General public education

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How does the average person learn about arthritis, in general, and how to manage his or her arthritis, in particular? Because arthritis is so common, and because it is so often seen as a 'natural' part of growing old, there is an odd dissonance: the disease which is the major cause of physical disability in the United Kingdom is rarely discussed in the mass media. The major national education medium is television; radio, newspapers, and journals come a poor second when judged by the size of their audience. One character in *Neighbours* (Australian made drama series shown on British television) with arthritis could do more for public perception and thus patient education than all the printed booklets currently available.

Arthritis is not one of the medical conditions seen as exciting nor is it associated with death. Despite the pain and disability it causes it is seen as dull. There is no thrill but much fear engendered by the diagnosis of arthritis. To the family doctor—often the only doctor who diagnoses and treats the disease—its very familiarity may often lead to less sympathy and information than patients might reasonably expect.

Other members of the primary health care team—practice nurse, district nurse, or health visitor—or the community occupational therapist may play a part in care. A patient who is admitted to hospital may receive more information from a specialist, either personally or through the multidisciplinary team. There is a shortage of rheumatology nurses, occupational therapists, and physiotherapists, however. This, combined with the low priority given by financially constrained health and social service departments to the chronically ill and the physically disabled, leaves the average patient with arthritis with a less than optimum service.¹

Thus the patient may be faced with media which are not interested, a blasé family doctor, and overstretched hospital services. Who fills this information gap? Firstly, rheumatology departments produce a varied and wide range of leaflets and booklets for their patients. Secondly, pharmaceutical companies produce a constant stream of booklets, tapes, posters, and videos for doctors to give or lend to patients; these are of increasingly good quality. Thirdly, the Arthritis and Rheumatism Council (ARC) has an education committee, made up of 23 doctors and one representative from the British Health and Allied Professions, which produces a wide range of booklets and leaflets on arthritis and its management with the dual objective of patient education and fund raising. Finally, voluntary organisations such as Arthritis Care provide much information.

Arthritis Care

Arthritis Care is the major national voluntary organisation concerned with the welfare and rehabilitation of people with arthritis. It has 50 000 members, over 500 branches in the United Kingdom, and a network of 41 part time regional organisers. A specialist self help group, Young Arthritis Care, meets the needs of people under 44 with arthritis. Members of its council are either directly elected or elected by the area liaison committees, which coordinate the work of branches. Of 46 council members, five are doctors, one is a rheumatology practice nurse, and one a social worker based in a rheumatology department. An increasing number of council members have arthritis.

The aims of patient education are to enable people with arthritis to manage their daily lives as independently as possible, to minimise the impact of the disease, and to maximise the effectiveness of the available help.

Arthritis Care meets the demand for patient education at three main points: through its branches and regional organisers, through its headquarters' welfare department, and through its specialist self help group—Young Arthritis Care.

Young Arthritis Care has a network of volunteer contacts (recruited, trained, and supported centrally) to give advice and support locally, in person and by telephone. Contacts also try to deal with the practical concerns of parents of children with arthritis, and the group organises a self care course in conjunction with Dista Products, who give the annual Dista award for young people with arthritis in recognition of their achievements.

The network of over 500 branches nationwide offers an opportunity for over 50 000 people with arthritis to meet socially once a month. Consultants, doctors, and paramedics often have connections with these branches. Voluntary local committees plan activities to encourage people to meet and gain support from each other. Transport to meetings is arranged, often with difficulty, and the value placed by members on 'getting out of the house' is high. Although most branches provide little formal patient education, the tricks of coping are passed on or learnt by observation. Friendships develop and the core of support offered helps to alleviate the depression and isolation that so often accompanies painful, chronic, disabling diseases like arthritis. Branch members and other members receive *Arthritis News*, a quarterly newspaper with a circulation of over 100 000 copies, full of news, information, advice, and features of interest to people with arthritis.

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Table 1 Number of inquiries received by the welfare department of Arthritis Care: 1990*

	June	July	Aug	Sept
By telephone	209	316	264	713
By letter	502	236	233	274
Total	711	552	497	987

*This table excludes requests for publications, which average 1500–2000 a month.

The 50 000 branch members represent only a small proportion of those with arthritis in the general community, however. Others may be helped through the work of the welfare department. Posters, word of mouth, magazine articles, or radio and television programmes promote interest in Arthritis Care; the welfare department receives a growing number of letters and telephone calls (table 1), especially since the introduction of the free Arthritis Care Wyeth Helpline. About half the inquirers want to discuss some aspect of their arthritis, and the other half its effects on their lives. One third of inquiries come from people with osteoarthritis and over a quarter from those with rheumatoid arthritis. The most common other forms of arthritis among inquirers are polymyalgia rheumatica and Reiter's syndrome, but those with rarer types of arthritis are also making contact. The welfare department is asked about both orthodox and alternative treatments, but it gives no medical advice and encourages inquirers to discuss matters with their doctors. Table 2 provides a breakdown of inquiries for a typical month.

There is a problem in steering a line between information and encouragement, and the need to balance objective scientific assessment against the reality of the relief that comes from diets, copper bracelets, physical treatments, or a wide range of substances. The experience of Arthritis Care suggests that many people with arthritis wish to be in control of their lives, including their diseases. Too often people with arthritis complain that their doctors dismissed them with a 'You will have to learn to live with it'. If that sentence was positive and backed up with information it would be appropriate. As a dismissal it is inadequate and makes it difficult for the telephone counsellor who wants to encourage patients to get the best out of their doctors.

Every letter receives a personal reply, albeit adapted from model letters on a word processor. The presence of three members of staff with

rheumatoid arthritis is a great advantage for telephone counselling. The increasing professionalism of the welfare department of Arthritis Care is marked: the staff includes a nurse, a colleague with extensive experience in a Citizens Advice Bureau, and an occupational therapist.

People do not see themselves as patients except when 'under the doctor'. Patient education materials need to be written not from the perspective of the rheumatology clinic but from that of the home, the neighbourhood, and society as a whole, and should be based on 'real' questions asked by 'real' people. Arthritis Care plans to meet the needs of those who ask for advice by developing a series of information sheets which will deal with the questions most frequently asked. They will be drafted by members of the welfare department, volunteers, members of Arthritis Care, or professionals associated with Arthritis Care. They will be approved by the chairman of the medical advisory committee, to which the chairman of ARC's education committee was recently co-opted in a welcome and reciprocal way, and the chairman of the welfare committee. They will be cheaply produced so that updating can be regularly undertaken at minimum cost, and add to the range of existing booklets/leaflets.^{2 3}

Public education is not just about arthritis but about changing attitudes to disabled people—a far bigger problem. Society still finds it difficult to accept the contribution that physically disabled people can make. Changing the physical and social environment within which people with arthritis live is a bigger battle. Individual disabled people see the need for attitudinal, environmental, and institutional change. What does this cartoon from *The Independent* say to someone who is disabled? And to those who are not?

Cartoon reproduced by permission of The Independent.

Table 2 Breakdown of inquiries March 1990*

Inquiries about treatment		Inquiries related to coping	
Treatment	No (%)	Aspect	No (%)
Pain control	28 (27)	Money	17 (30)
Diet and weight control	19 (18)	Equipment	16 (28)
Alternative medicine	15 (14)	Employment	8 (14)
Drugs	14 (13)	Family and social	8 (14)
Self help	13 (12)	Travel and mobility	1 (2)
Surgery	12 (11)	Bereavement	7 (12)
Doctors and rheumatologists	4 (4)		
Total	105 (99)	Total	57 (100)

*This table was based on a limited sample from the 722 inquiries in March 1990. The sample was 60 consecutive telephone calls, 60 consecutive letters, and 20 consecutive Helpline calls. Typically people raise more than one concern.

Role of the education subcommittee of the Arthritis and Rheumatism Council

The Arthritis and Rheumatism Council for Research was originally called the Empire Rheumatism Council. It was founded in 1936 as a voluntary organisation to finance research into arthritis and rheumatism. In 1964 its name was changed to the Arthritis and Rheumatism Council for Research in Great Britain and the Commonwealth.

The Arthritis and Rheumatism Council (ARC) has three main aims and objectives: to raise money for research into the cause and cure of arthritis and rheumatism; to promote a better understanding of rheumatic diseases among patients, doctors, and others concerned with patients' treatment and care and the general public; and to encourage the provision of better treatment for all who have these painful diseases. It is the second of these aims that encompasses the function of the education subcommittee.

The committee promotes a better understanding of rheumatic diseases among health care professionals, including doctors, doctors in training, and paramedical staff such as physiotherapists, occupational therapists, and nurses, and also among the general public, especially those with arthritis and, of course, their carers. The committee meets four times a year and has been in existence for 40 years. Membership of the committee is drawn from all over the country to ensure an even representation from all the main teaching centres and districts. In addition to practising rheumatologists, the committee has a number of co-opted members. These include the editors of ARC publications, a representative of the British Health Professionals in Rheumatology group, a representative of senior registrars who are training in rheumatology, the editor of the *ARC Conference Proceedings*, the ARC press officer, representatives of the Royal College of General Practitioners and the ARC epidemiology research unit.

The committee initiates and reports back on a number of basic educational topics at each of its meetings. For instance, the committee plans and commissions publications to send to those with rheumatic diseases throughout the United Kingdom. These publications have proved so popular that a number of items have been translated into various languages, and have been used internationally. People with arthritis or any other of the many different types of rheumatic diseases often have a desperate need to know more about what is happening to them, the treatments they are receiving, and what they can do to help themselves. The education subcommittee has distributed hundreds of thousands of booklets and sheets to those with rheumatic diseases. A new, redesigned series was started in 1985, and since then more than two million publications have been requested and sent out. Sometimes patients receive these handbooks from consultant rheumatologists or family doctors, but one of the tasks of the education subcommittee is to ensure that the booklets reach people who may not be able to get them from a local source, and for this reason the ARC uses the media extensively to make patients aware that such publications are avail-

able. This educational campaign extends throughout the year, but there is a peak of activity during National Arthritis Education week, which now takes place early in January. During this time members of the education subcommittee publicise particular topics in the press, on radio, and on television. After television programmes or radio 'phone-ins several thousand people request copies of particular handbooks.

The committee also awards grants to enable research into methods by which those with rheumatic diseases can be informed about their diseases. For instance, it has recently funded a study on information issues in the rheumatology clinic, which examines from the patient's point of view information they are given in the clinic, and assesses the use that patients make of what they are told.

DISSEMINATION OF INFORMATION TO DOCTORS AND MEDICAL STUDENTS

Education of doctors, both those in training and those already in practice, is one of the principle aims of the education subcommittee. The intention is to ensure that good treatment practice and the latest information on treatment reach both medical students and family practitioners. The ARC series of reports on the rheumatic diseases is sent to family doctors, hospital specialists, and medical students. The committee also commissions tape/slide instructional material, and the ARC slide collection is available to all rheumatologists in training. In the past the ARC has also arranged exchange fellowships for doctors from the United States to visit certain centres in the United Kingdom.

Additionally, the education subcommittee founded the Arthritis and Rheumatism Council prize in rheumatology, which is awarded annually in each of the medical schools in the United Kingdom. In this way it has increased awareness of the rheumatic diseases among doctors other than rheumatologists, and among those who are training the future doctors and medical students.

Scientific meetings are important for exchanging ideas and information about research in progress. The published proceedings of such meetings are widely read by the scientific and medical community, but publishing can be costly. The ARC has set up a cheap and rapid publishing service to ensure that the information is not lost, and the *ARC Conference Proceedings* series has now been in existence since 1985.

EDUCATION OF PARAMEDICAL PERSONNEL

The ARC education subcommittee has continued to encourage paramedical staff to develop their knowledge and skills in the care of the rheumatic patients, and postgraduate training bursaries are awarded annually to enable physiotherapists, occupational therapists, and chiropodists to undertake further training. Bursaries are also awarded to paramedical staff enabling them to attend congresses of the rheumatic diseases.

The education subcommittee of the ARC will continue to explore and develop methods of disseminating knowledge about the rheumatic diseases, and over the next few years it is commissioning an investigation as to the ways in which this can best be done. Although the amount of funding required to finance the activities of the education subcommittee is small compared with that needed by the research

function of the ARC, we believe that the money is well spent and provides an increased awareness of these crippling disorders.

- 1 *Arthritis: the painful challenge*. London: Arthritis Care, September 1989. (Free with SAE.) (Searle social research fellowship report 1989.)
- 2 *Information for people with arthritis*. London: Arthritis Care, September 1989. (Free with SAE.)
- 3 *Eating and moving*. London: Arthritis Care, September 1990. (Free with SAE.)