Arthritis Care: Transforming every day
From our Chair and Chief Executive

Welcome to our Annual Review for 2016. We are delighted to present our story for the year – reaching people in more ways with the information and support they need to live well with arthritis.

We are focused on busting the myth that arthritis is an inevitable part of ageing and the belief that nothing can be done. Over the last year, we have partnered with other charities to press for arthritis to be seen as a public health priority. We have delivered high quality services that help people recognise the symptoms of arthritis, know how to manage it and supported them to enjoy an active, healthy and independent life.

In 2016, we are proud to have helped more people through individual and telephone support, increased our local presence through 39 new support groups as well as supporting more young people and families than ever before.

We could not have achieved any of this without our fantastic supporters and volunteers. We would like to personally thank everyone who so generously gave their time, energy and money to Arthritis Care; together we have made such a difference.

I hope you feel as positive as we do when you read about our work, and please do contact either of us if you would like to know more about our achievements or plans for the future.

Peter Anscombe
Chair

Judi Rhys
Chief Executive
From the Chair of our newly formed England Volunteer Council

Arthritis Care has become a very important part of my life. I was diagnosed with rheumatoid arthritis nearly twenty years ago and have been a volunteer with Arthritis Care for the last six.

I’ve been involved with many volunteering activities, met inspiring volunteers and staff and made good friends along the way. The England Volunteer Council and Nation Committees are a wonderful opportunity for volunteers from across the UK to come together and have a voice in deciding how Arthritis Care should be developing. There is so much good work going on all over the UK. We can learn from and support each other so that we are enabling more people to successfully manage their arthritis.

Jane Dobson

From Jane Asher our President

Arthritis Care has almost 800 amazing volunteers, united in their goal of delivering support to anyone affected by arthritis. In 2016 our volunteers provided over 43,557 hours of their time (6,222 days) the equivalent of 28 full time staff.

Their understanding of arthritis, their ability to empathise and their huge knowledge make them invaluable.

I know that we would not be the same organisation without this vital support, and I’d like to extend my own personal thank you to them for their time and commitment.

Jane Asher, President
Our aim:
To grow Living Well with Arthritis as our primary local support service and, alongside our Helpline, local Branches and Groups, support over 26,500 people.

We achieved:
We delivered support to 29,993 people, 11% above our target.
The pain of arthritis can be difficult to manage and exhausting to live with, and in severe cases, long term, it can lead to feelings of depression and despair. Thousands of people with arthritis report having to manage their pain on a daily basis, impacting even on the simpler things in life like bathing, getting dressed or making a cup of tea.

Arthritis Care's ‘Living Well with Arthritis’ programme aims to support people to manage their arthritis and the pain it brings. Our committed Arthritis Care volunteers are based in communities around the country and host drop-ins and face to face sessions at local venues such as health centres, hospital clinics and community centres. Their personal experience of arthritis makes them the perfect choice for supporting others to make a change in the way they manage their condition.

"I am affected in every area of my life. My hands hurt so I can’t lift a kettle or saucepan without difficulty. Walking is painful and I don’t feel safe going out on my own now. Pain is a major factor. I can’t sleep because of pain down the right side of my body, my neck and my back. If I lie on my back I wake in agony. Walking, bending or stretching, everything that you usually have to do at some stage in a day is affected."

LC, 71 years old, living with osteoarthritis

Arthritis Care was asked to expand its highly successful commissioned service in West Berkshire in 2016, which supports people with decision making and offers an alternative to surgery. Over the last two years we have helped 544 people to make more informed choices about surgery and have saved the NHS £2.6 million.

High quality information helps people feel confident about the decisions they make, feel more in control and better able to manage their condition. Requests for our booklets soared by 42% in 2016 thanks to a much improved website, an increase in the number of people using our services and increased media coverage.

Impact

111,428 information booklets distributed, up 42%
667,667 users on our website, up 8%
85% visit our website for health information

In 2017
We will continue to develop the Living Well with Arthritis ‘hubs’ model working alongside branches and groups. We will develop new pilot services alongside Clinical Commissioning Groups in areas of identified need, starting in South Tees in early 2017.

arthritiscare.org.uk
Kevin’s story

Kevin was diagnosed with osteoarthritis in his fifties.

I had retired early to pursue a dream of sailing around the world with my wife. I started having problems with my knees about five years ago – predominantly pain and swelling. When I sought medical assistance in Turkey, I found out I had arthritis.

As time passed, I got less mobile. The long-term plans I had with my wife were put on hold. We decided sailing wasn’t an option anymore.

Back at home, I tried to manage everything on my own, but found myself struggling to sleep. I was trying to fight my condition but this left me exhausted all the time and each day became a grind. I was stressed and felt lost.

I met Annie, an Arthritis Care co-ordinator at my doctor’s surgery and went on to meet with her twice more. She gave me more of an understanding of fatigue which is common with arthritis, and the need to understand limitations, both issues I’d never really considered before.

My increased understanding alongside small adjustments to my lifestyle has given me a new lease of life. I have started volunteering with Arthritis Care at various events, such as pain management clinics and library drop-ins. I’ve learnt a tremendous amount and it’s great to meet people with similar issues. The participation and shared experiences have given me a more positive outlook on life. I now plan to go back to sailing in the spring and feel like there are so many more possibilities in my future.
Imagine being a mum who can’t pick up your child, tie his shoelaces or pull his covers up at night. That was me back in 2007 when I was diagnosed with rheumatoid arthritis.

Every time I tried to do anything, the pain was so severe I had to stop. I vividly remember looking into Matthew’s eyes and thinking, “I can’t be the mum you need.”

I started treatment soon after my diagnosis, which helped to control the pain, but my spirit was broken. I usually have a very ‘can-do’ attitude, but all I could hear was a little voice inside my head whispering: “You can’t”.

Arthritis Care changed my life. From the moment I walked into the Arthritis Care support group, I was greeted with such warmth. For the first time in months, I didn’t feel alone. The group offered me practical support that has made a real difference to Matthew and me. They helped me realise I could still be a good mum, I’d just have to do things differently. Arthritis Care has been with me every step of the way and I don’t know what I would have done without them.
Bringing people together

Our aim:
To establish 50 new volunteer-led local support groups alongside our branches to tackle the isolation of people living with arthritis in local areas.

We achieved:
We established 39 new support groups with another 10 in the pipeline.
Everyone deserves to have the support they need in their community to live well with arthritis. Unfortunately, we know many people don’t and we are working with volunteers to set up new groups. Groups are designed to respond to the need in the local community providing peer support, reliable information, exercise and valuable social activities.

“ I have observed many of my patients who attend the support group making real progress in their ability to manage their condition, and communicate with their rheumatology team about their arthritis. These are key ingredients in helping people keep their arthritis symptoms under control, and lead healthier, more rewarding lives. ”

Dr Henry Penn, Lead for Rheumatology, Northwick Park Hospital, Harrow

For many, groups provide that extra bit of motivation to get active. In Scotland, we have set up seven weekly walking groups run by 27 volunteers and attracting 60 walkers. One in four walkers were not physically active prior to joining the group and participants have reported increased confidence and wellbeing.

“ By volunteering, I am able to help other people. I like being able to understand what others are going through. I am able to relate to the frustration, anger and pain they feel because of their arthritis. Volunteering also helps me, because it takes my mind off my own pain and I focus on helping others. ”

Stan, Arthritis Care Champion volunteer

In 2017
We will establish 75 new Support Groups. We will also pilot an evaluation with three branches and three groups to understand more about the positive difference they are making in their community.
Elsie’s story

Elsie* was diagnosed with arthritis at 76 by her GP, she is now 80 and continues to live in her own home.

Looking back I realised I had withdrawn from almost all social contact. This really started when I developed arthritis in my hips and my neck. I found driving difficult and I stopped going to church because of the pain. Each day became the same as the next and I was feeling sad and lonely.

When I was told about the chance to meet with someone who could help me with arthritis, I felt as hopeful as I had felt in a long time. I was really keen to find out if there were ways I could manage the pain as I had given up on my GP being able to help.

Mary was such a support to me, warm-hearted and empathetic. She explained the importance of staying physically and socially active. We went through numerous techniques particularly low mood, positive thinking and pacing yourself. She gave me lots of encouragement. She motivated me and taught me skills that increased my confidence and self-esteem.

Around this time I was meeting with Mary, my brother died which had a devastating effect on me as we were very close. Mary helped with my loneliness and gave me the skills to overcome this. She took me out for coffee, which I really enjoyed. I looked forward to her visits each week. Looking back I had cut myself off from friends but Mary encouraged me to contact them and it was the push I needed. I joined a Tuesday club and a balance and walk club. I think more positively now and I understand the importance of staying socially active.

* name changed for privacy reasons

Elsie was supported by Mary who works on our Staying Connected in Later Life service.

Mary has been such a support to me, warm-hearted and empathetic.

* name changed for privacy reasons

arthritis-care.org.uk
Caitriona’s story

Caitriona was diagnosed with Juvenile Idiopathic Arthritis aged 12.

I was very down and depressed. You get forced out of bed to go to school, but that’s it – you don’t want to socialise or interact with people. I didn’t really talk to my friends. I stopped phoning and texting. It’s that feeling of self-pity and that no-one else understands what you’re going through.

The turning point for me was my first Arthritis Care weekend. Meeting other young people in the same boat as me, and being able to call and text them when you’re having a bad day, has been amazing.

Being involved with Arthritis Care has helped me find the resilience I needed to pursue a career in law. Lots of the volunteers at the Arthritis Care weekends are doctors now or working in law, and they help give me the strength to know I can do it. Arthritis Care has helped me to succeed in education and employment and taught me how to go out into the world and get a job.

“Arthritis Care has helped me understand how best to go out in the world and get a job.”
Transforming young people’s lives

Our aim:
To support over 500 young people and their families living with Juvenile Idiopathic Arthritis (JIA) in the UK, and develop a five year ‘Young People and Families strategy’ to significantly expand our reach.

We achieved:
We supported 513 young people and their families living with JIA and developed a five year strategy to be in every specialist Paediatric and Adolescent Rheumatology treatment centre.
Arthritis can have a devastating impact on the aspirations and achievements of young people. They can face long spells in hospital, disrupted schooling, challenging side effects from strong medication and often miss out on activities other young people may take for granted. One of the hardest things is feeling different to their peers, particularly as they enter their teens.

“When I was younger, I was really active and loved gymnastics and was really sporty. When I was 8, I got diagnosed with arthritis and it’s all over my body. Every morning my dad would have to carry me out of my bed into a warm bath just so I could start moving again as I couldn’t even open my hands or straighten my legs.”

Erin, diagnosed with Juvenile Idiopathic Arthritis aged 8

Young people living with arthritis and their families can now turn to an Arthritis Care Young People and Families Co-ordinator in a quarter of the treatment centres across the UK. Our Co-ordinators offer support in clinics as well as running programmes of activities. These are co-led by our amazing young peer support volunteers who were diagnosed with arthritis themselves as a child or teenager and are an inspiration to other young people.

“In 2016, 102 young people took part in residential weekend events across the UK. For many, this is the first time they have been away from their parents and gave them a chance to try activities they never thought they could, from gorge walking to kayaking, archery to abseiling, mountain biking to canoeing.”

“When I joined I was afraid of talking to strangers about my arthritis and didn’t like answering questions. But with your help I’ve become more confident about my arthritis and how to answer questions. Thank you for making me feel comfortable to have arthritis.”

Gemma, participant in one of our residential weekends

**Impact**

36 young peer support volunteers are now actively helping others

321 young people are engaging with us and each other on social media

**In 2017**

We will launch new Young People and Families services in Cardiff and the north west of England, and begin fundraising to expand our service to new treatment centres across the UK.

arthritiscare.org.uk
How we raised our money…

Our supporters helped us raise a fantastic £5,287,000 in 2016.

- **Legacies £3,089,000**
  Gifts in Wills are our biggest source of income.

- **Fundraising events £134,000**
  This includes income from any sponsored events such as London Marathon.

- **Direct marketing £373,000**
  Money raised by things like direct debits.

- **Membership £88,000**
  Income received from membership fees.

- **Trust, grant and corporate income £952,000**
  Income from corporate supporters, charitable trusts and grant-making organisations.

- **Contracted services £282,000**
  Income received from statutory organisations to pay for services.

- **Branch income £279,000**
  Money raised by branches to pay for their activities serving the local community.

- **Other £90,000**
  Income received from investments and miscellaneous.

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Our reserves:

**Arthritis Care held the following reserves at the end of 2016:**

- **Restricted Reserves £725,000**
  These are restricted grants or donations that haven’t been spent in the year and have been carried over.

- **Designated Reserves £1,314,000**
  These are largely funds held by local committees and branches that are not controlled centrally.

- **Free Reserves £2,398,000**
  Our policy is to hold between five and seven months’ operational expenditure as a contingency in case of a drop in income.
And how we spent it…..

We spent £5,375,000 on services for people living with arthritis.

- **Information £964,000**
  Print and online resources to help ensure people can live an independent life, receiving the support they are entitled to.

- **Practical support £2,107,000**
  Dedicated individual and group support to reduce the pain people endure and reduce isolation that arthritis can cause.

- **Volunteer-led support £867,000**
  Working with volunteers to improve people’s health and well-being and reduce isolation.

- **Campaigning for high quality services £146,000**
  Activities to improve services and ensure the voice of people with arthritis is heard and acted on.

- **Fundraising £1,291,000**
  Thanking supporters and activities to secure future income.

These figures are taken from the full Trustees’ report and financial statement for the year ending 31 December 2016, as audited by Sayer Vincent LLP. A full copy of the report is available on our website or on request.
Support for those living in isolation

Our aim:
We will pilot the Staying Connected in Later Life service in Scotland and understand its potential to be replicated in other areas of the UK.

We achieved:
We have continued the successful service in Northern Ireland as well as piloting this service in Nairn, Scotland.
Living regularly with pain limits the ability to live life to the full including undertaking many everyday activities, such as sleeping through the night, working, seeing friends or having an intimate relationship. This inability to participate can lead to social isolation and mental health issues.

The Arthritis Care Helpline provides vital support to those experiencing isolation. For many, it provides a lifeline when there is nobody else to talk to.

“It was someone I didn’t know, I’d never met, but he had the time to talk to me. He seemed to understand the despair I felt. He listened, reassured and gave me some practical advice. That conversation helped me beyond words.”

Jacqueline, living with rheumatoid arthritis, caller to our Helpline

We regularly check that what we are delivering is what is needed by people with arthritis. 66% of Helpline callers told us that they had made positive changes to their lifestyle as a result of the information they had been given.

In Northern Ireland, our amazing volunteers worked with 80 vulnerable older people through our ‘Staying Connected in Later Life’ service. This mentoring and befriending service helps older people at risk of isolation:

• cope better with their condition
• make positive changes
• feel less isolated
• have improved health and well-being
• regain an activity role in their community

72% of those we helped showed an improvement in their social life. 67% improved their mobility.

**Impact**

A quarter of users of our website visited the online community in 2016.

33% rise in users visiting our online community across the year with February 2016 reporting the highest ever traffic.

In 2017

We will increase the accessibility of the Helpline by extending the opening hours. We will fully review the online community and update the underlying technology.

Grace, member of our online community

My Forum Family has kept me sane. I have had fantastic support and, to be honest, without that support, I wonder if I’d have got through these last few months. Thank you.

Arthritis Care’s online community provides vital peer support 24 hours a day and for many, it can be comforting to know that you are not alone. The online community is packed full of stories, friendly advice and resources that help create that important sense of community.
Thank you

Changing the lives of people living with arthritis would not be possible without the thousands of individuals and organisations who supported us during the year. We would like to thank everyone for their contribution. Here is just a sample of organisations that have supported our work.

Abbvie Limited
AposTherapy
Barbour Foundation
BBC Children in Need
Big Lottery Northern Ireland
Big Lottery Wales
Charities Aid Foundation
Edith Florence Spencer Memorial Trust
Garfield Weston Foundation
Health and Social Care Alliance
(Scotland)
Health and Social Care Volunteering Fund
Hobson Charity Limited
Joan Ainslie Charitable Trust
P F Charitable Trust
Paths for All

Peacock Charitable Trust
Pfizer Limited
Pilkington Charities Fund
Roche Products Limited
The Constance Travis Charitable Trust
The John Coates Charitable Trust
The Jordan Charitable Foundation
The Lidbury Trust
The Lord Cozens-Hardy Trust
The Madam Betard Trust
The Monument Trust
The Schuh Trust
The Scottish Government
The Tompkins Foundation
The Westminster Foundation
Ulster Garden Villages

We would like to express a special thank you to all our volunteers, Branches and Groups that have supported the delivery of services this year, and the many who continue to do so.
Gifts in Wills
Huge thanks to all those who left a gift in their Will to Arthritis Care, including:

Frank Askew  Patricia Laing
Phyllis Beach  Margaret Constance Leafe
Diane Elizabeth Beavers  Judith Anne Liddell
Alfred Bennett  Elise R M McLauchlan
Doris Mary Bowdell  Eugene McManus
Reine Mary Cattini  Irene Otter
Hugh Collins  Ivy Walker Pearson
Letty Dunn  Corriswen Phillips
Dorothy Fraser Fairlie  Margaret Anderson Pope
Betty Margaret Fisher  Dorothy Evelyn Quaye
Gillian Margaret Forrester  Ronald Custer Rose
Catherine Joyce Gough  Georgina Margaret Stafford
John Herbert Frederick Gray  Jocelyn Beryl Steadman
Elizabeth Guy  John Rodney Walker
Betty Margaret Harris  Charles Raymond Wootten
Barry Hayne Holland  Joyce Dorothy Worthington
Marion Virginia Johnson  Jean Wylie Young
Sheila Lilian Jones

How your funding has made a difference, in the words of young people.
Arthritis Care activity weekend, Friday 30 September-2 October 2016
Arthritis Care is here to help you to live well with arthritis

If you would like support...

Call us on our free confidential Helpline:
0808 800 4050
(10am-4pm Mon-Fri)

Call our Supporter Services team to find out about joining Arthritis Care or information on your local branch or group on:
020 7380 6540

Email us:
info@arthritiscare.org.uk

Visit our website:
www.arthritiscare.org.uk

Join our Facebook page:
www.facebook.com/ArthritisCareUK

Follow us on Twitter:
twitter.com/arthritis_care

Registered Address
Arthritis Care
Floor 4, Linen Court
10 East Road
London N1 6AD
Tel: 020 7380 6500

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