

Living with Arthritis

Julie Barlow



The
British
Psychological
Society



BPS Blackwell

Living with Arthritis

I dedicate this book to my parents

JOAN AND GORDON POWELL

who never lost hope

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Julie Barlow



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This edition first published 2009 by the British Psychological Society and Blackwell Publishing Ltd
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Registered Office

John Wiley & Sons Ltd, The Atrium, Southern Gate, Chichester, West Sussex, PO19 8SQ, UK

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350 Main Street, Malden, MA 02148-5020, USA

9600 Garsington Road, Oxford, OX4 2DQ, UK

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Library of Congress Cataloging-in-Publication Data

Barlow, Julie (Julie Helen)

Living with arthritis / Julie Barlow.

p. cm.

Includes bibliographical references and index.

ISBN 978-1-4051-0809-6 (hardcover : alk. paper) – ISBN 978-1-4051-0810-2 (pbk. : alk. paper)

1. Arthritis—popular works. 2. Arthritis—Psychological aspects. I. Title.

RC933.B342 2009

616.7'22—dc22

2008044723

A catalogue record for this book is available from the British Library.

Set in 10/13pt Palatino

by SPi Publisher Services, Pondicherry, India

Printed in Malaysia

The British Psychological Society's free Research Digest e-mail service rounds up the latest research and relates it to your syllabus in a user-friendly way. To subscribe go to www.research-digest.org.uk or send a blank e-mail to subscribe-rd@lists.bps.org.uk.

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Abbreviations

AAR	adolescent arthritis and rheumatism
ACR	American College of Rheumatology
ANS	autonomic nervous system
anti-TNF	anti-tumour necrosis factor
AS	ankylosing spondylitis
ASE: Function	Arthritis Self-Efficacy Function
ASMP	Arthritis Self-Management Programme
CAM	complementary and alternative medicine
CBCL	Child Behaviour Check List
CBT	cognitive behavioural therapy
CDC	Centers for Diseases Control and Prevention
CDSMC	Chronic Disease Self-Management Course
DMARD	disease-modifying anti-rheumatic drug
ESR	erythrocyte sedimentation rate
FMS	fibromyalgia syndrome
GP	general practitioner
HADS	Hospital Anxiety and Depression Scale
HPA	hypothalamic-pituitary-adrenal
HRQOL	health-related quality of life
IWPD	INTO Work Personal Development Programme
JIA	juvenile idiopathic arthritis
LBP	low back pain
MHLC	Multi-Dimensional Health Locus of Control Scale
MMPI	Minnesota Multiphasic Personality Inventory
NAAB	National Arthritis Advisory Board (USA)
NAAP	<i>National Arthritis Action Plan: A Public Health Strategy</i>
NSAID	non-steroidal anti-inflammatory drug
OA	osteoarthritis

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PASE	Parent's Arthritis Self-Efficacy Scale
PIL	purpose in life
RA	rheumatoid arthritis
RNP	rheumatology nurse practitioner
SMART	Self-Management Arthritis Relief Therapy
SMC-AS	Self-Management Course for People with Ankylosing Spondylitis
WHO	World Health Organization

Acknowledgements

I extend my grateful thanks to the many research and practitioner colleagues I have worked with on arthritis-related studies that feature in this book, including Mary Grant, Jenny Hainsworth, Karen Harrison, Roy Jones, Thilo Kroll, Steve Macey, Lesley Powell, Ian Rowe, Karen Shaw, Janice Sheasby, George Struthers, Laura Swaby, Andy Turner, Bethan Williams, Chris Wright and Suzanne Wright. Thanks are extended to people living with arthritis who have taken part in my research studies, giving freely of their time and perspectives.

Introduction

Arthritis is a topic worthy of attention and one in which psychology and psychologists have crucial roles to play. For example, psychological theories may enable greater understanding of this painful, long-term condition and can be used to inform development of psychological interventions aiming to aid adaptation. Such interventions may be delivered by psychologists or psychologists may design and provide tutor training for interventions that can be delivered by others, including health and social care professionals, voluntary organisations or lay people living with arthritis who take on the role of peer educators.

Arthritis is a generic label used for over 100 different types of musculoskeletal, connective tissue and non-articular conditions, the most prevalent forms being osteoarthritis (OA), rheumatoid arthritis (RA) and ankylosing spondylitis (AS) in adults (Taal, Seydel *et al.*, 1993) and juvenile idiopathic arthritis (JIA) in children. Other forms of arthritis (e.g. systemic lupus erythematosus, Scleroderma, Sjogren's syndrome, psoriatic arthritis, and gout) are less common. Most forms of arthritis follow an unpredictable course of exacerbations and remissions, resulting in varying degrees of physical disability. Prognosis is uncertain, and, since there is no cure, treatment is ameliorative, aiming to alleviate inflammation, reduce pain and preserve or improve function. Medication remains the mainstay of medical management and can improve disease outcomes for many. However, medication can be associated with adverse side effects (Kean *et al.*, 1997; Thompson *et al.*, 1985), which are often a cause of concern for patients and their carers (J. Barlow, Harrison & Shaw, 1998). Other treatments that may be offered include physiotherapy, occupational therapy and podiatry. People with arthritis often require long-term monitoring and care by general practitioners (GPs) and/or hospital-based rheumatology

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clinics for more severe cases and conditions (e.g. RA). Despite regular treatment, many patients experience severe functional disability after 20 years of living with the disease (Fries *et al.*, 1996). Indeed, a recent community-based, UK study reports the rates of work disability among people with RA at 1, 2, 5 and 10 years after symptom onset as 14 per cent, 26 per cent, 33 per cent and 39 per cent respectively (Barrett *et al.*, 2000). The authors conclude that the move to earlier, more aggressive medical treatment has failed to influence the rates of work disability among this patient group. Thus, it is not surprising to find that many people with arthritis turn to complementary medicine (Resch *et al.*, 1997), express a strong desire to learn 'something I can do myself' (J. Barlow, Pennington & Bishop, 1997) and participate in psycho-educational interventions.

Arthritis is one of the most common, long-term conditions affecting millions of people worldwide. In the US, prevalence rates of self-reported arthritis are projected to increase from 15 per cent (37.9 million) in 1990 to 18.2 per cent (59.4 million) by 2020 (Helmick *et al.*, 1995) with older people, women, and those with less education or lower incomes being at greater risk. In the UK, diseases of the musculoskeletal system account for 46 per cent of all disability reported by adults living in private households (Martin *et al.*, 1988). The burden of rheumatic diseases is related to treatment and outcomes, described by Fries and Spitz (1980) as death, discomfort, disability, drug toxicity, dollars and dissatisfaction, mainly associated with current treatment. To this can be added quality of life for individuals living with arthritis, and their families. The burden of disease from a societal perspective is measured in monetary terms. Data from the US, Canada, the UK, France and Australia suggests that the cost of rheumatic diseases accounts for 1 to 2.5 per cent of the gross national product (March & Bachmeier, 1997). Until 1999 arthritis was not considered a major public health problem anywhere in the world, despite being the largest single cause of physical disability (Badley & Tenant, 1993) and being associated with increased rates of mortality (Pincus & Callahan, 1993). The US is the only country to have recognised that arthritis demands a public health approach. Following publication of the *National Arthritis Action Plan: A Public Health Strategy* (NAAP), the Centers for Diseases Control and Prevention (CDC) initiated a major programme in 1999 to both measure and reduce the impact of arthritis. The programme involves three core strategies:

1. fostering development of state arthritis programmes;
2. strengthening public health science;
3. developing health communication, health education, and health system quality improvement activities to reduce the burden of arthritis.

The last of these involves the development of tools and strategies to be used by state health departments and other partners. One strategy under development is a health communication campaign to increase physical activity among people with arthritis. In addition, the CDC has developed an online training programme for state health departments and others interested in a public health approach to arthritis. The CDC is also attempting to improve the clinical care received by people with arthritis by piloting system changes such as routine monitoring of functional status, ongoing self-management support and easy access to physical and occupational therapy in primary care.

At an international level and with the support of the World Health Organization, the period 2000–2010 has been designated the Bone and Joint Decade by health professionals from different specialities, scientific and patient organisations and governments. The overall purpose is to mobilise an offensive against diseases affecting the musculoskeletal system, particularly in terms of the development and promotion of improved therapeutic options.

This book aims to provide an overview of arthritis that is grounded in the realities of living with a long-term condition often characterised by pain, fatigue, physical limitations and psychological sequela such as anxiety and depression. Life with arthritis involves a continual process of adjustment, which is a useful illustration of how the human spirit can survive, maintain a sense of hope and even flourish in the face of adversity.

As well as the growing body of literature in psychosocial rheumatology, the book draws on my own research and research conducted with colleagues based in the Self-Management Programme, Applied Research Centre in Health & Lifestyle Interventions, Coventry University and in healthcare provision. I view the person with the condition as central to my research and have learned a great deal by simply listening to the stories of people with different types of arthritis covering the full age span – from young children to 90-year-olds. The lessons learned and the rich depth of understanding offered by qualitative approaches is

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used to complement quantitative investigations of pertinent issues. Thus, qualitative studies and associated quotes from such studies are used extensively in many sections of the text. A substantial section of the book is devoted to interventions with a psychological basis. Anything that promotes a positive change is of vital importance in the search to assist people with arthritis make the adjustments needed to attain a satisfactory quality of life. Indeed, psycho-educational interventions, especially those involving lay people as tutors, are well established in psychosocial rheumatology. One could speculate that this development has occurred in the face of the inability of medicine to offer a cure or successful alleviation of symptoms with no associated adverse side effects.

In Chapter 2, the disease characteristics of the main types of arthritis are described, along with epidemiological data, risk factors and disease management strategies that are typically employed. The book will focus on four main types of arthritis (i.e. RA, OA, AS in adults and JIA in children), allowing perspectives from across the age span (e.g. childhood to the older elderly) to be considered and, in the case of JIA, the perspectives of close family members. The chapter concludes by considering metaphysical explanations for arthritis and the use of complementary medicine.

Chapter 3 adopts a historical approach by reviewing early attempts to link personality characteristics with the onset of arthritis, particularly RA and AS. The difficulties of identifying causal links between personality and arthritis and links between stressful events and disease onset are discussed. The problems that can arise in obtaining a diagnostic label for the specific type of arthritis and the overlap between physiological and psychological symptomatology are reviewed. Finally, the relationship between disease duration and wellbeing, particularly depressed mood, is examined.

Chapter 4 describes the experience of living with arthritis from the perspectives of children through to older adults, and includes insight into the perspectives of carers (partners or parents). The chapter draws on the growing body of qualitative studies that aim to provide a picture of arthritis grounded in lived experiences and to generate rather than to test theory. An increasing number of such studies are appearing in the literature, a trend that reflects the increasing emphasis on patient-centred approaches to health care, and the need to listen to the voices of consumers (users) of services. This focus is in keeping with a number of

White Papers published in the UK (e.g. *Saving Lives: Our Healthier Nation*). Key areas perceived as problematic by people with arthritis and their carers are developed. For example, the essential task of managing persistent pain, chronic fatigue and feelings of loss of control are presented. This chapter sets the scene for later discussions of coping and self-management.

The psychological and social aspects of life with arthritis are intertwined. However, for the purpose of presentation, they are dealt with in Chapters 5 and 6 under the broad headings of psychological impact and social impact. The theme of considering both the people with arthritis and their carers is continued. In contrast to Chapter 4, most studies of psychological impact are based on quantitative methods, with many aiming to test psychological models. Reflecting the focus of the majority of psychological studies, the increased vulnerability to depression will be discussed in depth, including the relationship between pain, disability and depression. Other issues covered include the concept of control that emerges as a salient issue for people living with the disease.

Chapter 6 focuses on the way that arthritis can interfere with social relationships, and gives particular emphasis to studies of social support, spouses and other family members. The social model of disability is explored and issues connected with working life, resultant economic impact and the visibility of arthritis are discussed. The notion of visibility is examined in relation to children, adolescents and the myths about arthritis that are present in society (e.g. that arthritis is a disease of old age).

Chapter 7 discusses healthcare issues in arthritis, such as understanding more about the relationship between patient and healthcare professional, particularly in terms of encouraging individuals to play a role in their disease management. The issue of disease duration in relation to the amount of knowledge and coping skills attained by people with arthritis is reviewed. This leads to consideration of arthritis patient education focusing on the use of informational strategies and written materials as simple interventions that can be widely distributed at relatively low cost.

Chapter 8 covers the use of more complex psychological interventions in arthritis, many of which draw on social cognitive theory in their guiding principles. The most common interventions are based around cognitive-behavioural techniques and lifestyle management (e.g. exercise, diet). Self-management is well established in the field of arthritis, and

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encompasses lay-led interventions delivered in community settings. Given that people with arthritis spend the majority of the time managing their condition in the home environment, becoming a successful self-manager is of paramount importance. Interventions for children with JIA are included, although there are few studies published in this area.

Key issues covered are summarised in Chapter 10 and the way forward for psychosocial rheumatology is identified in the form of a research agenda.

Arthritis and Disease Management

Rheumatic diseases are among the oldest diseases known to man. They were recognised by Hippocrates in the fourth century BC, and the discovery of skeletal remains in North America suggest that rheumatoid arthritis may have existed 3000 years ago (Goemaere *et al.*, 1990). Similarly, the remains of ancient Egyptian mummies indicate the presence of ankylosing spondylitis. The term 'rheuma' was used in the first century AD, to indicate a flow of pain through the joints. The term 'rheumatology' first appeared in a textbook edited by Hollander and Comroe and published in 1949.

Classification of rheumatic conditions is hindered by the lack of aetiological evidence for many diseases. Nonetheless, classification systems have been developed, primarily by the American College of Rheumatology (ACR) 1987. At present, classification is determined by clinical and laboratory findings, including observation of abnormal anatomical structures and organ systems, the presence of suspected aetiological mechanisms, genetic factors and, occasionally, infectious agents, and the general manifestations of disease (Sangha, 2000). Thus, individual manifestation may suggest a broad category of disease or a syndrome rather than a firm diagnostic label. This situation is confounded even more by the potential overlap, clinically and pathologically, of many rheumatic conditions. The role of psychological factors in masking or overlapping physical disease has been acknowledged in the literature (J. Barlow, Macey & Struthers, 1993; Creed & Ash, 1992). However, it is not clear how often psychological factors are considered in practice.

Rheumatic disease, or the more commonly used term 'arthritis', has no clear boundaries. Rather the term arthritis is used to refer to over 100 different conditions. This book focuses on RA, OA, AS and JIA.

These types of arthritis have been selected for the following reasons. Firstly, OA is the most prevalent type of arthritis worldwide; secondly, RA tends to be the most common condition seen in many rheumatology clinics. Together, OA and RA account for a large percentage of disability worldwide (Sangha, 2000). The condition of AS has a similar prevalence to RA but differs in terms of the sex ratio (i.e. it is one of the few types of arthritis to have a male predominance). Finally, JIA is one of the most common diseases of childhood and can have long-lasting impact on both the child's and family's wellbeing. Each of these conditions is described in more detail below.

Osteoarthritis

Osteoarthritis (OA) is generally acknowledged to be the most prevalent form of arthritis and is a significant cause of disability, particularly among older people. For example, it is estimated that OA accounts for 12.3 per cent of all activity limitations in the USA (La Plante, 1988). Since there is no discrete onset, laboratory abnormality or pathognomic features, the condition is classified according to the joint affected (e.g. hip, knee, hand, spine, or other). Estimates of the prevalence of OA are imprecise due to the difficulties of diagnosis. Thus, prevalence rates vary according to the reporting methods used, the age and gender of study participants and the number of joints studied. Early epidemiological studies in the UK, using radiographic change as the detection criterion, found that almost everyone aged 65 and over had OA in at least one joint (Lawrence *et al.*, 1966). The incidence of moderate or severe OA in one or more joints increases with age; therefore, as the proportion of older people in the population increases, a growing number of older adults are likely to develop OA. Indeed, age is the principal predictor of OA regardless of joint site.

Risk factors for OA vary according to the joint affected and include age, female gender, obesity, genetic predisposition, occupation, trauma, repetitive use and excessive mechanical loading of joints (Croft *et al.*, 1992; Schneider *et al.*, 2005; Vingard, 1994). The last of these risk factors leads to a higher prevalence of OA among certain occupations, including mining (Felson *et al.*, 1994), ballet dancers (Andersson *et al.*, 1989) and athletes such as runners, weight lifters and footballers (Kujala *et al.*, 1995, Turner *et al.*, 2000). It should be noted that age, intensity and

duration of the physical activity causing strain on joints and the risk of injury associated with certain physical pursuits (e.g. football) are likely to be influential factors determining disease onset. (See the Appendix for an account of arthritis from an ex-professional footballer's perspective.) Both hand and knee OA appear to be more common among women (i.e. 1.5:1 to >4:1), suggesting that female sex hormones may represent a predisposition to disease onset and/or severity (Rosener *et al.*, 1986). However, there is an absence of clearly supportive data to confirm this notion. Obesity has been associated with OA of the knee but is less associated with OA of the hand or hip (Oliveria *et al.*, 1999). The importance of avoiding obesity was demonstrated in a prospective study showing that a weight loss of 5 kg was associated with a 50 per cent risk reduction of developing symptomatic OA of the knee (Felson *et al.*, 1992). A particular pattern of high fat distribution in the abdominal cavity has been linked to possible metabolic abnormalities or fertility problems (Zaadstra *et al.*, 1993). Basically, a high waist-to-hip ratio (an apple body shape) has been linked to risk of OA whereas a pear-shaped body has not.

In contrast to most other long-term conditions, smoking may have a protective effect in OA (Felson *et al.*, 1989). One possible biological mechanism through which smoking may play a protective role concerns the stabilisation of cartilage by tar and/or nicotine. This issue is likely to attract a great deal of attention, although it is unlikely that smoking would be recommended as a prophylactic due to its many adverse effects on health. Other factors that have been implicated in the development of OA include bone density and diet. However, further studies are needed to affirm these proposed linkages. An early study of 2389 older people with three or more symptoms of arthritis (Elder, 1973) found that people attributed their symptoms to ageing, the weather (e.g. cold, damp), injuries and heredity. Although there is no scientific evidence to support such claims, changes in temperature and humidity are consistently reported to influence perceptions of pain and stiffness by people living with the disease.

Osteoarthritis is characterised by progressive loss of articular cartilage and secondary reactions in the bone causing joint pain and stiffness, particularly at the start of movement. Bony enlargement of affected joints (osteophytes) can occur and mobility can become progressively restricted. The symptoms of OA are unpredictable and can follow a fluctuating course. Hutton (1995) suggests that since there is no treatment that can influence disease progression, clinical management should be

based on principles of logic and not doing harm. Control of pain is through low-toxicity analgesia (e.g. acetaminophen or paracetamol), and although considered a non-inflammatory condition, non-steroidal anti-inflammatory drugs (NSAIDs) are often prescribed. Two surveys conducted in the US found that a significantly higher proportion of patients preferred NSAIDs to acetaminophen (Pincus *et al.*, 2000; Wolfe *et al.*, 2000). Exercise, use of splints, use of aids (e.g. walking stick) can assist mobility. Interestingly, physical therapy is viewed as a cornerstone of treatment in Europe whereas rehabilitation and physical therapy do not form key features of treatment in the US, despite being recommended in the ACR guidelines (Sangha, 2000). A systematic review of exercise therapy in patients with OA of the hip or knee found that the positive effects on pain and physical function were not sustained over time unless patients attended booster sessions after the treatment period (Pisters *et al.*, 2007). However, exercise therapy did have longer-term positive effects on patient global assessment of effectiveness. Outcome for people with severe hip or knee OA can be improved with joint replacement, which tends to last between 10 and 20 years. Use of specific measures for assessing hip function (e.g. Oxford hip score) reveals that hip replacement results in less pain and functional difficulty for the majority of patients (McMurray *et al.*, 1999). However, Orbell *et al.* (1998) suggest that the extent of functional improvement following joint replacement surgery varies considerably. Measurement of physical functioning in OA can be difficult due to the use of adaptive aids, which make movements easier to accomplish. Measures that do not specify 'movement without the use of aids' may tend to underestimate the true degree of physical impairment. Most people with OA remain under the care of a general practitioner, and are only referred to hospital-based clinics when problems become severe. For example, people with severe OA of the hip may be referred to an orthopaedic surgeon if ability to walk becomes seriously impaired and a hip replacement is thought to be the best option. As may be expected, co-morbidity is common among older people with OA.

Rheumatoid Arthritis

Rheumatoid arthritis (RA) is a chronic, multisystemic, autoimmune disorder of unknown cause. It affects the majority of races with a

prevalence of approximately 1 per cent (Schumaker, 1988), although prevalence is lower among rural Sub-Saharan Africans and Caribbean Blacks and is higher among Pima Indians in the USA (Silman & Hochberg, 2001). Onset typically occurs between the ages of 20 and 50, and is more prevalent amongst women, with a gender ratio of 2.5:1 (Sangha, 2000).

The precise aetiology of RA remains largely unknown, although several interactive, risk factors are believed to be implicated. Family studies suggest there is a genetic predisposition to RA. For example, severe RA appears at four times the expected rate among first-degree relatives of people with RA who test positive for rheumatoid factor. Furthermore, approximately 10 per cent of people with RA have an affected first-degree relative (Silman & Hochberg, 1993). The hereditary predisposition has been linked to the human leukocyte antigen, HLA-DR4, although the precise mechanism is poorly understood (Hazes & Silman, 1990). The predominance of RA among women has led to investigation of sex hormones, menstrual and reproductive factors as possible risk factors. For example, it is widely known that pregnancy can be associated with disease remission, followed by exacerbations during the postpartum period (Spector *et al.*, 1990). Although evidence is inconclusive, there are indications that oral contraceptives protect or postpone development of severe RA (Spector & Hochberg, 1990). Several studies report an increased prevalence of RA among smokers (e.g. Silman *et al.*, 1996). Furthermore, smoking has been associated with greater disease severity independent of age, disease duration or treatment (Masdottir *et al.*, 2000). Other factors thought to predispose individuals to the development of RA include low socioeconomic status (Berkanovic *et al.*, 1996), low levels of education (Callahan & Pincus, 1988), stress (Persson *et al.*, 1999) and trauma (Al-Allaf *et al.*, 2001). Regarding the last of these, a case-control study compared 262 RA outpatients with age- and sex-matched controls (262) attending non-rheumatology outpatient clinics. Fifty-five (21 per cent) of the RA patients reported significant physical trauma (e.g. injury) during the previous six months before disease onset, compared with 17 (6.5 per cent) of the controls. Interestingly, history of trauma was more common among patients who were seronegative for rheumatoid factor. The authors suggest that those with seronegative RA might have a different form of inflammatory arthritis that is precipitated by physical trauma.

There is evidence of an increased mortality rate among people with RA (Spector & Scott, 1988) that is attributed to the disease itself, infection, renal, respiratory, gastrointestinal and cardiovascular disease. Regarding the last of these, a large study of 2262 deaths of patients with RA found that approximately 40 per cent were attributed to cardiovascular causes (Pincus & Callahan, 1986). There is evidence that stress, age, male gender, high functional impairment and low education are predictors of mortality (Wolfe *et al.*, 1994). Chehata *et al.* (2001) found that although individual measures of disease activity at a single point in time were not predictive of mortality, the mean level of disease activity over time did have a significant relationship. High levels of sustained inflammation appeared to be important predictors of premature death. A study in The Netherlands maintains that life expectancy is reduced by approximately seven years in men and approximately three years in women (Vandenbrouke *et al.*, 1984). A population-based study conducted in Minnesota found evidence of a widening mortality gap between patients with RA and the general population (Gonzalez *et al.*, 2007). The widening gap was due to the lack of improvement in survival among patients with RA compared to improvements in overall mortality rates in the general US population.

In RA, the synovial membrane becomes thickened and inflamed, eventually resulting in degeneration of the cartilage and ultimately the joint. Primary symptoms are persistent pain, stiffness, swollen joints and fatigue. Anaemia is a common. Rheumatoid arthritis is a systemic condition, and therefore people can feel generally unwell in addition to experiencing problems with specific joints. Typically, joints in the hands and feet are affected, with mild to severe structural damage resulting in varying degrees of physical dysfunction (Meenan *et al.*, 1991) that can pose problems for activities of daily living. Individual prognosis is uncertain (Parker *et al.*, 1990), with some people experiencing only mild disease of brief duration whilst others have a relentless progressive polyarthritis with marked functional impairment and disability. The condition can follow an unpredictable course of exacerbation and remission. The economic impact of RA in England for the year 1992 has been estimated at £1.256 billion (McIntosh, 1996), with 48 per cent of costs attributed to medical expenses and over 52 per cent of costs (£0.65 billion) due to lost productivity. Figures such as these make inability to work (i.e. work disability) a key issue in the management of RA and other types of arthritis that affect people during their working years.

Many people with inflammatory arthritis, including those with RA, are prescribed NSAIDs as the first-line drug treatment that is designed to reduce pain and swelling. Unfortunately, NSAIDs can have side effects on the digestive system (e.g. indigestion) and thus are often prescribed alongside proton-pump inhibitors which reduce indigestion and protect the stomach. Developments in the field include the use of NSAIDs called COX-2 inhibitors which are easier on the stomach but have been linked to increased risk of heart attacks and stroke. A second-line treatment comprises disease-modifying anti-rheumatic drugs (DMARDs) that aim to slow down the effects of the disease rather than relieve symptoms. It is important that patients are monitored for side effects if taking DMARDs (e.g. gold injections, methotrexate). Corticosteroids or 'steroids' are useful for reducing inflammation but can have a number of side effects if given at a high dosage for a long period of time. A recent development concerns biological therapies, such as anti-tumour necrosis factor (anti-TNF) that is given as an infusion or regular subcutaneous injections. The long-term side effects of anti-TNF are not known. Analgesics, such as paracetamol, may be used to assist with the pain-relieving effects of other drugs. Useful websites for finding out more about the drugs used to treat RA and other forms of arthritis are www.arc.org.uk or www.arthritis.org.

People with RA are advised to carry out regular, gentle exercise and to learn how to protect affected joints thus avoiding unnecessary strain. Splints may be used to help prevent permanent joint deformity. Finally, where joints become damaged beyond repair, joint replacement may be necessary to relieve pain and to improve function. Hip or knee replacements can be successful in reducing pain and increasing physical functioning among many people with arthritis. However, for some patients with RA, replacement surgery is less successful and they continue to experience pain and functional limitations after a period of 12 months (Keefe *et al.*, 1991). Gender differences have been identified among patients with RA referred for orthopaedic surgery in Finland (Hakkinen *et al.*, 2006) in that women had greater disability than men. Pain, muscle strength and disease activity had a major impact on disability, especially among the female patients.

People with RA often require long-term monitoring and care by specialised rheumatology clinics. The per-case cost of treatment for RA is 1.5 times greater than for OA (Yelin, 1998). However, the lower cost of treating OA has to be offset against its greater prevalence, and thus the

overall economic impact is highest in OA. The situation is further complicated by the toxicity of NSAIDs used to treat RA, OA and AS where gastrointestinal complications can result from NSAID usage (e.g. bleeds, perforations). Disease-related resource utilisation tends to be higher for RA, whereas for OA a large proportion of medical costs relate to the side effects of NSAIDs that may necessitate additional physician visits, diagnostic procedures and hospitalisation (Sangha, 2000). In recent years, the psychosocial burden of disease has received more recognition, although conversion of psychosocial burden and quality of life into reliable and valid economic parameters remains to be achieved.

Ankylosing Spondylitis

Ankylosing spondylitis (AS) is one of a group of diseases referred to as seronegative spondylarthropathies. This group of diseases include psoriatic arthritis, Reiter's syndrome, reactive arthritis, and arthritis associated with inflammatory bowel disease, ulcerative colitis and Crohn's disease. Ankylosing spondylitis is characterised by an early age of onset (under 40) and is one of the few rheumatic diseases to exhibit a male predominance, with reported sex ratios in the region of 3:1 male to female (Kahn & van der Linden, 1990). However, it has been suggested that the true ratio may be nearer 1:1 (Russell, 1985). Whilst the debate about male:female ratio remains unresolved, it is acknowledged that the diagnosis of AS is often missed in women, and more women are now being diagnosed with the disease (Arnett, 1989). Consensus regarding methodologies and diagnostic criteria is necessary before the issues of gender-differentiated clinical profiles and prevalence rates of AS can be explained. Prevalence estimates range between 0.1 per cent and 2 per cent (Gran & Husby, 2003), although there may be many subclinical cases that do not receive a diagnosis.

Disease aetiology remains unknown, although an association with the human leukocyte antigen HLA-B27 was identified over 20 years ago (Brewerton *et al.*, 1973), suggesting that a genetic mechanism may be involved. Approximately 95 per cent of patients with AS have the HLA-B27 antigen compared with only 7 per cent in the population as a whole (Ebringer *et al.*, 1978). Possession of this antigen does not necessarily mean that AS is inevitable. A trigger factor, possibly an intestinal infection, is believed to be responsible for the onset of symptoms. Some

patients assert that onset occurred following trauma (Jacoby *et al.*, 1985). However, the disease may have been present in a subclinical form and become more active due to the treatment received for the trauma (e.g. immobilisation). For many people, disease onset is gradual and insidious, affecting mainly the spine and sacroiliac joints, although other parts of the body (e.g. hips, shoulders, knees and eyes) can become involved. Onset may typically, but not always, manifest as sacroiliitis together with inflammation of entheses (points of union between tendon, ligament or capsule and bone) (McVeigh & Cairns, 2006). Gradual fusion of affected joints in the spine is known as 'ankylosis' and results in progressive functional impairment and the development of a typical hunched posture. Many people with AS will also develop osteoporosis. The disease is believed to follow a milder course among women, although consistent evidence to support this notion is lacking (Gran & Husby, 1990).

An international group, the Assessment in Ankylosing Spondylitis Society, is producing evidence-based recommendations for the management of AS (Zochling *et al.*, 2006). Traditionally, treatment has comprised medication and therapeutic exercise. The aim of medication, usually NSAIDs, is to reduce pain and inflammation thus enabling the patient to carry out regular strengthening and stretching exercises. The aim of the latter is to maintain mobility of affected joints, to improve or maintain posture and to achieve general fitness. The short-term effectiveness of a regular exercise programme has been demonstrated among hospital inpatients (Bulstrode *et al.*, 1987; Tomlinson *et al.*, 1986). However, the majority of people with AS are not admitted for inpatient care. Exercise has to be conducted in the home environment or in classes organised by physiotherapy departments and voluntary organisations, such as the National Ankylosing Spondylitis Society in the UK. One of the few studies among AS outpatients found positive effects of group exercise on thoracolumbar mobility, general fitness and self-reported estimates of global health (Hidding *et al.*, 1993). Van Tubergen and Hidding (2002) maintain that conventional treatment with NSAIDs and exercise is palliative and often does not control symptoms in the longer term.

A relatively new development in the treatment of AS is the use of anti-TNF drugs. These drugs have been used in the treatment of RA and are now licensed for use in the treatment of AS in some countries but are very expensive. McVeigh and Cairns (2006) argue that the high

financial costs may be outweighed by the immense improvements in pain and function that can help some patients to remain in work and out of hospital. However, although anti-TNF can result in marked clinical improvements in trials, this treatment is not always effective and is not suitable for all AS patients (Claudpierre, 2005).

After diagnosis, some patients continue to be monitored in hospital-based clinics, whilst others may be referred back to community-based medical practitioners for long-term health care. People with AS can be referred to a physiotherapy department for advice on home exercise activities and may also receive a short course of hydrotherapy, although such treatment is dependent upon the availability of local facilities. Interestingly, there is evidence that people with AS tend to underestimate their functional difficulties (Hidding *et al.*, 1992) and use unusual movements or gadgets to assist in problem areas (Abbott *et al.*, 1994). Underestimation of functional difficulties and coping with daily activities through novel adaptations can mask true functional impairment in both clinical assessments and research studies.

Juvenile Idiopathic Arthritis

Contrary to the general belief that arthritis is a condition of 'old age', some forms of arthritis begin in childhood. Arthritis in children has been known as juvenile chronic arthritis (JCA), juvenile rheumatoid arthritis (JRA) or juvenile idiopathic arthritis (JIA). All of these terms appear in the published literature but refer to the same condition. The most recent term, JIA, will be used throughout this text. Juvenile idiopathic arthritis is one of the most common chronic diseases of childhood, with prevalence estimates ranging from 0.16 to 1.13 per 1000 children (Benjamin, 1990), suggesting that there are over 15,000 children with JIA in the UK, for example. Peak ages of onset are between 1 and 3 years, with incidence being twice as high among girls compared to boys (Cassidy & Petty, 1990). The disease is a significant cause of physical disability and blindness. Mortality has been estimated at between 2 per cent and 4 per cent (Cassidy & Petty, 1990), although the possibility of mortality remains a largely taboo area.

Classified as a heterogeneous group of disorders, JIA is characterised by persistent inflammation of the joints that presents before 16 years of age (Munthe, 1990). The condition is categorised into three subgroups:

1. systemic onset disease, characterised by fever and a rash;
2. pauciarticular disease (four or fewer joints affected in the absence of systemic features);
3. polyarticular disease where five or more joints are involved in the absence of systemic features.

Systemic onset disease affects between 10 per cent and 25 per cent of children with JIA, has a peak age at onset of 2 years and is equally prevalent among boys and girls. Onset is acute, with remittent fever, a rash, fatigue and possible inflammation of glands and vital organs (e.g. heart). Joint inflammation typically follows systemic onset. Complete recovery occurs in 50 per cent of cases, whilst a third will develop polyarticular JIA. The latter occurs in 30 per cent to 40 per cent of children with JIA, and predominates in younger girls. Arms, legs, hands and feet are affected, and prognosis tends to be poor. Children with polyarticular onset are those most likely to have active disease in adulthood and are at risk of permanent joint damage. Pauciarticular onset is the most common form of JIA, accounting for between 40 per cent and 50 per cent of cases. Onset typically occurs before the age of 5 years and, again, predominates among girls, usually affecting wrists, knees and ankles. Prognosis is generally good with the disease lasting for a few years only. Nonetheless, following a summary of outcomes from both retrospective and prospective studies, Duffy (2005) concluded that a significant number of patients continue to have active disease during adulthood and live with significant damage and disability. For example, a UK study of 231 adults with long-standing JIA found that 43.3 per cent had active arthritis as indicated by clinical parameters and 54.4 per cent had active disease using laboratory measures (e.g. C-reactive protein). The proportion with severe disability using a score of >1.5 on the Heath Assessment Questionnaire was 42.9 per cent (Packham & Hall, 2002).

The disease follows an unpredictable course, and thus for many children life with JIA fluctuates between periods of active disease and remission. Typical symptoms include pain, stiffness, swollen joints, fatigue, lack of appetite and general irritability. Prognosis is uncertain and in the absence of curative treatment, primary therapeutic goals are to reduce pain and inflammation, maintain joint function, promote muscle strength, prevent disability and control extra-articular manifestations such as iritis. Disease management is complex, involving a combination of diverse therapies (e.g. medication, wearing splints and

exercise) and regular visits to various outpatient clinics such as rheumatology, ophthalmology and physiotherapy. In addition, JIA requires constant monitoring and performance of self-care activities. The responsibility for day-to-day disease management quickly shifts from health professionals to parents and children. Adolescents are expected to play a greater role in the management of their disease in accordance with their growing independence and autonomy.

The impact of JIA and its management upon the family is considerable. Up to one-third of the child's free time may be lost due to arthritis (Southwood & Malleon, 1993), and the family's involvement in health regimens can severely restrict personal time, holidays and leisure pursuits. Concordance involves the negotiated agreement between patients, or their representatives, and the medical team (Marinker *et al.*, 1997). Since the term *concordance* conveys equal respect for the health beliefs of both patients and medical practitioners, it is less value-laden than terms such as compliance and adherence. This issue is discussed further in Chapter 7. Concordance in relation to JIA is believed to be less than optimal and forms a major area of concern (Kroll *et al.*, 1999). Not only may poor concordance reduce the potential benefits of treatment for individual children and their families, but on a wider scale it may lead to increased healthcare costs (Rapoff & Christophersen, 1982; Varni & Wallander, 1984).

Metaphysical Explanations for Arthritis

Psychologists have long been aware of the interaction between perceptions of stress and the physical body. The immune system can be influenced by stress, with negative emotions (e.g. anger, fear and resentment) causing the formation of chemicals in the body. For example, it is accepted that stressful life events and daily hassles can aggravate many long-term diseases, including arthritis. Metaphysical explanations build on this understanding by using the body parts and functions as a map of the individual's wellbeing whereby the physical expression of illness is believed to reflect emotional imbalance, maladaptive patterns of learned behaviours or non-serving thought patterns. With the growth of interest in complementary medicine, it is worth considering metaphysical explanations for arthritis and whether the insights gained are of value for individuals with the disease. A detailed examination of

metaphysics is complex and beyond the scope of this text; interested readers are referred to the burgeoning literature on this topic (e.g. Hay, 1984).

One of the basic premises of metaphysics is that we create our own reality. Since it is extremely unlikely that people deliberately and consciously chose to have pain and disease, it is important that individuals are not held to blame for their conditions. Rather, they are in need of assistance and support in attempts to find, understand and address the causes of their conditions and how they may promote healing (i.e. bring the whole system into balance). The insight provided by metaphysics is just that and should be used accordingly. Although typical patterns and associations have been noted and published, each person is unique and may not fit with established norms and views. The same holds for medical care; one person may react totally differently to the next when given NSAIDs for example.

The way the joints function determines the degree of freedom and grace expressed in our movements and the direction we are taking at a given point in time or in our lives in general (Shapiro, 1990). Any restriction in joint functioning is believed to indicate a problem in that area. Characteristic symptoms experienced by many people with arthritis include pain, stiffness, inflammation and fatigue. The metaphysical explanation views pain as a warning sign that the area corresponding to the pain needs attention and that the pain can be an indication of suppressed anger or bitterness. Stiffness of joints can indicate rigid thinking, self-criticism, or lack of self-worth. There can be fear around the notion of allowing new and different ideas to enter the mind and one's life. Metaphysically, inflammation is associated with unexpressed anger that manifests physically as hot, red, swollen joints that in turn cause restrictions of movement. Thus, there can be sensations of being restricted in one's life, restrained, confined or tied down. We may wish to be doing something different or even to be somewhere different. There may be a growing inability to be flexible in our thoughts and behaviours; an inability to 'go with the flow'. This state can reflect a lack of self-trust and a hardened attitude towards life. Rather than acknowledge these feelings about ourselves, we tend to project them outwardly towards others, placing ourselves in the role of victim rather than of co-creator of our world and the way we live (Shapiro, 1990). Fatigue can indicate weariness with life and a need for both mental and physical rest. We can experience an inner tiredness because we are

trying to keep going or to cope with our life. Fatigue can suggest a loss of purpose and direction, and a need to increase the joy and love we experience.

The main sites of arthritis in the body are feet, knees, hips, spine, shoulders and neck. Feet, legs and spine are all concerned with support of the self, thus problems in these areas may be associated with feelings of lack of support. The feet are our foundation and control the direction we move in. Hence, as well as lack of support and insecurity, foot problems can indicate conflict with direction and movement. Similarly, the knees are connected to movement, direction, and flexibility; they are the body's shock absorbers (Shapiro, 1990). Fluid is associated with emotions, therefore swollen knees can indicate emotional defence or resistance against the way that life is unfolding. Resentment and anger can be 'stuffed' behind the knees with the resultant inflexibility and rigid thinking typified by comments such as 'Why should I change?' The hips are associated with moving forward in life, reflecting one's hopes, dreams, goals and also fears. As well as lack of support, the spine represents how well supported we feel in our lives and how we carry our own issue or burdens and the burdens of others. Hence, we can feel overburdened with cares, weighed down or sense that we have 'someone on our back'. The shoulders represent our ability to reach out and enjoy life, with pain indicating a fear of moving in the wrong direction or a failure to grasp life with both hands. Finally, the neck represents our support of ourselves, our ideas and our flexibility of outlook. A stiff neck can suggest an inability to look around and see all sides of the picture. In sum, problems with the main sites of arthritis represent notions of lack support, insecurity, inflexibility, and failure to reach out and enjoy life to the full.

In the metaphysical literature, arthritis is believed to indicate a lack of self-love (e.g. Belot, 1999). Furthermore, since the individual lacks love for the self, it is difficult for them to accept love from others. This situation can result in conflict within the body and conflict in relationships. Rheumatoid arthritis, where the immune system starts to attack itself, indicates a deep dislike of the self, arising from shame, guilt, a deep sense of worthlessness and self-criticism, or long-held anger, bitterness and stiff attitudes (Shapiro, 1990). The 'attack' on the self manifests as painful and limited movement, lack of fluidity, and difficulty in freely expressing feelings and beliefs. Thus, the person with RA can become unassertive, inhibited and self-sacrificing, unable