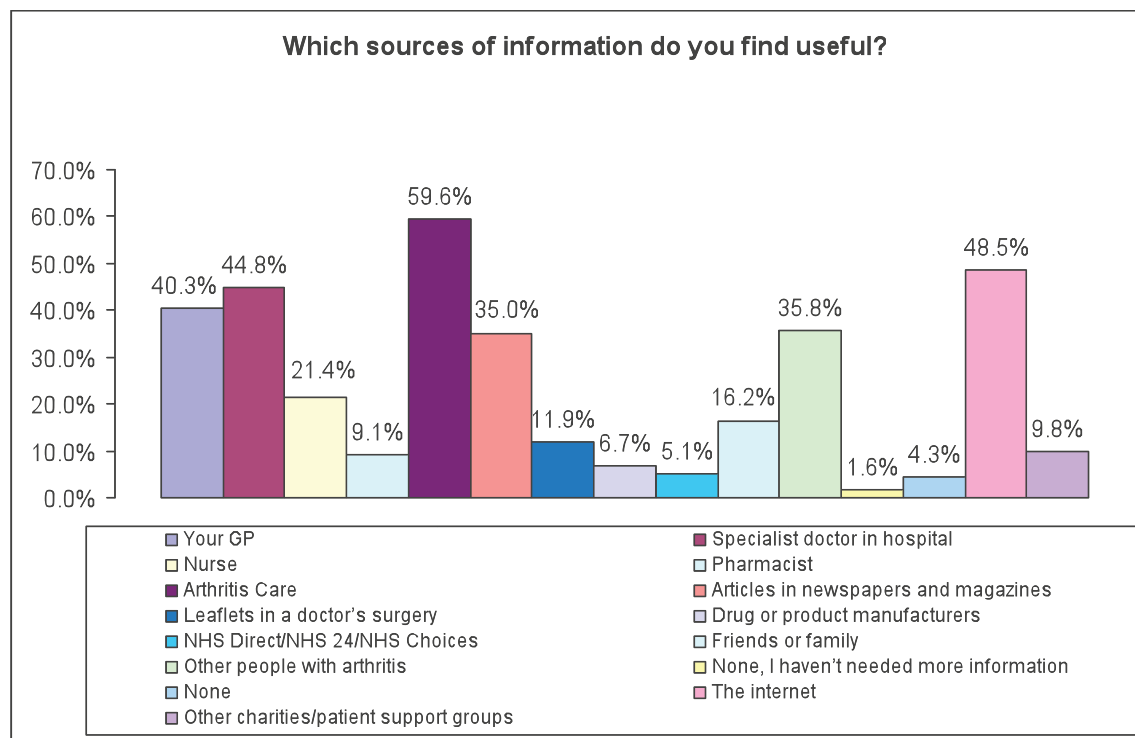


Table 4

Which of the following sources of information have you found useful? [Please tick all that apply]	Count	%
Your GP	842	40.3%
Specialist doctor in hospital	935	44.8%
Nurse	447	21.4%
Pharmacist	191	9.1%
Arthritis Care	1246	59.6%
Articles in newspapers and magazines	731	35.0%
Leaflets in a doctor's surgery	248	11.9%
Drug or product manufacturers	141	6.7%
NHS Direct/NHS 24/NHS Choices	107	5.1%
Friends or family	338	16.2%
Other people with arthritis	748	35.8%
None, I haven't needed more information	34	1.6%
None	90	4.3%
The internet	1014	48.5%
Other charities/patient support groups	204	9.8%
Skipped question	174	7.70%
TOTAL	2263	100%

Graph 8 shows which sources of information people have found useful. Many participants (59.6%) said that Arthritis Care provided them with valued support. The internet's popularity is evident but the GP and specialist consultant remain trusted deliverers of information. More people under the age of 65 years relied on their specialist doctor in the hospital than those over the age of 65 (an 11% difference).

CONCLUSIONS

Arthritis Care's survey shows that arthritis pain causes significant difficulties for a large number of respondents and limits their ability to live life as fully as possible or to conduct many everyday activities. This includes sleeping through the night, working or having an intimate relationship.

Nearly all respondents, regardless of age, gender, nationality or type of arthritis, said that they lived with at least mild pain every day, with many describing their everyday pain as severe.

The survey results show that many people living in chronic pain are waiting a long time to see a health professional since the onset of symptoms, leading to a delay in diagnosis and treatment. This can result in the condition getting worse. This can lead in turn to an aggravation of the pain, deformities, increased operations and time off work. Greater awareness of arthritis and the importance of seeking prompt medical attention would lead to earlier interventions and would therefore significantly mitigate this situation.

The fact that a greater number of people with OA said that they experienced pain every day than people with RA may be attributable to the greater effectiveness of currently available treatment for RA in particular, but it also suggests that people with RA are more closely monitored than people with OA.

A large number of respondents rated the information and support they received from Arthritis Care very highly, suggesting that there is significant value in health professionals signposting their patients to additional support from charities such as Arthritis Care.

To the extent that GPs in particular are the first port of call for most people wishing to see a doctor, it is important that they are alert to – and able to – quickly identify the symptoms of arthritis-related pain, and promptly refer patients for specialist treatment and/or to organisations such as Arthritis Care for additional support.

RECOMMENDATIONS

1. **Members of the public experiencing chronic or recurring pain** should:
 - a. avoid suffering in silence and visit a health professional
 - b. seek other sources of accredited information such as via Arthritis Care's free and confidential helpline.
2. **Governments across the UK** should:
 - a. promote greater awareness of the need that people experiencing chronic or recurring pain should visit a health professional without undue delay
 - b. ensure that the training for health professionals around arthritis, musculoskeletal conditions and chronic pain is adequate
 - c. develop a national database of arthritis and chronic pain-related cases.
3. **Health professionals** should:
 - a. be especially alert to symptoms of arthritis-related pain in their patients
 - b. regard pain as the 5th vital sign*
 - c. take a 'whole person' approach to diagnosis and prognosis for the effective treatment for arthritis-related pain, based on what patients themselves say they have difficulty doing as a result of their pain
 - d. signpost patients with symptoms of arthritis-related pain to Arthritis Care and other voluntary organisations for additional information and support, including information on how they can better self-manage.

*The four widely recognised vital signs are blood pressure, pulse, respiration and temperature

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