

# Real lives, real difference

Arthritis Care Annual Review 2005



ARTHRITIS CARE

*Empowering  
people with arthritis.*



# What we do

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There are nine million people with arthritis in the UK – that's nine million individuals, plus their families, each affected in a unique way. With the help of our supporters, Arthritis Care aims to make a positive difference to these people's lives.

Arthritis Care is the UK's largest organisation working with and for all people who have arthritis. People with arthritis form our membership, are involved in all of our activities and direct what we do.

## We believe...

**in choice for people with arthritis. The first step towards making positive choices is easily accessible, reliable information.**

- Our volunteers help guide people to the information they need.
- Our successful information booklets deal with the issues that people with arthritis themselves tell us are important.
- Our popular website gives people with arthritis direct and immediate access to the facts they need, when they need them.
- Our professional helpline offers highly rated, confidential support and personalised information.
- Our bi-monthly magazine *Arthritis News* is a stimulating mix of news and features on living positively with arthritis.

## We believe...

**in supporting people with arthritis in living their lives to the full.**

- Our extensive network of local groups provides opportunities for people to meet others with arthritis in a welcoming environment.
- Our ground-breaking self-management programmes – delivered by trained people with arthritis – help people learn ways to take control of their arthritis.
- Our lively internet forums provide opportunities for people to talk to others with a shared interest at a time of their choosing.
- Our friendly hotels provide breaks for people with arthritis, their family and friends in four popular seaside resorts in the UK.

## We believe...

**in speaking up for people with arthritis and their needs, and pushing for change.**

- Our Campaigners Network takes on issues important to people with arthritis in their local areas, from accessing hydrotherapy to the provision of parking for disabled people.
- Our vigorous national campaigning teams work across the UK to promote civil rights for people with arthritis and to improve health and social care provision.
- Our international work aims to make arthritis a priority for policy makers.
- Together, from local to international actions, we work to give people with arthritis a voice.

**To help us in our work for people with arthritis we rely on the financial support of individuals and organisations, and on the time given so generously by our volunteers. To those people: thank you for helping us in all we achieved in 2005.**

## A brighter future for people with arthritis



Arthritis Care is all about people. The reason we exist is to support people with arthritis. People with arthritis control our organisation and set its direction. And people – our volunteers and staff – are our greatest asset.

Arthritis certainly hit the headlines in 2005, with controversy surrounding some drug treatments. Sound information is vital at times like this, and our website and helplines team were able to provide immediate and up-to-date information to people who were concerned about medicines they were taking.

More positively, the year saw real action in the European Union to increase funds for research into arthritis. Our leading role in collaborating with other organisations also representing people with arthritis was an important factor in this success. People with arthritis in the UK can be proud of the part they played in this.

We have worked closely with the Welsh Assembly Government and the English Department of Health on developing strategies for arthritis services, making sure the perspective of people with arthritis is taken into account. Like other people with arthritis, I look forward to seeing services improve once these strategies are published. In Scotland and Northern Ireland we have continued to push for similar initiatives.

Underpinning these major activities is our continuing work to provide information and support to people with arthritis throughout the UK.

Arthritis Care ended 2005 in good financial shape and thanks is due to all our donors for that, as well as to the staff team for its prudence. I am always aware though of how much more needs to be done to help people, and how much more Arthritis Care could achieve with additional funds.

Arthritis Care will be celebrating its 60th birthday in 2007. To get us in shape for hitting this milestone, 2006 will see us taking a good look at all of our activities. A consultation involving people with arthritis will help us look for new ways in which we can meet the needs of people with arthritis: the entire reason we are here.

Terry Oliver, chair of trustees

## Ready and eager for new challenges



One of the great qualities of this organisation is its ability to adapt and endure. As a new chief executive in 2005, I promised to help bring stability to Arthritis Care after a number of restructures in recent years. A year on, thanks to the fantastic efforts of staff, volunteers and members, we are now far more able to shape our own future rather than have it shape us.

This is not just about greater financial stability, although that is a big part of our progress. It is also about developing a clearer focus on what we are here to do, and how we can do it better. For example, we established a formidable reputation for our pioneering work in developing self-management programmes during the 1990s and in recent years we have expanded our training portfolio. However, we have recognised that there is much more we can do.

Therefore, in 2005, we refocused in this area. We put in place new, more robust ways of measuring what and how we deliver so that we can respond better to a changing environment. With governments hungrier than ever to see more people benefit from this sort of service, the timing could not have been better.

We also moved to co-ordinate our highly valued information services like never before to meet a rising demand, partly stimulated by our successful campaigning. Raise awareness of arthritis, as we have done, and you stimulate demand for help and support – and we are now better prepared for this.

So as Terry Oliver illustrates on this page, we have managed to 'get arthritis on the agenda'. In a new world where a different emphasis is being placed on how and where healthcare and support is delivered, Arthritis Care is ready and eager to meet these new challenges.

This means we are focused on what people want and we avoid the fatal assumption that this will always be what we currently offer.

Our achievements in 2005 put us in an excellent position to build a positive future: I hope you enjoy sharing some of these in this review of the year.

Neil Betteridge, chief executive

# An influential voice

**Arthritis Care represents people with arthritis at a local, national and international level and raises awareness of their needs. We influence decision-makers to make sure people with arthritis get a better deal.**

## Working with other organisations

Arthritis Care stepped up to offer support and information when a painkiller hit the headlines. In January 2005, thousands of people were devastated by the news that co-proxamol was to be withdrawn due to concerns about overdosing. Many were taken off the medication and Arthritis Care received calls from distressed people with arthritis who urged us to act on their behalf.

We recognised that GPs were not well enough informed about the continuing availability of the drug and in December 2005, as a result of consultation with Arthritis Care, the Medicines and Healthcare products Regulatory Agency agreed to clarify this. People genuinely in need of co-proxamol have a better chance of receiving it now that their doctors have been put in the picture.

## In 2005...

- **MEPs voted to support the needs of 100m people with arthritis in Europe, thanks to our work**
- **325 members of the Arthritis Care Campaigners Network spoke up for the rights and needs of people with arthritis in their area**

## Putting arthritis on the map

The future looks brighter for people with arthritis across Europe following a successful campaign by Arthritis Care to push arthritis up the health agenda. Following lobbying by Arthritis Care, MEPs tabled a motion calling for more funding for research in this area and the prioritisation of arthritis in the EU.

The motion also called for an end to discrimination against disabled people and better access to the full range of treatments for arthritis across the EU. It received overwhelming support, with over half of all MEPs signing it, and it is now an official policy of the European Parliament. This virtually unprecedented outcome is extremely important for future plans to support the needs of all people with arthritis across Europe.

## Speed dating with Assembly Members

Question: How do you grab the attention of busy Welsh Assembly Members? Answer: You take them speed dating. Arthritis Care used a fun opportunity to contact Welsh Assembly Members and deliver a serious message about the importance of exercise for people with arthritis. By participating in the All Party Group on Healthy Living speed dating event, Arthritis Care representatives and politicians had three efficient, quality minutes together. Now Assembly Members will better understand some of the issues faced by their constituents, thanks to Arthritis Care.

*'By lobbying their MEPs, people with arthritis have put arthritis firmly on the health agenda in Europe'*

**Martin Jones, senior campaigns manager for Arthritis Care**

*'I would like to thank Arthritis Care for standing up for those of us for whom co-proxamol is the only effective pain relief'*

**Margaret Alvarez, person with arthritis from Lancashire**

*'It is very important we ensure people who develop public health messages are aware of the impact of arthritis'*  
**Hywel Evans, policy and campaigns manager for Arthritis Care in Wales**



'people are not aware how many people have arthritis'



Young voices with arthritis are not often heard, despite the condition affecting 12,000 children in the UK. Twelve-year-old Danielle McTurk did not have access to a dedicated children's rheumatology service when she was diagnosed. On World Arthritis Day 2005, Danielle spoke out to highlight the need for such a service in Northern Ireland. She also helped launch Arthritis Care's Manifesto for Arthritis – a call for better facilities and treatments for people with arthritis.

'I think the manifesto is important because people are not aware of how many people have arthritis and that we do really need money so kids can meet each other. I've been able to meet other children through Arthritis Care.

'Arthritis has a great effect on my life, and that of my family. I thought it would be a good idea to let others know about arthritis, that it's not just aches and pains, and that it does affect children as well.'

# A valued resource

**Arthritis Care knows how powerful knowledge and individual assistance can be for people with arthritis. We provide information and support for people with arthritis at every stage of their lives.**



## Information for all

People with arthritis told us they wanted top quality, accessible information – and that is what they get, thanks to a project to revamp Arthritis Care’s booklets that started in 2005. We consulted over 100 people with arthritis to find out how our booklets could be enhanced and used their feedback and ideas to produce a new, improved range.

Our research showed that people trust information produced by Arthritis Care and want to be able to identify it as ours straight away, so we have adopted an easily recognisable image for our booklets.

People with arthritis told us they still wanted information on a wide range of topics including diet, exercise and emotions, in a format that was easy to read. We responded by ensuring our new range of booklets address all aspects of living with arthritis, using plain language and a larger, clearer font size.

## In 2005...

- 96 per cent of people questioned said they had received good or excellent service from our helpline
- over 440,000 people gained information from our website

## Helplines reach new people

In August 2005, a media campaign led by Arthritis Care highlighted the effects of osteoarthritis. The consequent huge rise in calls to the helpline served to show how much the one-to-one support is valued by people with arthritis.

We’ve made some changes because we want our service to be more readily available to those who need it. In September 2005, we extended the opening hours of the helplines freephone service from four to six hours each weekday\*. We are reacting to changing demands and email is proving increasingly popular.

The parents of newly diagnosed children made great use of The Source, the helpline for young people with arthritis and their families.

## Bringing information to life

Not everyone likes reading or fully takes in words from a page. But information is important to all people with arthritis. Arthritis Care put its lateral thinking into practice in south Wales in 2005 and gave a series of informal presentations – called Talking Books – inspired by Arthritis Care’s information booklets.

The talks got people engaged in the issues they’ve told us matter, such as managing pain, exercise, healthy eating, and treatment including complementary therapies.

## Working with Boots

Arthritis Care explored another way to give people the tools they need to help themselves when we teamed up with Boots the Chemist and the National Rheumatoid Arthritis Society. The partnership enabled us to educate pharmacists across the UK and to provide simple tips to people with arthritis on how to make a difference to their quality of life themselves.

*‘I like the stresses placed on positive aspects of living with the disease, which are demonstrated throughout the booklets’*

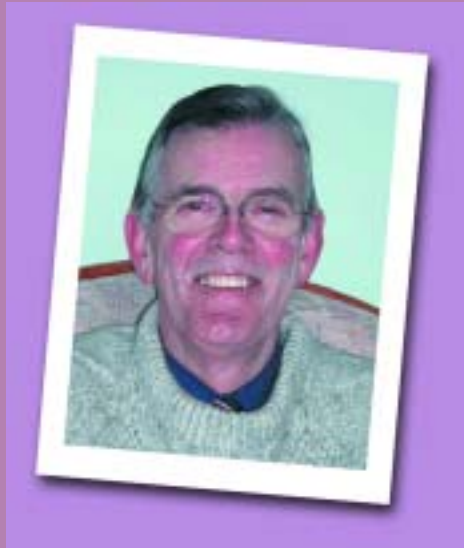
**Person with arthritis from Wrexham, north Wales**

*‘You were so helpful and knowledgeable when I rang the helpline – I was most impressed.’*

**Helpline user from south London**

*‘Working with Arthritis Care has enabled our pharmacists to offer people with arthritis useful lifestyle advice and additional support to help them manage their condition more effectively.’*

**Julie Hanmer, programme manager, pharmacy development, Boots**



# 'it is great to be able to give something back'

The fact that Mike Kibble-White knew very little about arthritis when he was diagnosed was his motivation to ensure that information on arthritis became more widely available. Mike, an Arthritis Care volunteer, took our booklets to hospitals, GP practices and libraries as part of a three-year project in Scotland funded by the Big Lottery Fund.

'The benefit of good information to a person with arthritis is that you learn a lot more – it takes the fear away and you know the right questions to ask. If I had known about the booklets when I was first diagnosed, it would have made my life much easier.

'There is so much information in the booklets and it is very well presented. Medical professionals do not always have the time to go into all the detail, and the spiel that they give you often washes over you as you are worried, frightened and in pain.

'I've had a lot of really good care from rheumatologists, so it is great to be able to give something back.'

# A leader in self-management

**Arthritis Care's self-management programmes help people with arthritis live their lives to the full. As well as our specially tailored new courses, our flagship programme, Challenging Arthritis, continues to turn people's lives around.**

## Challenging Pain courses

People with long-term chronic pain in South West England have a quicker route to the help they need after Arthritis Care recognised that people were facing long waiting lists for formal pain clinics. We developed a new self-management course, called Challenging Pain, for which a clinical trial began at Derriford Hospital in Plymouth.

The course helps people to tackle pain in a number of ways, including by developing their self-confidence and practising better breathing techniques. Being able to manage their pain means that people can do more with their lives, such as enjoy a family holiday for the first time.



## In 2005...

- 120 people with arthritis gained confidence and skills to help them find and stay in work through our Preparing for Work programme
- Arthritis Care trained 12 Lithuanian volunteers to run self-management programmes to benefit people with arthritis in their country

## Support for care workers

As well as educating people about their condition, we recognise that those who care for people with arthritis also need support. To help people better understand arthritis, awareness-raising workshops were delivered to 141 care home staff in Denbighshire and Carmarthenshire in Wales, looking at the practical impact the condition can have. This project was supported by a grant from the Welsh Assembly's Equity and Advocacy Grants Programme.

*'The Challenging Pain course has meant I have developed a better pattern of sleeping, which helps with the pain'*  
**Participant on Challenging Pain course, from South West England**

*'I wish that all our care home staff could learn from an arthritis awareness course.'*  
**Care home worker from Pembrokeshire, at an Arthritis Awareness course**

*Thanks to the Challenging Arthritis course I have a greater knowledge and understanding of my condition. I was encouraged to keep exercising and can now manage to walk four miles, which is a real boost.*  
**Challenging Arthritis course participant, from London**



'I learnt to  
recognise my  
skills'

Finding and staying in work can be a challenge when you have arthritis. Arthritis Care piloted the Preparing for Work course in East Anglia in 2005 in recognition of the support needed by people with arthritis who want to get back into work. The course helped Anita [not her real name], a registered nurse, find work.

'When I moved to the UK, I couldn't do anything – I couldn't work, and the painkillers made me feel like a zombie. I saw the course advertised and realised I needed to do something. Meeting others with arthritis was good, as was getting information on managing arthritis and finding work. I received help with my CV and job interviews.

'One of the things I learnt on the course was to focus on the positives and not go into the interview saying "I can't do this". Before I did the course I would have gone to an interview and talked about how much pain I was in. I learnt to focus on what I can do and to recognise my skills.'

# A magnet for volunteers

**Arthritis Care's volunteers are crucial to the organisation's success. They help us to reach even more people with our work and keep us in touch with people's needs.**

## Going rural

Reaching people who might not otherwise access our information is an important part of our work. Over 30,000 people attended three rural shows in the north of England in 2005 – and Arthritis Care was there too, not wanting to miss the opportunity to help people from remote communities. Volunteers on Arthritis Care's information stand helped the general public get a better understanding of arthritis and were on hand to answer questions about Arthritis Care's work.

## Fight for arthritis

A kickboxing competition in Northern Ireland in 2005 showed how imaginative people can be in their awareness raising activities. Arthritis Care volunteer Shane McCaffrey, who has arthritis himself, organised and competed in the competition. His aim was to raise funds and let other people with arthritis know what can be possible when living with the condition.



## In 2005...

- **volunteers provided much valued social support and information to over 16,000 members, through our local branch and group network**
- **volunteers raised over £60,000 to help our work by taking part in the Flora London marathon**

## Information on the move

Although distributing information in hospitals is one way to help people with arthritis, up to 95 per cent of people with arthritis never get referred to a consultant. Therefore, it is essential that we also get the information that helps them to places they go outside of hospitals. Taking this on board, Arthritis Care gained government funding to widen its outreach of information services in a variety of settings in Northern Ireland.

Arthritis Care volunteers delivered information to a range of outlets, from GP surgeries, health centres, libraries and pharmacies, to residential nursing homes. Tens of thousands of people with arthritis accessed information to help them make positive changes to their lives as a result.

*'By attending rural shows, we have reached a number of people who hadn't heard of Arthritis Care before.'*

**Marie Blackburn, information volunteer and North England regional committee chair from West Cumbria**

*'By putting a poster and some leaflets in my local library and health centre, I know I've helped other people with arthritis find Arthritis Care'*

**Barbara Weekes, information volunteer from Portadown**

*'I've been given a second chance as a result of my anti-TNF treatment. I organised the kickboxing competition as I wanted to raise awareness so that other people can get the treatment.'*

**Shane McCaffrey, fundraising and campaigning volunteer from Antrim**

# 'the classes helped them manage their lives much better'

Sally Boyce is a volunteer at the Arthritis Care Caernarfon branch in North Wales. She set up a tai chi group for people with arthritis to promote the message that gentle exercise is beneficial.

'Our branch members in Caernarfon were keen to introduce mobility into the programme and tried out tai chi three years ago. It has turned out to be a great success.

'To generate support for further sessions I applied for and won a grant from the Gwynedd Key Fund to introduce a tai chi programme in two communities – Caernarfon and Bangor. We also tapped into opportunities by winning funding from the Older Persons' Strategy, released by the Welsh Assembly.

'At the end of the 10-week course participants' confidence had improved. They found they had much less pain in their joints and were surprised that they could do more than before. They had reduced neck rigidity, and one or two were a lot steadier on their feet and more flexible. The classes helped them manage their lives much better.'



# A personalised service

**Arthritis Care recognises that one size rarely fits all; that everyone has different needs. We strive to address this in our work by delivering services that are inclusive. We also work to dispel some of the myths about who is affected by arthritis.**

## Raising awareness that children can have arthritis

12,000 children in the UK have arthritis – a fact that is not well enough known. In 2005, Arthritis Care’s school-based arthritis awareness workshop in South England helped spread the message that arthritis affects children as well as adults.

A series of practical exercises, including carrying out tasks whilst wearing gardening gloves, helped the pupils to understand the difficulty of having arthritis in your hands. Arthritis Care is developing plans to roll out the programme to more schools.



## Signing information

Having more than one condition can sometimes be a barrier to getting the help you need. In Scotland, people with arthritis and hearing impairments were given an exciting opportunity to receive arthritis information and self-management training in British Sign Language. The innovative programme funded by NHS Greater Glasgow Health Board and Scottish Business Achievement Award was delivered in conjunction with Deaf Connections.

The adapted Challenging Arthritis course aimed to equip participants (both deaf and hard of hearing) with the skills to manage their own condition. All volunteers and participants had deaf awareness training, provided by Deaf Connections.

## In 2005...

- Arthritis Care’s work with young people in Northern Ireland was commended by the Arthritis and Musculoskeletal Alliance as an example of good practice
- Around two million people watched Sally Watt deliver her message about what young people with arthritis can achieve, on GMTV

*‘The arthritis workshop in our school was great because you can see what people go through, like all the pain.’*  
**Child at school awareness workshop in north Devon**

*‘For the participants, being together with other deaf people and discussing arthritis mattered hugely to them.’*  
**Gordon Blythe, training volunteer from Glasgow**

'they wanted to know if I had a normal life, which I do'



Twenty-three-year-old Sally Watt from Staffordshire appeared on ITV's *GMTV* to raise awareness of young people with arthritis during Arthritis Care Awareness Week 2005.

'A lot of people don't know that young people can have arthritis. I wanted people to see me and think she's got it and she's leading a full life – I can do that. I have met so many young people with arthritis who don't think that they can do things. I wanted to say to them that you can.'

'I talked about my own personal story and how I get around things. I also talked about what the pain is like. It was really difficult to describe what arthritis feels like. I think they wanted to know if I had a normal life, which I do.'

'I felt that people should know that arthritis affects some people really badly. I think that drugs for arthritis are sometimes overlooked in favour of drugs for other conditions, and therefore raising the profile of arthritis is important.'

# Trust and company donors 2005

We are unable to include all of our generous supporters in this list, but would like to thank everyone who has contributed to our work in 2005 including individual members and supporters, community groups, companies and trusts.

We are especially grateful to those who have remembered Arthritis Care in their wills and those who have set up tribute funds in memory of their loved ones.



## UK-wide

Abbott Laboratories Ltd  
Starkie Bence Charitable Trust  
Chapman Charitable Trust  
The Ian Fleming Charitable Trust  
Gargunnoch Estate Trust  
GMS Estates Limited  
Miss E C Hendry's Charitable Trust  
The J P Jacobs Charitable Trust  
The Jordan Foundation  
The Lidbury Charitable Trust  
The Lord and Lady Lurgan Charitable Trust  
The Morton Charitable Trust  
Napp Pharmaceuticals  
The Peacock Charitable Trust  
Pfizer Ltd  
The Pilkington Charities Fund  
The John Pryor Charitable Trust  
Sir Cliff Richard Charitable Trust  
Sovereign Health Care Charitable Trust  
The Tanner Trust  
The Toler Foundation  
The Valentine Charitable Trust  
The Alfred & Beatrice Weintrop Charity  
The Late St Patrick White Charitable Trust  
Wogen Anniversary Trust  
Wyeth

## England

The Charity Box  
Jobcentre Plus  
The Beatrice Laing Trust  
Leeds Hospital Fund  
Lloyds TSB Foundation for England & Wales  
Nottinghamshire County Council  
The Cecil Pilkington Charitable Trust

## Wales

Carmarthenshire County Council Older  
People's strategy  
Denbighshire County Council Chairman's Charity  
Denbighshire County Council Strategy for  
Older People  
Flintshire County Council Strategic  
Development Scheme  
Merthyr Tydfil County Borough Council Key Fund  
Neath Port Talbot Communities First  
Florence Shute Millennium Trust  
Wrexham Local Health Board

## Scotland

The Appletree Trust  
Cupar Floral Art Club  
Douglas Charitable Trust  
East Dunbartonshire Council  
Forth Valley NHS Board  
The Hugh Fraser Foundation  
Miss Agnes H Hunter's Trust  
Ladbroke's  
Largs Rotary Club  
The Nancie Massey Charitable Trust  
Bill & Margaret Nicol Charitable Trust  
The Robertson Trust  
West Lothian Healthcare NHS Trust

## Northern Ireland

Bombardier Aerospace (NI) Foundation  
Department for Health, Social Services and  
Public Safety – Children's Fund  
Department for Health, Social Services and  
Public Safety – Executive Programme Funds  
Department for Health, Social Services and  
Public Safety – PIPPA Project  
RailRoad Charity Fund  
SHS Sales & Marketing Limited

We would also like to thank the Big Lottery Fund for its many donations to our work.

# Annual income and expenditure

## Arthritis Care income 2005



■ Voluntary income
■ Activities for generating funds and investment income
■ Representation and campaigning
■ Information
■ Training
■ Voluntary-run branch activities
■ Hotels

2005	2004
£m	£m
4.26	4.82
0.30	0.30
0.36	0.25
0.54	0.61
0.50	0.44
1.04	1.13
<u>1.55</u>	<u>1.61</u>
<b>8.55</b>	<b>9.16</b>

## Arthritis Care expenditure 2005



■ Fundraising and marketing
■ Representation and campaigning
■ Information
■ Training
■ Voluntary-run branch activities
■ Hotels
■ Governance

0.88	1.03
0.87	0.95
1.76	1.96
1.01	1.22
2.17	2.75
1.85	1.77
<u>0.13</u>	<u>0.32</u>
<b>8.67</b>	<b>10.00</b>
(0.12)	(0.84)
0.04	0.85
<b>(0.08)</b>	<b>0.01</b>

Net resources expended before investment and actuarial gains and losses

Investment and actuarial gains and losses

**Net movement in funds**

These gains and losses comprise the changes in value of the Arthritis Care Pension Scheme as calculated by actuaries on behalf of the Pension Fund and Investments held centrally and by our voluntary run branches.

The full accounts for 2005 are available on request (call 020 7380 6540), or can be downloaded from our website ([www.arthritis.org.uk](http://www.arthritis.org.uk)).

## Arthritis Care

Arthritis Care is the UK's largest organisation working with and for all people who have arthritis

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(10am to 4pm weekdays)  
[www.arthritiscare.org.uk](http://www.arthritiscare.org.uk)

Registered Charity No. 206563

Legal Status:  
Charitable company limited by guarantee and not having a share capital.  
Each member of the board and member of the charity guarantees the company the sum of £1.

ACR112

