



## Arthritis Hurts

### The emotional impact of arthritis pain

#### Executive Summary

Depression is a significant but often neglected effect of arthritis.

Three in five (68%) people with arthritis who responded to Arthritis Care's pain survey said they feel depressed when their pain is at its worst. This has a significant impact on their quality of life, and places a greater demand on health services.

Arthritis Care's survey results indicate that the emotional impact of living with arthritis pain is not being given sufficient attention.

50% of respondents said they felt helpless as a result of arthritis-related pain. This figure rises to 67% among 18-34 year-olds, most of whom said that the pain also stopped them from going out socially. 40% of respondents said that they used relaxation techniques to deal with their pain, while 29% said it helped talking to someone else with arthritis. 21%, however, said that nothing makes them feel better when they are in pain. A significant 81% said that people close to them did not understand their pain.

There is much that can be done to mitigate the emotional and psychological impact of arthritis. Medication where clinically advised, coupled with pain self-management programmes, can substantially reduce the severity of depression as well as enhance response and remission rates for people with musculoskeletal pain. This can also result in moderate reductions in both pain severity and pain-related disabilities.

The impact of psychological interventions is not limited to pain and physical function, but can be experienced as improvement in psychological well-being and overall quality of life.

People with arthritis need to be supported by their GP and/or rheumatology specialist to manage the emotional impact of arthritis. In particular, more should be done to help avoid the onset of depression due to unmanaged pain. People with arthritis should be supported to self-manage, for example through exercise and healthy eating, and referral to organisations like Arthritis Care.

## Arthritis Hurts

### Emotional Impact of Arthritis Pain survey report – January 2011

#### Background

Arthritis is the biggest cause of physical disability in the UK [1], affecting up to 10 million people [2], including 12,000 children [3], and accounting for 30% of GP visits [2]. It is the most common cause of chronic pain in the UK [4], with pain being the most common symptom of living with arthritis [5].

Of the average 11,000 annual contacts to the Arthritis Care helpline, around 85% are about pain [6]. At the beginning of the year, this level can be as high as 95%, especially in January, when people are feeling low after the holidays and less mobile because of inclement weather. Around 5,150 people per year receive information about pain management via the helpline [7].

The main topics of discussion with the Arthritis Care helpline team regarding pain are about medical treatments, emotional support and managing arthritis [6]. Arthritis Care wanted to ask people with arthritis about how pain affects them to improve services to help support them to better manage their arthritis pain.

The first report from the survey, *Arthritis Hurts – The Hidden Pain of Arthritis* published in 2010 [8], highlighted the everyday impact of pain on people's lives. This report publishes new data about the impact of arthritis pain on people's emotional wellbeing.

#### Methodology

The online survey was promoted in 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

When their arthritis pain is at its worst:

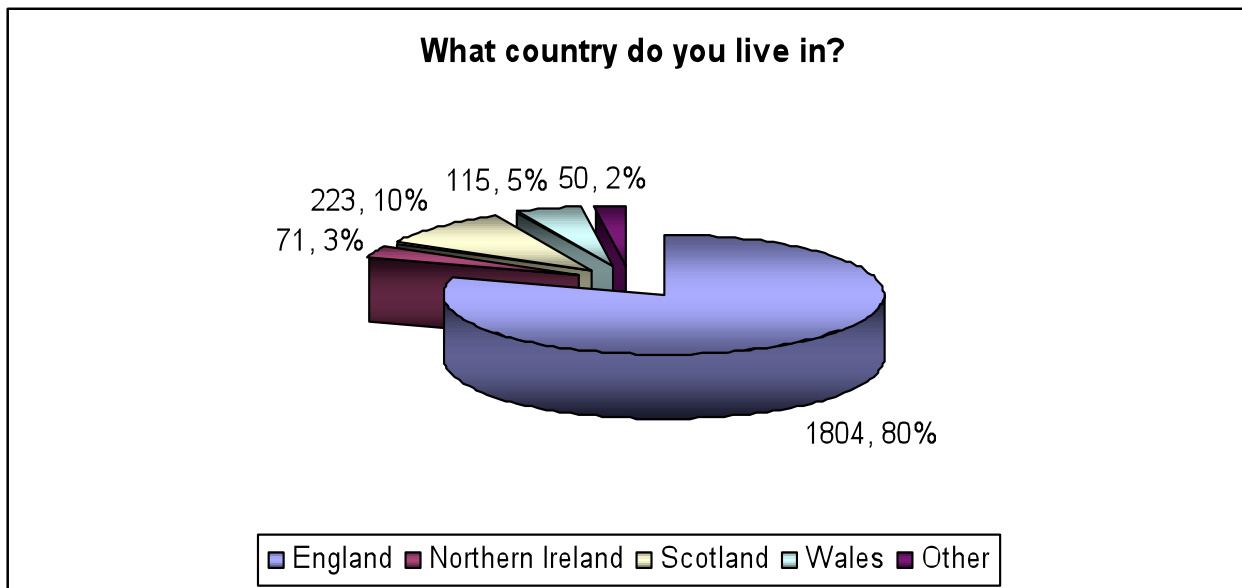
- 68% of respondents feel depressed
- 81% of respondents feel tired
- 50% of respondents feel helpless
- 85% of respondents feel people close to them don't understand their pain.

#### Results

Out of the 2,263 surveys collected, 1,782 (78.7%) of respondents were female, 481 were male. Most of the participants were White British (89.3%). The greatest numbers of respondents were between 45-64 years, equating to 59.7% but most were of working age (82%).

There were more male participants in the 65+ age range (26.6%) than female (14%) and more females in the 35-44 age range (15.71%) than male (10.6%). 80% (1,804) of participants were from England, 9.8% (223) Scotland, 5.1% Wales (115) and 3.1% (71) from Northern Ireland (Graph 1).

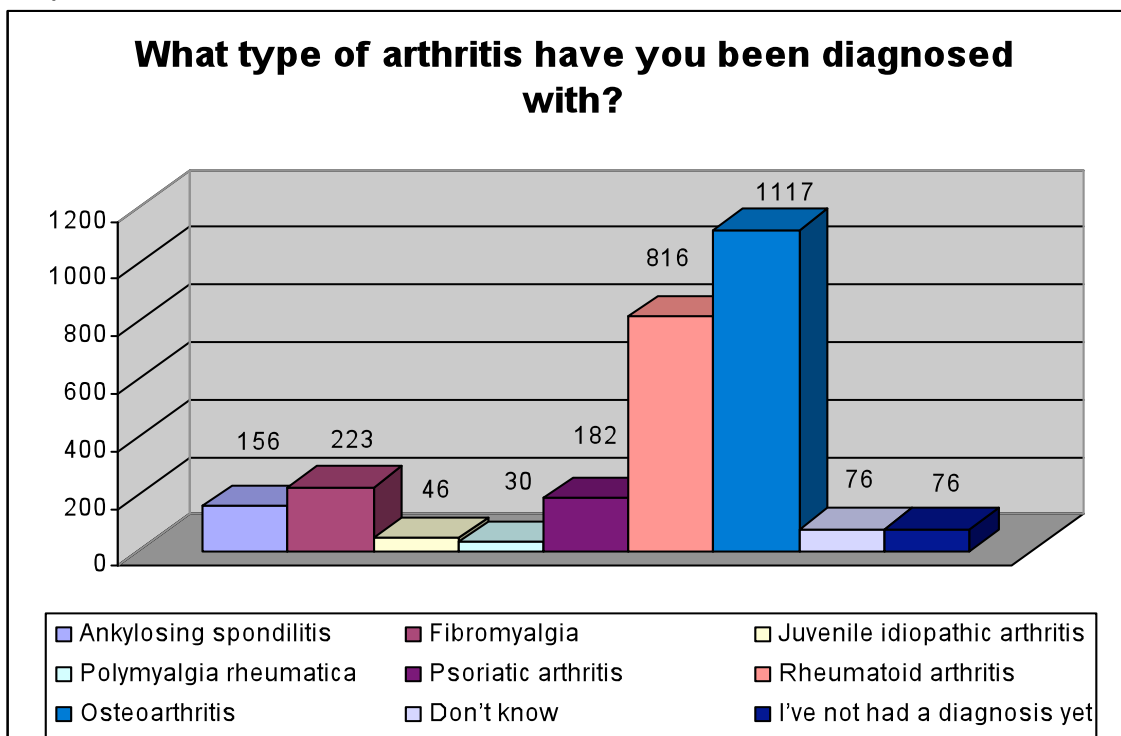
Graph 1



Type of arthritis

Just over half (50.9%) of the participants had osteoarthritis (OA) and 37.2% rheumatoid arthritis (RA) (Graph 2). Of those, 7.92% stated they had both conditions. There were fewer female participants with ankylosing spondylitis (AS) than male (6% and 10.2% respectively) and more people over the age of 65 years living with OA. See Graph 2 for the types of arthritis the respondents were diagnosed with.

Graph 2



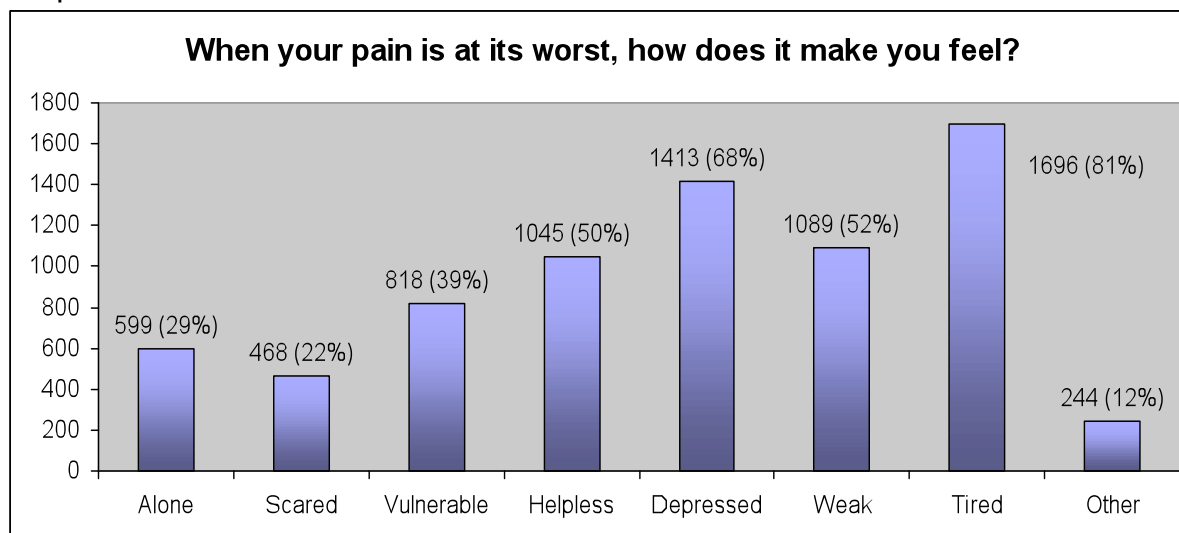
Emotional impact of arthritis pain

One in four of all people in the UK will live with depression at some point in their lives. It can be an often neglected effect of arthritis [9].

Of all the respondents to the Arthritis Care survey, 67.6% of participants stated that their arthritis pain, when at its worst, makes them feel depressed, 50% felt helpless, 52.1% weak and 81.2% tired (Graph 3).

It should be noted that in this survey we did not ask about a formal diagnosis of depression but did ask whether arthritis pain, when at its worst, made the participant feel depressed. We also asked questions about the emotional impact of their pain and how they deal with it.

Graph 3



In this study, more females than males (65% female vs 53% male) stated that their arthritis pain, when at its worst, made them feel depressed. Fewer men felt alone (29% women vs 16% men) or scared (24% vs 9%).

Arthritis Care's survey found that slightly more people with RA stated they felt depressed than with OA (67% RA vs 61% OA), and more people in Scotland felt vulnerable than in England, Northern Ireland or Wales, but fewer people in Scotland felt depressed (Table 1).

Table 1

| When your pain is at its worst, how does it make you feel? [Please tick all that apply] | England % | NI % | Scotland % | Wales % | Whole group % |
|---|-----------|------|------------|---------|---------------|
| Alone   | 26%       | 31%  | 23%        | 32%     | 29%           |
| Scared  | 21%       | 27%  | 18%        | 24%     | 22%           |
| Vulnerable  | 35%       | 35%  | 39%        | 45%     | 39%           |
| Helpless  | 47%       | 45%  | 43%        | 50%     | 50%           |
| Depressed   | 63%       | 66%  | 57%        | 66%     | 68%           |
| Weak  | 48%       | 54%  | 50%        | 50%     | 52%           |
| Tired   | 75%       | 70%  | 78%        | 81%     | 81%           |

It has been reported that people with RA are twice as likely than those with no arthritis at all to experience depression but are unlikely to talk to a doctor about it [10]. Depression can affect a person's adherence to treatment regimens [11].

943 of respondents to Arthritis Care’s survey were living with OA and 642 with RA. On the whole, the RA group seems to be more affected emotionally by their arthritis pain than the OA group (Table 2).

Table 2

| <b>When your pain is at its worst, how does it make you feel? [Please tick all that apply]</b> | <b>OA</b> | <b>RA</b> | <b>% OA</b> | <b>% RA</b> |
|--|-----------|-----------|-------------|-------------|
| Alone  | 224       | 212       | 23.8%       | 33.0%       |
| Scared   | 191       | 162       | 20.3%       | 25.2%       |
| Vulnerable   | 345       | 267       | 36.6%       | 41.6%       |
| Helpless   | 415       | 351       | 44.0%       | 54.7%       |
| Depressed  | 579       | 428       | 61.4%       | 66.7%       |
| Weak   | 413       | 363       | 43.8%       | 56.5%       |
| Tired  | 705       | 526       | 74.8%       | 81.9%       |

There were 180 (8%) 18-34 yr olds in our study. 67% of this young group felt depressed, 61% felt weak and 80% felt tired when their arthritis pain is at its worst.

More women than men stated that their arthritis pain stopped them from going out socially (64% vs 40%) (Table 3).

51% of our younger participants (18-34 yr old group) stated their arthritis pain stopped them from going out socially.

Table 3

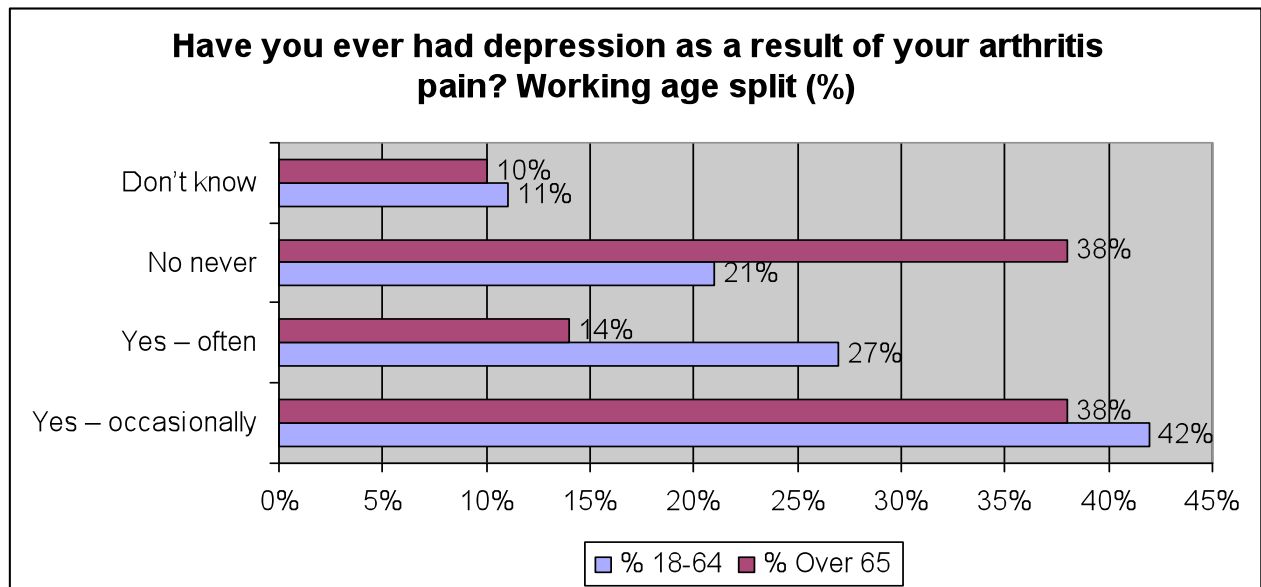
| <b>Does pain prevent you from doing any of the following activities [please tick all that apply]</b> | <b>Male</b> | <b>Female</b> | <b>% Male</b> | <b>% Female</b> |
|--|-------------|---------------|---------------|-----------------|
| Sleeping through the night   | 219         | 809           | 45.5%         | 45.4%           |
| Working  | 148         | 593           | 30.8%         | 33.3%           |
| Having an intimate relationship  | 177         | 790           | 36.8%         | 44.3%           |
| Going out socially   | 193         | 1135          | 40.1%         | 63.7%           |
| Looking after the house  | 297         | 1197          | 61.7%         | 67.2%           |
| Gardening  | 165         | 878           | 34.3%         | 49.3%           |
| Doing the weekly shop  | 50          | 188           | 10.4%         | 10.5%           |
| <b>TOTAL</b>   | <b>481</b>  | <b>1782</b>   | <b>100%</b>   | <b>100%</b>     |

We also asked whether the participants had ever had felt depressed as a result of their arthritis pain and a total of 1,362 (65.2%) stated Yes-occasionally or Yes-often. These results correlate with the previous question – When your pain is at its worst, how does it make you feel, where 68% ticked the depressed option.

More people in Northern Ireland often feel depressed as a result of their arthritis pain than in Scotland (33% NI vs 22% Scotland).

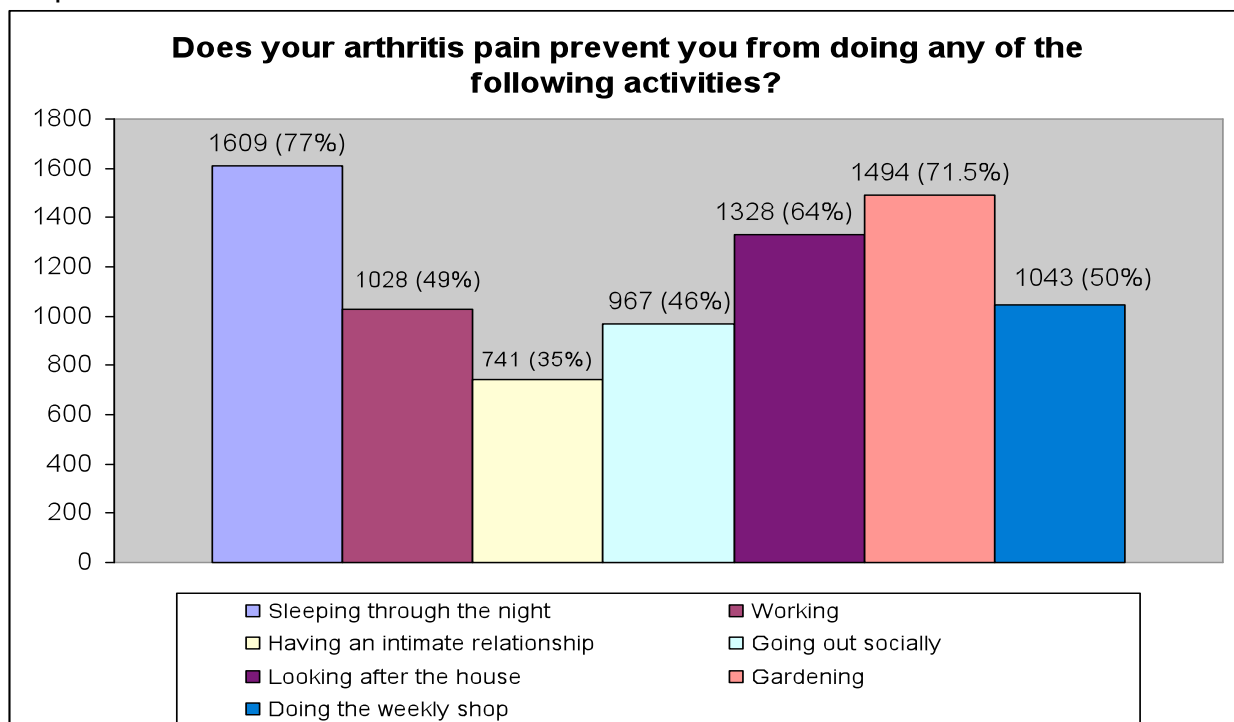
In this study 1,863 (82%) were of working age (between 18-64yrs). People over the age of 65 seemed to have less depression than those who were of working age – 38% stated they'd never had depression as opposed to 21% in the working age group (Graph 4).

Graph 4



A high number of participants (77%) said that their arthritis pain prevented them from sleeping through the night and 741 (35.5%) stated this pain prevented them from having an intimate relationship (Graph 5).

Graph 5



There weren't many differences between men and women with regard to their everyday pain or severe pain causing difficulties with these activities (Table 3).

Nearly 50% (1,016) of the whole group said that ‘talking to someone close to you’ made them feel better about their arthritis pain. However only 14.8% said that the people close to them really understood how this pain affected them.

It has been documented that talking things through with family and friends may be one of the most valuable strategies we have to help us to deal with our state of mind [9].

This study found that men and women deal with their arthritis pain slightly differently. More women than men felt that talking to someone close to them or someone with arthritis helped them to feel better about their pain.

However it can be noted that the trends are more or less the same.

Of the whole group, 814 (40%) used relaxation techniques, and 29% said it helped talking to someone else with arthritis. 21% said the nothing makes them feel better about this pain.

Nearly 60% of participants stated that they found Arthritis Care as a source of useful information and 44.8% stated this for their specialist doctor (Table 4).

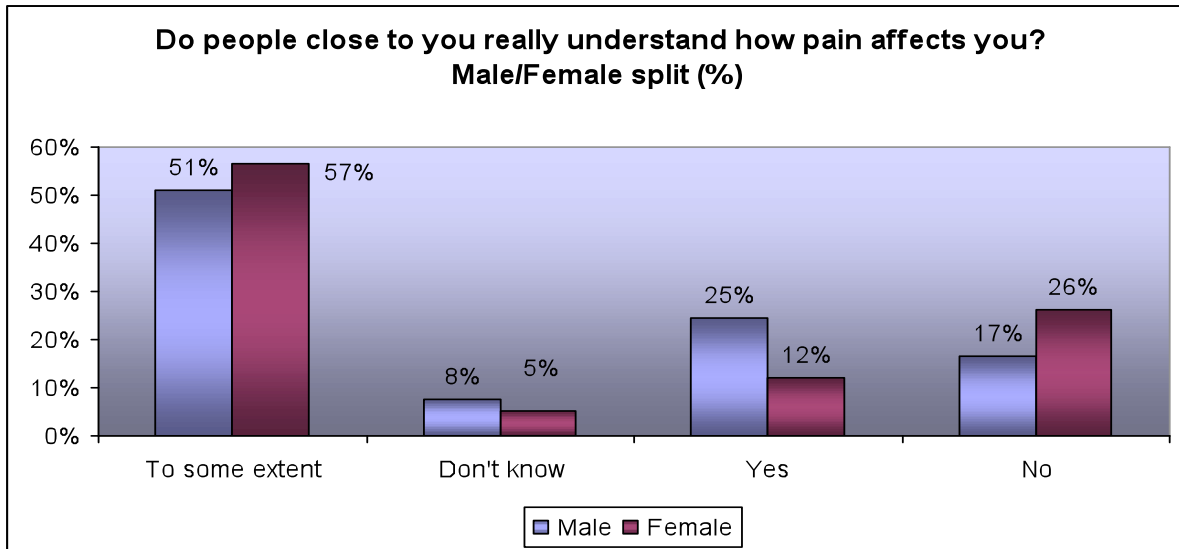
Table 4

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

There were differences between men and women when it comes to people close to them really understanding how the pain affects them.

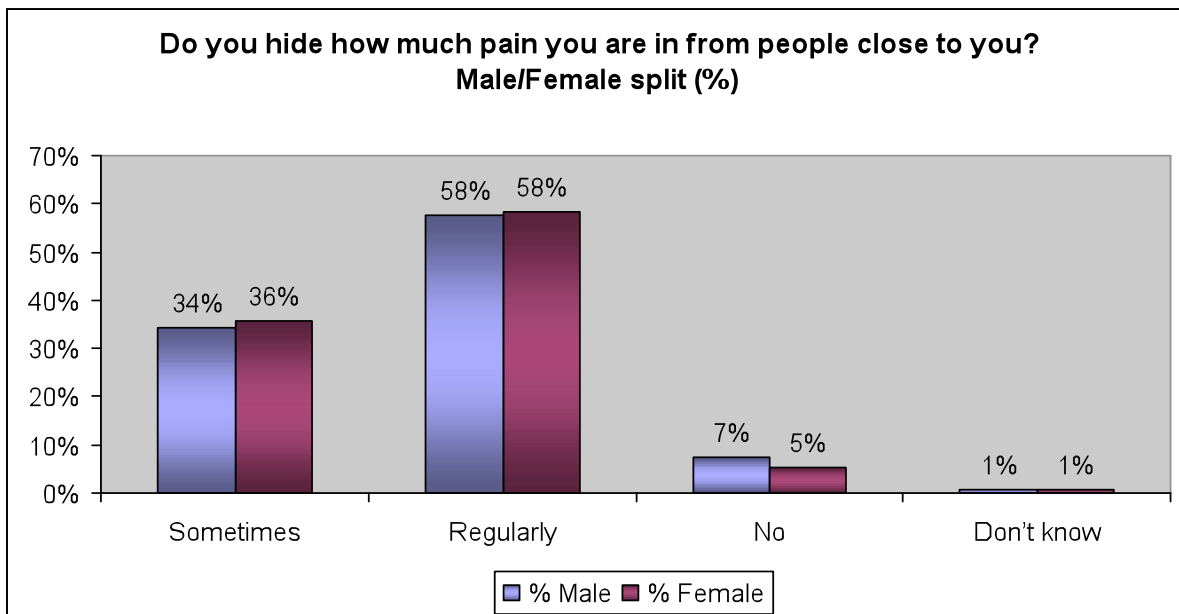
Earlier results stated that more women talk to people close to them than men. However more men than women felt these people really understood their pain (25% vs 12%) Graph 6.

Graph 6



In this study there were only marginal differences between men and women when asked how much they hide their pain from people close to them (Graph 7).

Graph 7



Cont/...

## Discussion

Studies on patients' experience with depression show that this condition is still associated with substantial social stigma. The nature of depression is such that patients may be quite reluctant to mention their thoughts and feelings. Patients expressed concerns about certain aspects of the treatment for depression, and how the lack of insight regarding depression severity substantially delays seeking treatment and decision-making. Patients can expect their GP to be a first and main source of objective information and discussion about depression and treatment, and to provide emotional support for decision-making [11].

Loss of independence (due to arthritis pain) in relation to enforced changes in working lives can result in negative emotional reactions including depressed mood, frustration, bitterness, anger mood swings, feelings of inadequacy and loss of choice, self esteem, self confidence and job satisfaction [12].

Environmental barriers come from inappropriate design of infrastructures that effectively not only limit access to buildings and public transport, but also freedom of movement once inside.

Arthritis pain can have a huge impact on a person's self-esteem causing them to feel frustrated, dependent and unattractive at times. A low self-image can impact negatively on relationships and performance at work, so it is important that people with arthritis pain are able to discuss these feelings with the appropriate healthcare professional.

There are links between gradual loss of ability to carry out simple every day tasks that the majority of us take for granted, such as getting dressed and making a cup of tea and psychological well being. Pain and depression are among the leading causes of decreased work productivity [13].

Once diagnosed, medication where clinically advised coupled with self-management programmes can substantially lessen the severity of depression as well as enhance response and remission rates for people with musculoskeletal pain. This intervention can also result in moderate reductions on both pain severity and pain-related disabilities [13].

People with arthritis can find themselves living with chronic multiple challenges or stresses and it has been identified that i) leading an active life and ii) taking control of one's life can help substantially [14].

However, it has been reported that people with RA give up two-thirds of their leisure activities following the onset of disease [15].

In a Cochrane review of patient education in people with RA, there was a 12% decrease in depression and a 4% decrease in pain found when comparing patient education with no patient education [16].

Patients and healthcare providers need to be aware that the impact of psychological interventions is not limited to pain and physical function, but can be experienced as improvement in psychological well-being and overall quality of life.

## Conclusion

The survey shows that three out of five respondents say they have been depressed because of arthritis-related pain. More research needs to be carried out to further establish the link between different types of arthritis and depression.

People with arthritis need to be supported by their GP and/or rheumatology specialist to manage the emotional impact of arthritis. In particular, more should be done to help avoid the onset of depression due to unmanaged pain: people with arthritis should be supported to self-manage, for example through exercise and healthy eating.

There is much that the voluntary sector – and Arthritis Care in particular – can do to provide information and support to people with arthritis, both in terms of emotional support and in managing their condition. Health professionals should direct people with arthritis to organisations such as Arthritis Care wherever appropriate.

For people with inflammatory (for example, rheumatoid) arthritis in particular, early intervention is key, as highlighted in the National Audit Office's 2009 report on *Services for People with Rheumatoid Arthritis*. For them, prompt referral for specialist treatment can help reduce the onset or worsening of associated symptoms of depression.

## Recommendations

- GPs, clinicians and allied health professionals (AHPs) should provide information and support to people with arthritis to self-manage. This should include signposting people with arthritis to Arthritis Care's website ([www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)) and Helplines (0808 800 4050), and to relevant pain services such as cognitive behavioural therapy, as required.
- GPs, clinicians and AHPs should be on the lookout for the signs of depression among people with arthritis or suspected arthritis, and respond in accordance with the principle of shared decision-making and NICE's guidance on *Depression in Adults* (CG90).
- GPs, specialist and practice nurses and other AHPs should provide – and be trained to provide – support to people with arthritis on managing the emotional impact of arthritis.
- GPs should ensure prompt referral for specialist treatment for people with inflammatory arthritis.

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## References

1. 1 in 5: The prevalence and impact of arthritis in the UK. Arthritis Care (2002)
2. Musculoskeletal Services Framework. Department of Health (2006)
3. Silman AJ, Hochberg MC. Epidemiology of the Rheumatic Diseases. 2nd Ed. Oxford Medical Publications (2001)
4. Pain in Europe: A report. [SQ12 & Q1]. NFO World Group / Mundipharma International Ltd. (2003 -2008)
5. OA Nation Report, 2004 – TNS/Arthritis Care Survey 2003, Q16
6. Data from Helplines Pro database, Arthritis Care (2009)
7. The Pain Files: Arthritis Care Helplines Data, 2009. Arthritis Care (2009)
8. Arthritis Hurts report – launched at Arthritis Care Awareness Week campaign – May 2010
9. Depression – Sarah Rastrick. Arthritis News June/July 2004
10. Doctors should watch for depression in rheumatoid arthritis patients Arthritis Today – Arthritis Foundation
11. Depressed patients' perception of depression treatment decision-making. Simon D, Loh A, Willis C, Harter M doi;10,111/j.1369-7625.2006.00424.x
12. Living with Arthritis, Barlow J, 2009 British Psychological Society. Blackwell publishing Ltd
13. Optimised antidepressant therapy and pain self-management in primary care patients with depression and musculoskeletal pain. American Medical Association JAMA May 17 2009-Vol 301, No 2099-2110
14. Coping with stress among middle aged and older women and men with arthritis. Iwasaki Y, Butcher J International Journal of Psychosocial Rehabilitation. Jan 2007 1-30
15. Leisure activities in rheumatoid arthritis: Change after disease onset and associated factors. Wikstroem I, Isacson A, Jacobson L (2001) British Journal of Occupational Therapy 64(2), 87-92
16. Riemsma et al 2002 (Cochrane review)