

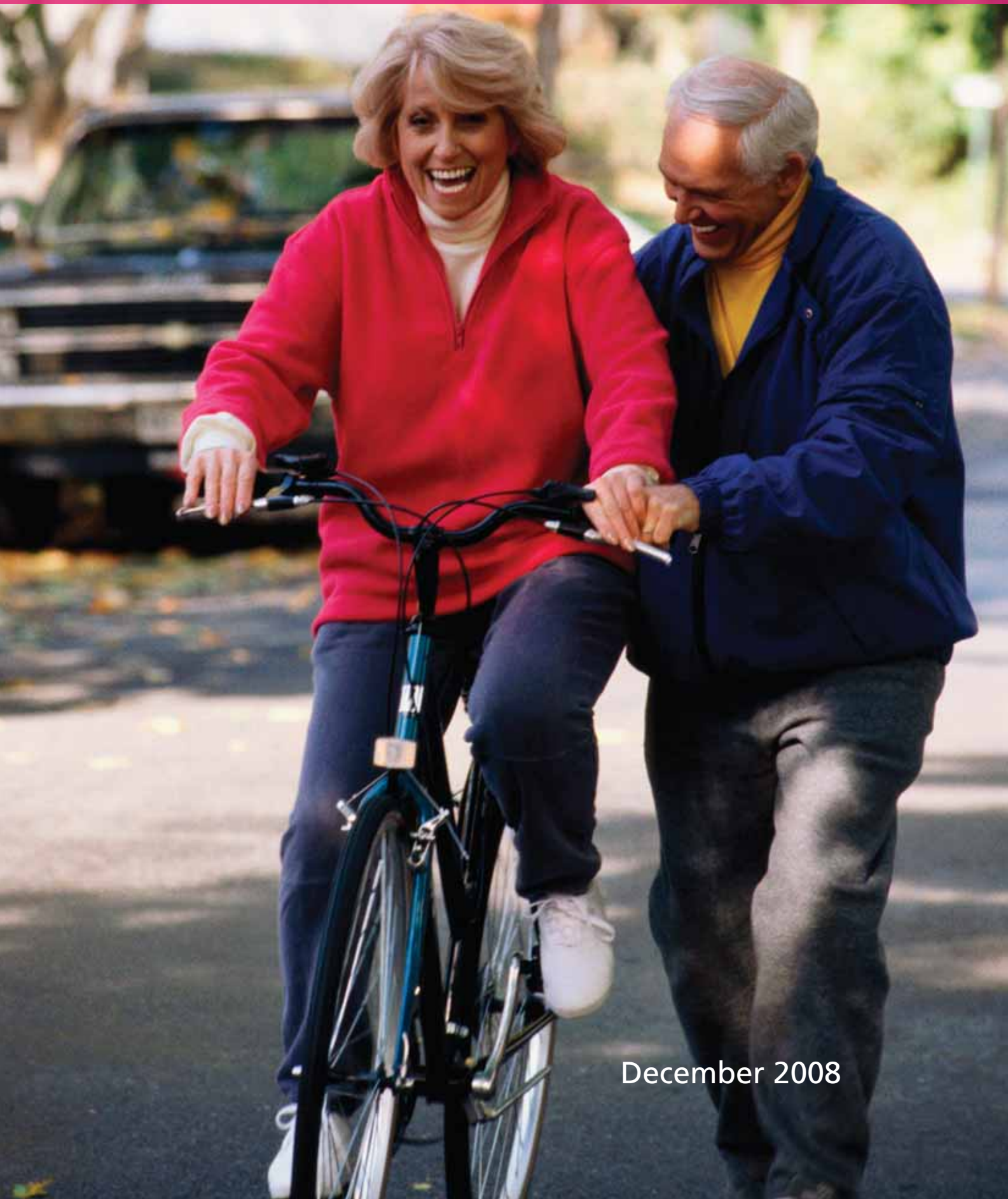
Living with Arthritis

Experiences of people living with
arthritis in Northern Ireland



ARTHRITIS CARE

*Empowering
people with arthritis.*



December 2008

Executive Summary



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Introduction

1.0 Introduction

Card Group was commissioned by Arthritis Care Northern Ireland to analyse the responses of people with arthritis to a series of questions using a self-completion questionnaire.

This report presents the findings.

1.1 Methodology

The paper-based questionnaire was constructed by Arthritis Care, taking into consideration the respondents' ability to complete it. Arthritis affects people across the age spectrum. The nature of this condition and other influences including dexterity problems, visual impairment and age, may have necessitated parents or carers to respond to the questionnaire on behalf of the person with arthritis.

The questionnaire was distributed to 1000 members and non-members across Northern Ireland in September 2008 with a 6 week response deadline.

Responses were input by Arthritis Care and forwarded to CARD Group for quality checking, analysis and reporting.

Due to rounding, some percentages in tables and charts may not add up to 100%.

Card Group was commissioned by Arthritis Care to analyse the opinions of people with arthritis on access to services and the impact of living with arthritis. This report presents the findings from a wide base of respondents across the range of age groups.

The survey was conducted using a paper-based questionnaire sent to 1000 members and non-members across Northern Ireland. The questionnaires were distributed in October 2008 and responses input by Arthritis Care in November 2008.

The data suggests the majority feel that they are not sufficiently informed of the nature of arthritis, the medication or pain management available. 4 in 10 respondents have an insufficient understanding of the range of treatments available. 6 in 10 have had their condition dismissed by a health care professional. 6 in 10 are rarely, if ever, asked for their opinion on managing their arthritis.

The greatest impacts on the quality of life for someone living with arthritis are pain and mobility issues, with travel and depression also ranking highly.

While treatment would be preferred when needed, the majority of clinics arrange appointments within 24 weeks. However, almost all of those waiting for anti-TNF treatment have been waiting for more than a year.

Two thirds of those responding have another long-term condition and two thirds of these feel they do not receive equal support in managing their conditions – the majority saying their arthritis received less support.

People with arthritis are generally happy to inform others of their condition without worrying about how this will affect perceptions and feelings towards them. More than half of respondents feel that arthritis has a strong influence on their personality. However, it is apparent that family and friends of respondents are not fully aware of the implications of the condition. A third of respondents' families and a quarter of friends were judged by respondents as only having an adequate understanding.

A concern from the findings is the lack of understanding and quality of information supplied when diagnosed. 68% of respondents stated that the quality of information on medication was less than acceptable and 42% have a below average understanding of the range of treatments available.

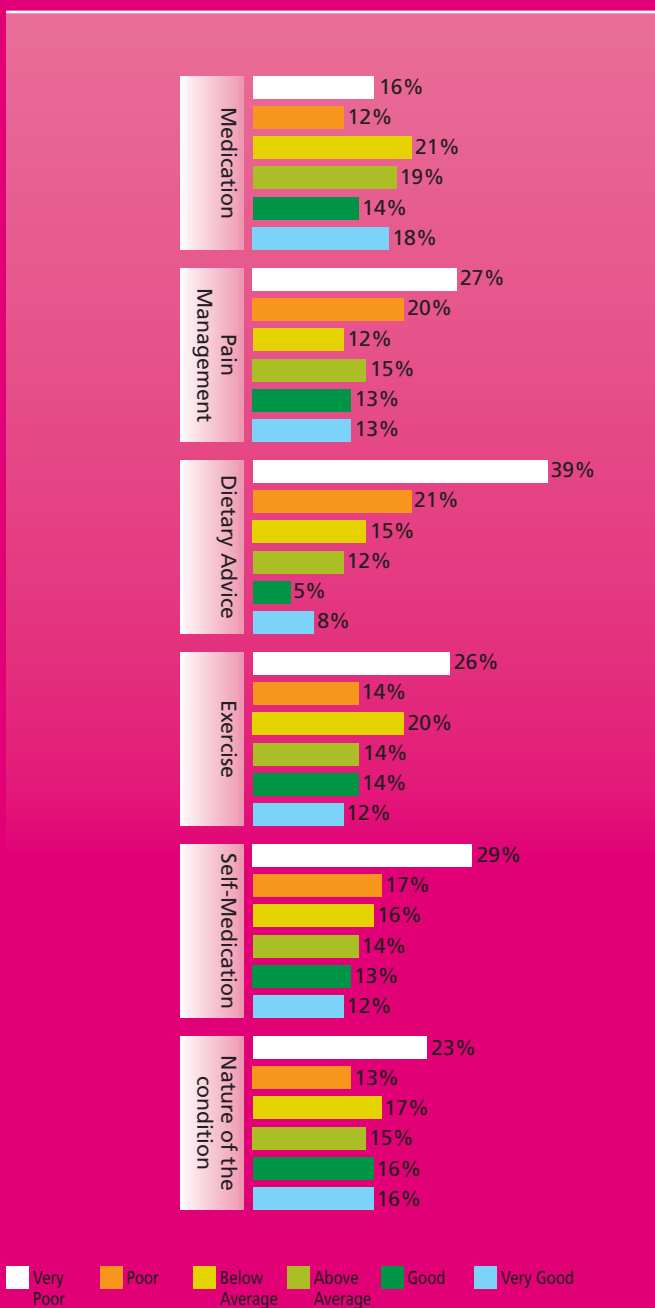
The most useful sources of information supplied to people with arthritis primarily came from GPs, consultants or Arthritis Care. A most significant finding was that when people were diagnosed with arthritis, over three quarters felt that they did not receive an acceptable level of support – either personally, or for their families or carers.

Arthritis Care provides valuable services to those who use them, with every service offered ranking above average in usefulness.



2.0 Analysis

295 responses were received by the deadline of 5 November 2008 which represents a 30% response rate. This is deemed to be adequate and provides a confidence interval of less than 6% at a 95% confidence level.



2.1 Information on arthritis at diagnosis

2.1.1 Quality of information received when newly diagnosed

Taking into consideration the impact arthritis has on lives, information at diagnosis is vitally important. A rating of 5 or 6 might be expected to each of the options, whereas a rating of 1 to 4 could be deemed to be less than acceptable. Responses received are represented in the bar chart left.

49% of respondents stated that the quality of information received about **medication** when diagnosed was below average with 28% stating the information was poor.

59% of respondents stated that the quality of information received on **pain management** was below average with a high 47% stating the information was poor.

Perhaps the most significant finding was on **dietary advice** with 75% stating that the information provided was below average and only 8% believing that the information received was very good.

The findings relating to **exercise** and **self-medication** are similar in that 60% and 62% stated that the quality of information received at diagnosis was less than acceptable. 40% and 46% respectively rated it as either poor or very poor.

Responses relating to information received on the **nature of the condition** was rated poorly, with 53% stating it was below average and only 16% returning a maximum rating.



Rank	Information Source	Weighted Score
1	GP	425
2	Consultant	381
3	Arthritis Care	347
4	Friend or Relative	112
5	Rheumatology Nurse	87
6	Internet	73
7	Other	72
8	Practice Nurse	48
9	Pain Nurse	30
10	District Nurse	12

Understanding of treatments available



Explanation of risks and benefits per treatment

1 - Poor understanding	22%
2	19%
3	17%
4	13%
5	11%
6 - Full understanding	17%
Grand Total	100%

Level of emotional support given when first diagnosed

Rating	Personally	Family/Carer
1 - Not Satisfied	29%	40%
2	22%	22%
3	19%	16%
4	14%	8%
5	7%	6%
6 - Very Satisfied	10%	7%

2.1.2 Most useful source of information when diagnosed

When asked to prioritise the source of the most useful information when diagnosed, respondents rated GPs top, consultants second and Arthritis Care third. Weighted scores were then calculated by multiplying the priority 1 answers by 3, priority 2 answers by 2 and adding all three together.

The difference between the weighted scores of the top three options and the others emphasise their value to respondents.

2.1.3 Understanding of treatments available

58% of respondents felt they had an above average understanding of what treatments are available for arthritis, while 23% felt they have poor or little understanding.

58% thought the explanation given by the health care team into the risks and benefits of the different treatments was poor.

"I have a good understanding NOW of treatments - but NOT at the point of diagnosis. My health care team may well have explained things fully but I can't say for sure - I certainly didn't take it all in at the time." (female, aged 56-64)

2.2 Support

2.2.1 Emotional Support when first diagnosed

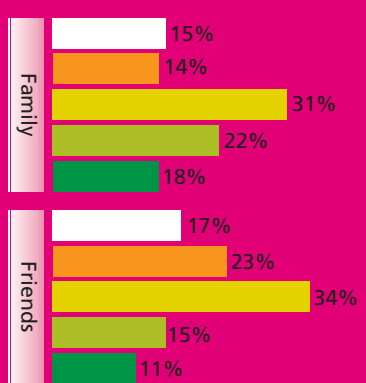
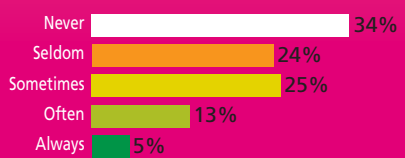
Significantly 70% rated the emotional support at diagnosis as below average. Just over half (51%) returned the lowest ratings while only 17% indicated an acceptable level of satisfaction.

78% replied they were not satisfied with the emotional support provided to the respondent's family or carer when first diagnosed.



Dismissed by	Count
GP/Doctor	80%
Consultant	18%
Physiotherapist	3%

Rank	Weighted Score
1 More information from my health care team	435
2 Speaking to other people with Arthritis about their experience	329
3 A better relationship with my health professional	224
4 More information from other sources	217
5 Support from a patient organisation	153
6 Increased support from my family/friends	101



1 - little understanding 2 3 4 5 - strong understanding

2.2.2 Has your arthritis ever been dismissed by a healthcare professional?

62% of respondents have had their arthritis dismissed by a healthcare professional; of these 80% indicated the GP dismissed their condition and a further 18% stated their consultant.

"The Consultant who diagnosed me said you will have arthritis for the rest of your life and closed my file and gave me a slip for physiotherapy."
(Female, aged 25-40)

2.2.3 Prioritise what would make you feel more confident?

The table shows respondents' weighted ranking of what they felt would make them feel more confident in discussing their concerns about their arthritis with a healthcare professional.

2.2.4 The frequency that your opinion is asked for by your healthcare professional?

58% of respondents stated that their opinion about the treatment of their condition is never or seldom asked for by their healthcare professional as opposed to 18% who are asked for often or always.

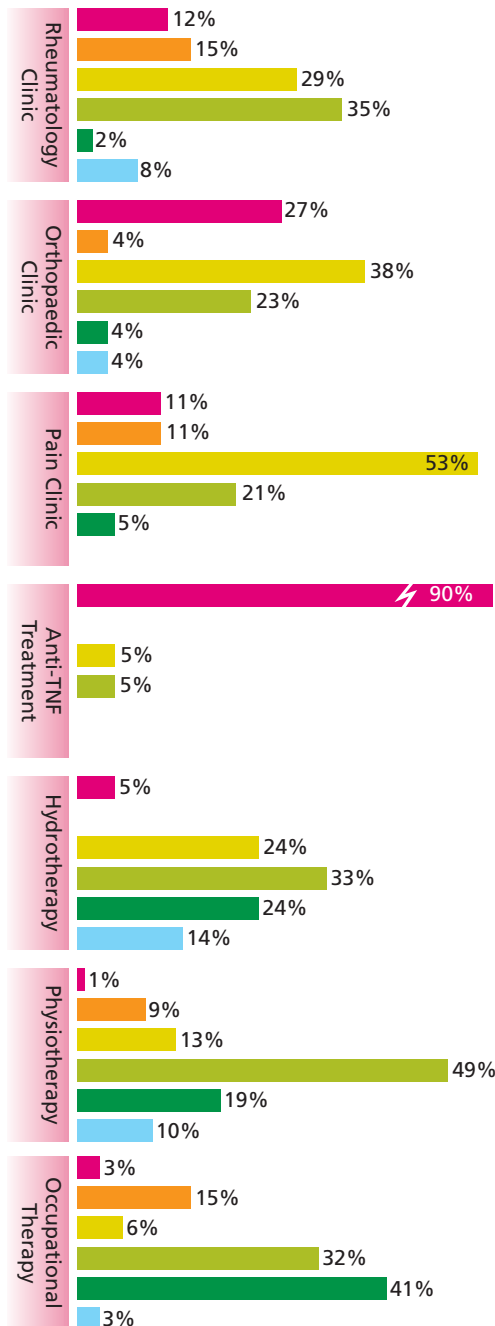
2.3 Living with arthritis

2.3.1 Social Impact

58% feel that arthritis has an influence on their personality, but only 38% are comfortable in telling social contacts about their arthritis.

Arthritis influences 21% of respondents on how they feel about themselves with an even split of negative and positive feelings.

It might be expected that family would have a better understanding of arthritis than friends. The chart shows that respondents feel that 29% of families and 40% of friends have a below average understanding of arthritis.



53 Weeks Plus 25-52 Weeks 13-24 Weeks 05-12 Weeks 01-4 Weeks 0-1 Week

2.3.2 Waiting Times

24 individuals stated they were on a waiting list for anti-TNF treatment. Quite alarmingly 90% are waiting more than a year for treatment (with some more than three years) making a considerable difference to someone living with arthritis.

The majority of respondents waiting for other forms of treatment were generally seen within 24 weeks.

Supporting comments indicate that as arthritis is a "flare up" condition, timely treatment is important.

"I would like our appointments to be quicker with more information on new drugs and be able to access pain clinics when needed." (Female, aged 41-55)

2.3.3 Impact on quality of life

Pain and mobility issues feature significantly among those with arthritis as issues which impact on the quality of life. Travel and depression are also ranked highly.

Rank	Impact	Weighted Score*
1	Pain	1668
2	Mobility Issues	1353
3	Travel	633
4	Depression	617
5	Financial Situation	443
6	Attitude of other people	368
7	Lack of support from employers	111

*Weighted score was obtained by multiplying the priority 1 answers by 7, priority 2 by 6 and so on, then adding all seven answers to get a combined score.

Alongside their arthritis, 64% of respondents have co-morbidity with another condition such as diabetes, heart disease, hypertension and depression. 59% of respondents feel that they do not receive equal support from the Health Service to manage their conditions and of those 68% indicated that arthritis receives less support than the other condition.



2 Analysis

2.4 Arthritis Care

Of the respondents who attended an Arthritis Care self-management course 91% thought it useful. Ratings are consistently high for all courses with at least 73% responding that conferences were above average and 85% rating information services as good.

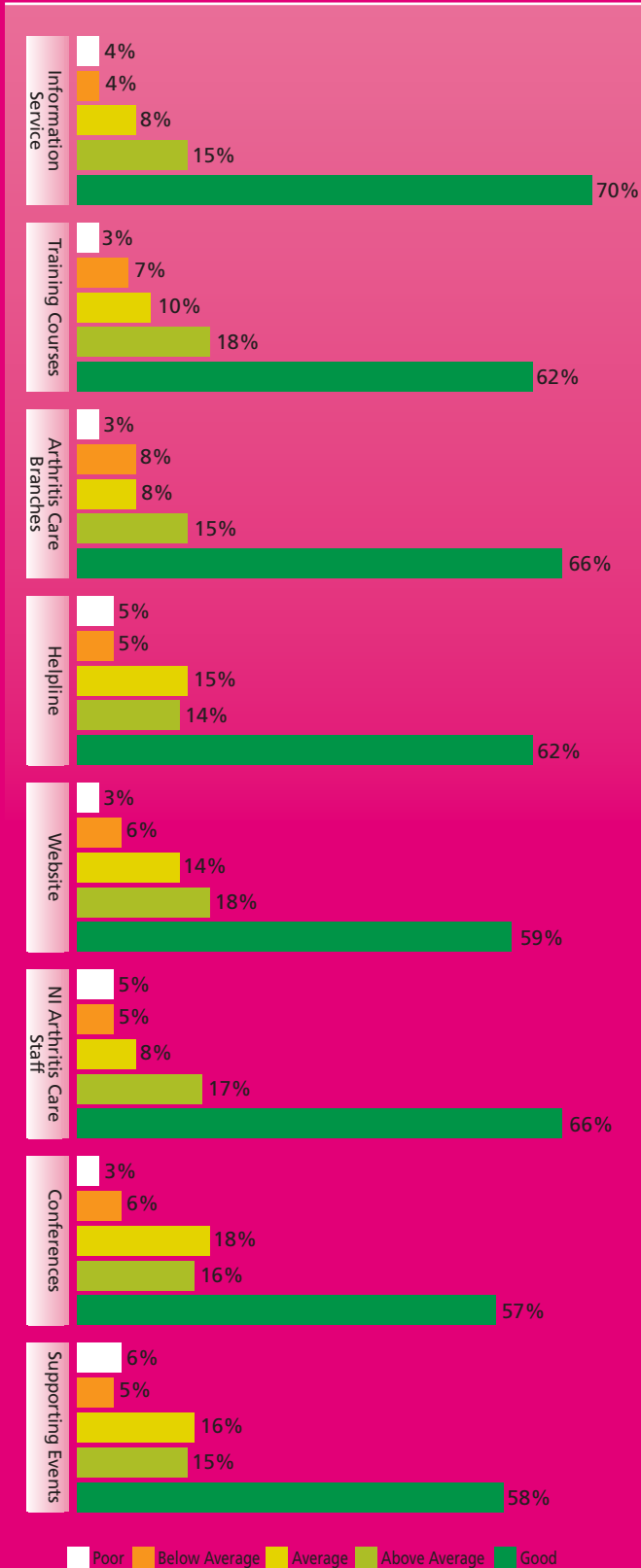
There is no one service favoured by respondents- all are equally popular, showing that the Arthritis Care provides valuable services.

Information services were rated highly with 70% returning the highest rating. This is reflected similarly in training courses, as can be seen from the following statements.

"The self-management course helped me realise it was not the end for me. I realised I could cope living alone."
(Female, aged 65-74)

"I attended an Arthritis Care management course and found it helpful, it increased my knowledge and confidence."
(Female, aged 56-64)

"Life changing - FOR THE BETTER."
(Female, aged 56-64)



Recommendations

Arthritis Care recommend that there should be:

A higher priority for arthritis on the health agenda

- 90% of those waiting for anti-TNF treatment have been waiting for over a year
- 68% of respondents state that information received on medication at time of diagnosis was less than acceptable
- 59% of respondents stated that information received on pain management was below average

Better education for GPs to ensure they understand the seriousness of arthritis

- The data indicates that of those respondents that have had their condition dismissed by a health care professional, 80% of these were by a GP
- 74% of respondents stated that their understanding of pain management was less than good
- 53% of respondents have a below average understanding of the nature of the condition
- 58% of respondents state that their opinion about the treatment of their arthritis is seldom or never asked for by their healthcare professional

"No feedback or followup from my local health centre. More caring attitude from my healthcare professional is needed."

(Female, aged 65-74)

Access to Self-Management to enhance people's skills and knowledge in managing their condition

- Self-management courses are valuable and beneficial with 80% of respondents rating those offered by Arthritis Care as useful or very useful.

"After attending an Arthritis Care self-management course, I'm more confident in making choices about treatment and addressing concerns with health professionals." (Female, aged 41-55)

"I enjoyed the 6 week course, it helped me understand my illness better. I learned to live with it, I do my best and have kept my job."

(Female, aged 56-64)



ARTHRITIS CARE

Empowering people with arthritis.

Improved support mechanisms for those living with arthritis, their families and carers

- Over three quarters of respondents felt that they did not receive an acceptable level of support personally or for their family or carer at diagnosis.
- Arthritis Care was rated close to the GP and consultant as the most useful source of information when diagnosed
- Arthritis Care provides emotional support and quality information for people with arthritis and their families
- Respondents stated that speaking to other people with arthritis about their experience would make them feel more confident.

"I would like everyone diagnosed with arthritis to be referred to an arthritis management course as early as possible, so that they can talk to others with the same illness and not feel as though they are alone." (Female, aged 56-64)

"I appreciate what the Arthritis Care Branch do and get advice and companionship from the group." (Female, aged 75+)

Enhanced Partnership working between sectors to improve quality of services for people with arthritis

- 59% of respondents have co-morbidity with another condition and feel they do not receive equal support from the Health Service to manage their condition
- Comments support patient-centred care, where services are focused on the individual
- 70% of respondents rated information supplied by Arthritis Care as very good which could be shared and integrated with other organisations services.

For further information please contact:

Arthritis Care Northern Ireland
The McCune Building, 1 Shore Road, Belfast BT15 3PG
Tel: 028 9078 2940
email: nireland@arthritiscare.org.uk
website: www.arthritiscare.org.uk

Registered Details:
Registered Charity No's. 206563 and SCO38693
A company Limited by Guarantee Registered in England No. 529321
Registered Office: 18 Stephenson Way, London NW1 2HD