LOOKING AHEAD

Best practice for the care of people with ankylosing spondylitis (AS)

National Ankylosing Spondylitis Society (NASS)

Foreword

NASS is the only registered UK charity working entirely for people with AS. It has three main tasks: to provide information for people with AS and their families; to campaign on their behalf for better services; and to support research into the condition.

NASS was founded in 1976 and since then it has seen an impressive growth in our understanding of AS and a long awaited improvement in the range of available therapies.

More than 300 years after the initial recognition of AS we have arrived at a challenging and exciting moment in the history of this condition. But despite many new opportunities it is abundantly clear that much still remains to be done.

NASS is seeking to develop its activities to improve the experience for patients and their families and welcomes the action points outlined in this document as an important part of this process.

There are some centres of excellence for the treatment of AS in the UK. NASS as an organisation and patients as individuals value them and the staff who run them highly. But the number of these centres in the NHS is limited and too few patients receive optimum care as a result. This has a huge impact not only on individuals and their families but also on society. It is time for this to change, particularly since we now have the knowledge and tools to do things better.

NASS owes a great deal to those individuals who have worked on the Looking Ahead project and I would like to thank them for their commitment and hard work.

They have produced a set of recommendations which will be of real value in improving the diagnosis, treatment and ongoing management of people with AS and we are grateful to them.

Jane Skerrett

Director, NASS
April 2010

Debbie Cook replaced Jane Skerrett as Director in June 2011.

Looking Ahead: Best practice for the care of people with ankylosing spondylitis (AS)

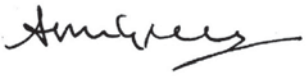
I welcome this new publication from the National Ankylosing Spondylitis Society (NASS).

It is vital that we all ensure that patients with ankylosing spondylitis receive the best possible care. Looking Ahead will help support clinicians in their work as well as giving patients the vital information they need to manage their condition.

I wish NASS every success with this invaluable publication.

Professor Deborah Bax
President
British Society for Rheumatology
March 2010

The Chartered Society of Physiotherapy is delighted to support NASS in the publication of this important initiative which not only highlights the treatment options for people with AS but also emphasises the crucial role that Chartered Physiotherapists play in the diagnosis, treatment and long term management of this condition which is often overlooked.



Ann Green
Chairman of the Council of the Chartered Society of Physiotherapy

Endorsed by:

Contents

Acknowledgements

Members of the working group

- Trish Cornell BSc (Hons),
  Senior Rheumatology Practitioner, Poole Hospital Foundation NHS Trust,
  Nurse Advisor to NASS

- Dr Karl Gaffney FRCP FRCPI,
  Consultant Rheumatologist Norfolk & Norwich University Hospital NHS Foundation Trust, Honorary Senior Lecturer, University of East Anglia

- Dr Andrew Keat MD FRCP,
  Consultant Rheumatologist, Northwick Park Hospital

- Dr Kirsten MacKay MD FRCP,
  Consultant Rheumatologist, Torbay Hospital and South Devon Healthcare NHS Foundation Trust

- Dr Helena Marzo-Ortega MRCP PhD,
  Consultant Rheumatologist, United Leeds Teaching Hospitals Trust, Honorary Senior Lecturer, Leeds Institute of Molecular Medicine, University of Leeds

- Jane Skerrett, Director,
  National Ankylosing Spondylitis Society (NASS)

- Liz Van Rossen MCSP,
  Extended Scope Practitioner in Rheumatology Physiotherapy, East Kent Hospital University Trust

- Professor Paul Wordsworth MB BS FRCP,
  Nuffield Department of Orthopaedics, Rheumatology & Musculoskeletal Sciences, Nuffield Orthopaedic Centre, Oxford

We are grateful for input on imaging from Dr Charles Wakeley, President of the British Society of Skeletal Radiologists, Consultant Musculoskeletal Radiologist, Bristol Royal Infirmary and Dr Winston Rennie, Consultant Musculoskeletal Radiologist, Leicester Royal Infirmary.

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Executive summary

1. Ankylosing spondylitis (AS) affects 2–5 adults per 1000 in the UK. It usually begins in early adult life and may cause life-long spinal pain and progressive restriction. Fifty per cent of people with AS also experience inflammation and damage at other sites, especially the hip and the eye.

2. AS causes substantial personal costs and costs to society: a major component of these costs relates to work disability.

3. The recent introduction of biologic drugs has provided opportunities to reduce the suffering of people with severe AS dramatically and to improve their quality of life and work productivity.

4. In spite of recent developments in health care, many people with AS in the UK do not receive optimum care because of delayed diagnosis and lack of access to appropriate expertise.

5. Early recognition of key features of AS is essential for effective treatment. Chief among these is the identification of inflammatory back pain (IBP) in primary care settings and its differentiation from other causes of back pain.

6. In the past, diagnosis was heavily reliant on the presence of radiographic changes in the sacroiliac joints which often take years to develop. The application of magnetic resonance imaging (MRI) techniques may detect abnormalities early and allow earlier diagnosis. This means that diagnosis can now be made before radiographic changes have occurred.

7. People with suspected AS should be referred early to a rheumatologist for assessment.

8. Specialist services for the diagnosis and management of AS are unevenly distributed throughout the UK leading to unequal access to optimum care. NHS Trusts should ensure that all patients have access to expert multidisciplinary teams, including specialist spinal surgeons, and the full range of appropriate treatments and support.

9. All patients with AS should have access to all conventional treatments, including physiotherapy when needed, community support for exercise programmes, and biologic therapies delivered according to national guidelines.

10. AS typically advances slowly over many years, often leading to insidious decline in physical and social abilities. Co-morbidities, such as osteoporosis and cardiovascular disease usually develop silently. Therefore people with AS should be offered regular long-term monitoring by appropriately trained and resourced members of the expert multidisciplinary team.

What is ankylosing spondylitis?

Ankylosing spondylitis (AS) is an inflammatory condition of the spine which often produces pain, stiffness, deformity and disability throughout adult life.

It usually begins in adolescence or early adulthood, a critical period in terms of education, work and establishment of social frameworks and relationships. It is one member of a group of rheumatic conditions characterised by inflammation in the spine known as the spondyloarthropathies (SpA)[1]. Four distinct members of the SpA family are recognised: ankylosing spondylitis; psoriatic arthritis; reactive arthritis and enteropathic arthritis associated with inflammatory bowel disease. Spondyloarthropathies may begin in childhood or teenage years, juvenile SpA often presenting with uveitis, hip, knee and/or foot involvement. In many cases this does not evolve into typical AS. Undifferentiated forms of SpA exist in both adults and children and these may or may not progress to a distinct form.

AS is a chronic progressive disease. It is characterised by periods of fluctuating intensity, leading to slowly increasing spinal and peripheral joint damage. Minimising the effects of disease progression and complications requires early recognition, careful long term monitoring and prompt appropriate treatment.

The prevalence of AS is between 0.2 – 0.5% of the adult Caucasian population (2–5 per 1000)[2]. It is likely that approximately 200,000 people suffer from AS in the UK[3], a figure that is around twice the number of people with multiple sclerosis, for example (Multiple Sclerosis Society. What is MS? June 2009). The prevalence of SpA as a whole is similar to that of rheumatoid arthritis.

The symptoms and signs of AS are characteristic[4] but may be difficult to distinguish from other more common kinds of spinal pain by the non-specialist clinician. The key symptom in early disease is inflammatory back pain (IBP). The onset of back pain and stiffness is usually gradual being especially severe at night and following immobility. For many people sleep is disturbed, often causing them to get out of bed in the night to move around so as to improve their back pain and stiffness. Several variations on this theme have been published to guide recognition of IBP[5,6] *(see figure 1)*. In contrast to symptoms of degenerative spinal pain, pain and stiffness in AS may be at their worst first thing in the morning and may improve considerably with stretching and light exercise. Persistence of disease leads to progressive spinal stiffness which may be accompanied by deformity. Up to 25% of people with AS eventually develop complete fusion of the spine which leads to substantial disability and restriction[7].

Fifty per cent of people with AS also suffer from associated disorders at sites distant from the spine. In particular, 40% experience episodic eye inflammation (iritis), 16% develop psoriasis and 10% inflammatory bowel disease[8].

Symptoms of AS usually begin during the second to fourth decades and are often present for a long time before the diagnosis is made. Some studies identified an average delay of 10 years between onset of symptoms and diagnosis, the period generally being much longer in women than men[9,10]. Delays in diagnosis and treatment are key issues that this initiative seeks to remedy.

Although most people with AS live a normal lifespan, there is an increased risk of premature death from cardiovascular disease in particular[11].

The cost to the individual and society

The cost to the individual

Since many people with AS are neither deformed nor have peripheral joint abnormalities, much of the burden of living with AS is invisible. The spectrum of severity means that although many people with AS live active and rewarding lives, others experience progressive spinal pain and immobility. The effects on lifestyle and interpersonal relationships are only now being recognised. Work disability is a major problem with more than 50% of affected individuals suffering work instability[12]. In addition, one-third of people with AS give up work before normal retirement age and another 15% reduce or change their work because of AS. The work capacity of people with AS in the middle decades of life is similar to that of people with rheumatoid arthritis[13].

Being unable to work has important consequences for the individual and his/her family through both loss of earnings and the loss of self-esteem that a career and income provide. Individuals with AS are more likely to be divorced or never to have married and women with AS are less likely to have children[14]. More subtle effects such as depression, fatigue and poor sleep may also exert a profound influence on quality of life.

The financial and personal costs of living with AS are substantial[15]. Time away from work, cost of drugs and other treatments, including regular exercise, together with increased insurance premiums, reduced earnings and pension rights renders many people with AS financially disadvantaged compared with their healthy peers. These financial issues are compounded by the personal costs of disease complications, side-effects of both medical and surgical treatment, co-morbidities such as bowel, skin and eye disease and, for those with the most severe forms of AS, a reduced lifespan.

The cost to society

The loss of up to one third of people with AS from the workplace has important cost implications both for the individual and society. This is compounded by changes in work patterns and the failure of many individuals with AS to achieve their chosen career or fulfil their potential[16]. Financial costs include the loss of tax revenue from those patients and carers unable to work, and the cost of paying disability living allowance (DLA) and carer's allowance. The direct costs of treatment include primary and secondary care costs, drug costs and social care costs.

A proportion of individuals with AS may require major joint or spinal surgery. Since surgery may be necessary at a relatively young age, it is common for replaced joints, especially hips, also to require revision at some stage. This has important personal and economic consequences and contributes to disease-associated mortality. Those with impaired mobility may require assistance with transport and this may impact on personal and family life as well as life at work. It is clear that societal costs rise exponentially as physical function deteriorates.

Why are these recommendations needed?

Care for people with AS in the UK varies considerably in quality. The aim of this document is to improve the lives of people with AS and their families by promoting good practice.

In spite of variations in practice in the UK there is widespread international consensus on key aspects of diagnosis and treatment. This document outlines the major problems that exist and provides solutions to them in the form of multidisciplinary professional guidance for the diagnosis and management of AS. As such, it provides a unique reference guide to address and help solve some of the difficult issues relating to the management of AS. It intends to facilitate the development of appropriate clinical services nationwide by providing a benchmark against which patients and their advocates can assess locally available services.

The key problems which inhibit universal high quality care for individuals with AS in the UK are:

Recognition of possible AS

Underpinning the problems with providing universal high quality care to people with AS is the low profile of the disease among both the medical profession and the general public. As a consequence people who develop symptoms have no familiarity with the disease: medical professionals confronted by people who may have AS may not consider it as a possible diagnosis and specialist services are under-developed in many instances.

Until recently AS was perceived as a relatively mild disease with few treatment options with the result that relatively little research has been done and many of the effects of AS were unrecognised.

Pathways of referral for people who may have AS

The chief problem is delayed diagnosis: many people go undiagnosed for 8 – 11 years[10]. The relative rarity of AS compared with the high incidence of mechanical back disorders together with the limited familiarity with AS in primary care make the diagnosis of all but the most extreme cases a difficult and challenging prospect. Over 30% of GP consultations are for musculoskeletal conditions[3] with low back pain the second most common complaint after upper respiratory problems as the reason for visiting a GP[17]. As a result pathways for managing back pain in primary care focus on the physical treatment of mechanical pain and on identifying "serious" causes such as cancer and the requirement for spinal surgery.

Why are these recommendations needed?

Making the diagnosis

The diagnosis of AS relies on the presence of clinical symptoms of IBP in conjunction with typical radiographic features of sacroiliitis *(see figure 2)*[18]. However most patients have normal x-rays in the early years of disease making it impossible for the diagnosis of AS to be made. This stage of the disease is often referred to as "early AS" or axial SpA. Some authors have used the term "non-radiographic" AS to highlight the fact that radiographic examinations may show no abnormalities at this stage[19]. In fact these radiographic changes may take a long time, sometimes more than 10 years to develop[9].

In the last decade magnetic resonance imaging (MRI) has been shown to identify inflammatory changes in the sacroiliac joints and spine at a much earlier stage, before radiographic abnormalities are detectable[20,21].

A new consensus has now been reached to adopt criteria for classification of AS in which evidence of sacroiliac joint inflammation as shown on MRI can be used *(see figure 3)*[22]. With these criteria it is now possible for a diagnosis of AS to be made before radiographic evidence of structural damage at the sacroiliac joints is detectable.

Access to the right specialists

For the best possible outcomes, people with AS should be managed by a rheumatologist. Those who are expert in other forms of spinal pain are not necessarily specifically skilled in treating inflammatory back pain and associated conditions; nor may they be part of a multidisciplinary team expert in this disease area.

Why are these recommendations needed?

Access to the right treatments – both medical and surgical

Conventional drug treatment of spinal disease is restricted to non steroidal anti inflammatory drugs (NSAIDs); other agents which are helpful in peripheral joint disease are generally ineffective in the spine. The last decade has seen the introduction of highly effective treatments, namely the TNF alpha blocking agents, which offer substantial improvements in symptom control and quality of life. In consequence, early diagnosis and appropriate access to treatment is critical.

In addition, further advances with improved imaging have greatly enhanced the safety and effectiveness of surgical treatment which should be considered when appropriate.

Long-term follow-up and management

For the right decisions to be made at the right times, people with AS need long-term monitoring by appropriate experts and/or ready access to advice or treatment when necessary.

Consideration of these issues has led to the recognition of seven key problems faced by people with AS which often limit access to optimum treatment, linked to a set of recommendations, adherence to which would overcome them. Since adopting these recommendations may not always be a simple process, a set of appropriate steps or "actions" has also been drawn up to help achieve them.

It would be a sad reflection on healthcare in the UK if these simple but vital steps could not be speedily adopted for the great benefit of many people with AS, both now and in the future.

Problems, Recommendations and Actions 1

PROBLEM 1: The diagnosis of AS is considered too late

Many people with AS have symptoms for years before the diagnosis is made. Current evidence indicates an average delay of 10 years between symptom onset and diagnosis[10]. The most characteristic early features of inflammatory back pain may not be readily identified so that the diagnosis of AS is often only considered once spinal symptoms have become chronic and disabling and irreversible spinal changes have already begun.

Many patients and their families have low awareness of the condition and healthcare professionals may not consider it through lack of familiarity and knowledge. Until recently, the benefits of early diagnosis and treatment have been perceived as modest so that making the diagnosis of AS may have been thought of as offering little benefit to the patient. But this is now far from the case. By delaying the diagnosis, irrevocable damage may occur at an especially formative phase of young adult life and opportunities may be missed to avert irreversible damage.

Services for people with back pain are changing. In primary care, these are increasingly being streamlined by the introduction of musculoskeletal triage services and back pain assessment pathways. Such changes are undoubtedly helpful for many people with spinal pain but there are important shortcomings: little provision is made for the identification of inflammatory back pain and often these services are staffed by health professionals with limited experience in inflammatory diseases. As a result many individuals with inflammatory back pain who enter the system miss out on an opportunity for correct diagnosis and are not assessed or managed by an appropriate expert.

RECOMMENDATION 1

Back pain assessment pathways should include a system for the recognition of inflammatory back pain

ACTION 1

- Inflammatory back pain *(see figure 1)* should be considered in all patients under 40 years of age presenting with chronic back pain of greater than 3 months duration.
- Spinal pain triage services should have systems in place for achieving this and individuals fulfilling these criteria should be referred to a rheumatologist rather than other specialists.
- Professionals involved in spinal pain triage should be appropriately trained in inflammatory as well as mechanical spinal disorders.

Problems, Recommendations and Actions 2

PROBLEM 2: Getting to the right expert

Even if the possibility of AS is considered, many individuals do not receive a prompt and accurate diagnosis nor the best advice regarding management because they do not consult an expert.

AS is not the prime area of expertise for most physiotherapists and orthopaedic surgeons; it is mainly dealt with by rheumatologists. Hence individuals in whom this diagnosis is suspected should be assessed by a rheumatologist in the first instance. The rheumatologist should be part of a multidisciplinary team with expertise in clinical assessment, appropriate imaging, metrology, physiotherapy, occupational therapy and effective drug therapies. This team should have easy access to musculoskeletal radiologists, ophthalmologists, gastroenterologists, dermatologists and specialist surgeons (orthopaedic and spinal) in order to manage related problems (uveitis, inflammatory bowel disease, psoriasis, spinal deformity). This approach is essential for the delivery of good quality care and the achievement of the best possible outcome.

RECOMMENDATION 2

People with suspected AS should be referred to a rheumatologist

ACTION 2

- Individuals who have inflammatory back pain and/or features suggestive of AS should be referred to a rheumatologist with knowledge and understanding of this condition and access to a multidisciplinary team.
- Referral to an orthopaedic surgeon or physiotherapist as a first choice is usually inappropriate.

Problems, Recommendations and Actions 3

PROBLEM 3: The criteria for early diagnosis are inadequate

Establishing the diagnosis early is challenging, even when AS is suspected: clinical assessment of the spine is difficult and there are no confirmatory diagnostic signs.

Until recently, a combination of clinical and radiographic features was used to establish the diagnosis. These diagnostic criteria were laid down as the modified New York criteria in 1984[18]. With the exception of advanced bilateral radiographic sacroiliitis (which can take up to 10 years to become evident), no individual feature is confirmatory of the diagnosis. This means that in most cases irreversible damage has already occurred and patients have endured many years of symptoms before the diagnosis is made. In other words, the modified New York criteria do not allow for a diagnosis of early (non-radiographic) AS/axial SpA to be made.

MRI can demonstrate both acute inflammation and chronic damage in the skeleton and the value of this imaging technique in the early assessment of suspected AS has been confirmed in recent years[23]. Indeed MRI of the spine and sacroiliac joints using fat suppression techniques provides valuable diagnostic information in patients with normal or equivocal plain radiographs[21]. MRI also has the advantage of demonstrating or excluding other pathologies that can mimic SpA[24]. Although inflammation usually starts in the sacroiliac joints in AS, it is now clear that inflammatory spinal lesions (commonly thoracic) can occur in the absence of definitive sacroiliac joint changes[25].

This knowledge has led to the recent development of new criteria for the classification of early AS/axial SpA which highlight the value of MRI and HLA-B27 testing in individuals with inflammatory spinal pain[22]. In addition an international consensus has now been reached to define AS/SpA related MRI sacroiliitis in order to allow for the standardised implementation of these criteria[26]. It is important therefore that these investigations are performed using adequate techniques[27] and that they are interpreted by the right specialists.

RECOMMENDATION 3

The diagnosis of early AS/axial SpA should be made without waiting for X-ray changes: MRI is the investigation of choice

ACTION 3

- The diagnosis of early AS/axial SpA should be based on current ASAS criteria *(see figure 3)*.
- HLA-B27 testing is diagnostically valuable in individuals with inflammatory back pain *(see figure 3)*.
- MRI of thoraco-lumbar spine and sacroiliac joints should be done in patients with normal x-rays.
- Interpretation should be undertaken by an expert musculoskeletal radiologist.
- In clinical practice the diagnosis of AS can be made by following a simple algorithm *(see figure 5)*.

Problems, Recommendations and Actions 4

PROBLEM 4: There are inequalities in access to optimum care

Everyone with AS should have access to optimum treatment modalities, whether for early disease, disease flares, disease complications or late-stage skeletal damage. The treatment of AS needs to be patient-centred and adapted to individual needs. This requires fast and flexible access to a specialist centre with a multidisciplinary team able to provide the full range of appropriate services. Patient experience indicates that for many patients this is simply not available.

Ideal practice should include assessment of all potential manifestations of the disease (axial, peripheral, entheseal, and extra-articular features) including parameters of disease activity, pain, function, disability and structural damage such as hip involvement or spinal deformity. It should also take into account social factors, work status, other co-morbidities and concomitant medications. This approach is vital if the right management options are to be chosen.

For ideal management, the full range of effective treatment modalities must be available in secondary care and, where appropriate, in primary care. Physiotherapy and exercise is central to the treatment of AS[28]. Access to physiotherapy and hydrotherapy services should be readily available, as should support for self-managed exercise. Occupational advice is also essential for maintenance of employment though it is rarely available. Patients should have access to urgent clinical review or advice via telephone and/or e-mail. Such helpline services could be provided by specialist nurses or physiotherapists as is widespread practice for rheumatoid arthritis. The importance of flares of disease or periods of work instability must be recognised. Surgical advice and treatment should be provided by orthopaedic and/or spinal surgery teams experienced in treating people with severe AS.

The wishes and expectations of the patient are critical to planning optimum management. In order to interact with the medical team for maximum benefit there should be opportunities for education (patient and family), benefits advice and psychological input. People with AS need information in a form which is most helpful to them; education programmes and patient help groups are known to bring significant improvements in self efficacy and motivation for AS patients. Patient education programmes may also generate cost savings through reduction in work days lost.

RECOMMENDATION 4

People with AS should have access to all appropriate specialists and treatments

Problems, Recommendations and Actions 4

ACTION 4

- Optimum care is provided by a rheumatologist working with an expert multidisciplinary team and ready access to relevant specialists experienced in managing AS and its co-morbidities especially gastroenterologists, ophthalmologists, dermatologists, and specialist orthopaedic and spinal surgeons.

- The expert multidisciplinary team should include a rheumatologist, specialist physiotherapist and specialist nurse, musculoskeletal radiologist, occupational therapist and an employment/benefit advisor.

- All patients should have access to specialist physiotherapy, including hydrotherapy, and hospital or community based exercise programmes.

- Telephone advice should be offered and/or early clinical review if required to manage flares or complications.

Problems, Recommendations and Actions 5

PROBLEM 5: Access to effective drug treatments

The principal problem facing many patients is access to biologic therapy. People with AS often endure long-standing symptoms for which they traditionally have low therapeutic expectations. Some people with AS, therefore, underplay these symptoms and consequently may not know of or consider themselves to be suitable or eligible for anti-TNF therapy. Historically, many clinicians have also considered AS to be either of modest severity or largely untreatable with the consequence that many patients will have been discharged from or lost to regular clinical follow-up.

While the clinical value of non-steroidal anti-inflammatory and other drugs should not be underestimated, the profound benefits of TNF blockade are now clear for symptom control, lifestyle benefits and effects on work capacity, although inhibition of structural damage has not yet been demonstrated. There is no doubt that, in addition to symptom control, work instability, progressive spinal restriction and co-morbidities should be taken into account when assessing the need for biologic therapy. National guidance on the appropriateness of anti-TNF therapy is clear though provision of this treatment requires considerable administrative and clinical support and/or Primary Care Trust approval on an individual basis. Many eligible people do not receive such treatment.

Thus there are several blocks to the free availability of the right treatment at the right time for individuals with AS, especially poor understanding of the disease, limited therapeutic expectations, prescribing restrictions and funding constraints for provision and support of biologic therapies. Provision of the right treatment at the right point in the disease needs expert input.

RECOMMENDATION 5

People with AS should be made aware of the availability of anti-TNF therapy and offered treatment if eligible

ACTION 5

- All patients should be evaluated for anti-TNF treatment.
- Treatment decisions should be guided by the National Institute for Health and Clinical Excellence (NICE) technology appraisal guidelines for the use of anti-TNF *(see figure 4)*.

Problems, Recommendations and Actions 6

PROBLEM 6: Many people with severe spinal deformity can benefit from spinal surgery but are not offered it

Spinal deformity in people with AS is not rare. In severe cases patients are unable to look forward comfortably or look people in the eye. This produces social isolation, neck pain and unsteadiness in addition to practical difficulties. Before the advent of MRI, surgical correction was associated with substantial morbidity and mortality. However, with modern means of pre-operative assessment and treatment in specialist spinal units, surgical intervention may be highly effective in correcting posture, and assisting comfort and self-confidence. Many patients with gross deformity are never offered the chance to consider surgical treatment.

Spinal surgery for the treatment of deformity in AS requires a highly skilled specialist team and adequate facilities. Assessment of the need for spinal surgery should take into account both physical and psychological factors, including personal and work-related issues. Many people currently do not have access to such treatment although it may be highly effective.

RECOMMENDATION 6

People with severe spinal deformity should have access to expert surgical assessment and treatment

ACTION 6

- Units involved in the treatment of people with AS should have links to a specialist spinal team with expertise in the surgical treatment of people with AS either through direct association or via tertiary centres.

- People with severe, deforming AS should know that surgical treatment is available. Those wishing to explore this prospect further should be appropriately assessed, both medically and psychologically, before a decision to proceed or not is made.

Problems, Recommendations and Actions 7

PROBLEM 7: There is inconsistent monitoring for people with AS

Long-term monitoring for people with AS has been highly variable. Many individuals become disillusioned with the care and treatment options available and become "lost to follow-up". People may fail to be monitored long-term because of service expediency, poor patient experience of the service and limited understanding by clinicians of the natural course of AS.

For most individuals disease progression is relentless although slow and sometimes quiet with long periods of relatively modest, unchanging symptoms. Clinical manifestations in AS are truly heterogeneous; in addition to axial and peripheral joint symptoms, enthesitis, osteoporosis and involvement of non-articular organs such as the eye (anterior uveitis) or the heart (carditis, valvular involvement) may cause important morbidity. Indirect effects of AS such as respiratory difficulty due to costovertebral disease and toxic effects of treatment including renal impairment, hypertension and gastrointestinal disturbances may also be problematic.

For these reasons disease monitoring is of major importance both to detect progression and to allow for timely and effective interventions. Monitoring need not be frequent but should be determined by symptoms, severity, patient preference and drug therapy. Periodic monitoring of patients with AS should include a comprehensive history to explore clinical symptoms, laboratory tests and imaging[29]. The Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)[30] is the recommended instrument to assess disease activity and function is usually assessed using the Bath Ankylosing Spondylitis Functional Index (BASFI)[31] or Dougados Functional Index[32]. A number of other validated instruments exist for the assessment of additional features including peripheral joint lesions, enthesitis, fatigue, sleep quality and spinal pain and should be used as appropriate. In addition, a regular record of spinal mobility should be kept. The Bath Ankylosing Spondylitis Metrology Index (BASMI)[33] is widely used for this purpose. Progression of skeletal changes can be monitored by use of the modified Stoke Ankylosing Spondylitis Spine Score (mSASSS)[34] but radiographs to assess bone damage need not be performed more than once every two years[35].

RECOMMENDATION 7

People with AS should be followed up regularly and have ready access to expert reassessment

Problems, Recommendations and Actions 7

ACTION 7

- At initial assessment, all patients should have a comprehensive clinical assessment to include disease activity scores, functional assessments, metrology indices and imaging undertaken and interpreted by an appropriately trained person.

- All patients should be re-evaluated periodically by a health specialist with expertise in AS, under the supervision of a consultant rheumatologist, and serial measures recorded. The interval depends on the activity and severity of their disease. Regular evaluation should include the need for changes in physical, pharmacological or surgical treatment.

- Periodical assessments of bone health/osteoporosis, co-morbidities, renal function and cardiovascular risk should be undertaken.

Afterword

Good management extends beyond healthcare

As this project highlights, there is a lack of awareness of inflammatory back pain and AS as a debilitating condition among the general public and even in the health service. In a recent survey of NASS members, about a third waited over a year before even seeing their GP about their symptoms. Although we do not know the reasons for this, we can surmise one of them might be that they thought it was "ordinary" back ache for which there was no treatment beyond pain relief and the passage of time.

Once a diagnosis is made, although it can bring a sense of relief, it can also be a difficult and frightening moment: an individual is not likely to know anything about AS or to know people with the condition. Imagine the typical patient – a young man in his twenties – who has had an active sporting, social and work life. Suddenly he has to accept he has a chronic, incurable condition and what seems to be an uncertain future.

Although these seven recommendations deal with the medical management of AS it should be emphasised there is a great deal that the individual can do, in partnership with their health team but also working on their own, to achieve the best possible outcome. It is important that their health team recognise that the impact of AS is not simply experienced in medical terms and managed with inputs such as drugs and physiotherapy.

Awareness of the need for regular exercise and the effort, motivation and access to facilities needed to bring this about; of the psychosocial issues during education and career planning; the challenge of getting and staying in work; the occupational and social support and public attitudes to deformity all play roles in building and maintaining well being.

Information needs

The question of information needs has not been selected as a recommendation on its own, important though it is, because it is such an enormous topic.

Education and advice should be provided by appropriately skilled professionals backed up by literature and suggestions about approved websites. Such information is essential so that people with AS can participate actively in treatment decisions. Advice should also cover benefit entitlements, careers, exercise, genetic and family counselling, obesity, smoking and work issues. People will have different information needs over their lifetime and different age groups are likely to access information in different ways.

Over time, what will help to give the individual the best outcome is the right information presented at the right moment and in the right format.

Exercise for life

Exercise is not just a useful addition to the management of AS: it is one of the cornerstones of treatment. Exercise helps in the maintenance of flexibility and good posture and also assists with pain management and well being.

The ideal range of available services should include:

- Advice on self management at the time of diagnosis from a physiotherapist who has received training in the needs of AS patients, and further swift access to advice if symptoms are worse because of a flare or some other change.

- Access to hydrotherapy sessions on a regular basis. Exercising in a warm, shallow hydrotherapy pool protects the joints and enables people to stretch and move in a way which they cannot do on land. Members of NASS highlight that access to regular hydrotherapy has been a key element enabling them to keep working because it has helped with their pain levels and mobility. There is a trend in the NHS to offer only occasional short courses of hydrotherapy, to reduce access to hydrotherapy pools or even to close pools altogether as they are seen as resources which are expensive and peripheral rather than central to the well being of many patients including those with AS.

- Access to an inpatient course like those offered by the Royal National Hospital for Rheumatic Diseases in Bath and other centres: such courses have a number of objectives but they include helping people to learn about their disease and how to manage it; to reduce pain and stiffness through graded exercises and stretches and to meet other people with AS and exchange information and coping strategies with them.

NASS runs over 94 local groups which meet regularly throughout the year either to use a gym or a hydrotherapy pool or to do both. NASS would like to see support for all our groups from the local NHS services and encouragement and support from the NHS for more to form.

There will always be individuals who prefer to exercise alone or who cannot access a group activity. If they are a young adult with a good level of fitness in place they may prefer to use a gym or health club. NASS would like to see exercise prescriptions offered to people with AS.

The impact on life

Work

Around one third of people with AS give up work before retirement age and of those who are in work, either part time or full time, a quarter (26%) said in a recent survey that their AS had affected their career progression. Moreover, 30% were worried about losing their job *(NASS Survey on Work 2009)*.

NASS would like to see staying in work accepted as a legitimate clinical outcome and recognition that "work" is not merely a matter of being in work or out of work but of productivity, career progression, pension rights, full time versus part time work and possible early retirement because of ill health.

Sadly in the UK, a reduction in work days lost is not set against NHS costs; this is an area that NASS has already highlighted and will continue to highlight. Decisions made by the Department of Health which impact on the budget of the Department of Work and Pensions and are taken without consideration of this impact are not a sensible use of resources either for the individual or for society as a whole.

Psychosocial impact

The further effects of living with this chronic condition, particularly for those people with severe AS, can be extensive. They include worries about family life, social and sexual limitations, constraints on favoured activities such as particular sports, anxiety about work, the unpredictability of flare ups and their impact as well as apprehension about how the disease may affect their posture over time.

As has already been highlighted, people with AS are more likely never to have married or have children and if they have married, are more likely to have divorced than the general population. They are also likely to experience more depression.

Support from an organisation like NASS, the opportunity to meet other people with AS through NASS groups or exercise groups organised by the local hospital, internet forums, conferences and NHS information days are all helpful in breaking down the sense of isolation that many people feel.

But the full impact of AS on an individual is only beginning to be acknowledged, and studied and considered as part of the overall treatment and management of the disease.

Jane Skerrett

Appendices

Fig 1. Commonly used criteria to diagnose inflammatory back pain

Calin Criteria *(Calin A et al JAMA 1977;237:2613-4)*

- Age at onset less than 40 years
- Back pain more than 3 months duration
- Insidious onset
- Associated with morning stiffness
- Improvement with exercise

The criteria are fulfilled if at least 4 of 5 parameters are present

ASAS Criteria *(Sieper J et al Ann Rheum Dis 2009;68:784-8):* **Back pain of more than 3 months duration is inflammatory if:**

- Age at onset less than 40 years
- Insidious onset
- Improvement with exercise
- No improvement with rest
- Pain at night (with improvement on getting up)

The criteria are fulfilled if at least 4 of 5 parameters are present

Berlin Criteria *(Rudwaleit M et al Arthritis Rheum 2006;54:569-78):* **Back pain of more than 3 months duration is inflammatory if:**

- Associated with morning stiffness > 30 minutes
- Improvement with exercise but not by rest
- Awakening in the second half of the night because of back pain
- Alternating buttock pain

The criteria are fulfilled if at least 2 of 4 parameters are present

Fig 2. The modified New York criteria for the diagnosis of ankylosing spondylitis *(van der Linden S et al Arthritis Rheum 1984;27:361-8)*

1984 Modified New York Criteria

Clinical criteria:
- Low back pain and stiffness for more than 3 months that improves with exercise, but is not relieved by rest
- Limitation of motion of the lumbar spine in the sagittal and frontal planes
- Limitation of chest expansion relative to normal values correlated for age and sex

Radiological criterion:
- Sacroiliitis grade ≥ 2 bilaterally or grade 3–4 unilaterally

Definite AS is diagnosed if the radiological criterion is associated with at least one clinical criterion

Fig 3. ASAS classification criteria for axial spondyloarthritis (SpA) in patients with back pain for more than 3 months and age at onset less than 45 years *(Rudwaleit M et al Ann Rheum Dis 2009;68:777-83)*

Sacroiliitis on imaging* plus ≥ SpA feature#	or	**HLA-B27 plus ≥ 2 other SpA features#**
#SpA features • inflammatory back pain • arthritis • enthesitis (heel) • uveitis • dactylitis • psoriasis • Crohn's/colitis • good response to NSAIDs • family history of SpA • HLA-B27 • elevated CRP		***Sacroiliitis on imaging** • active (acute) inflammation on MRI highly suggestive of sacroiliitis associated with SpA • definite radiographic sacroiliitis according to modified NY criteria

Fig 4. National Institute for Health and Clinical Excellence (NICE) guidance for the use of anti-TNF therapies in the treatment of ankylosing spondylitis
(NICE technology appraisal guidance 143: Adalimumab, etanercept and infliximab for ankylosing spondylitis, May 2008)

NICE guidance for anti-TNF therapy

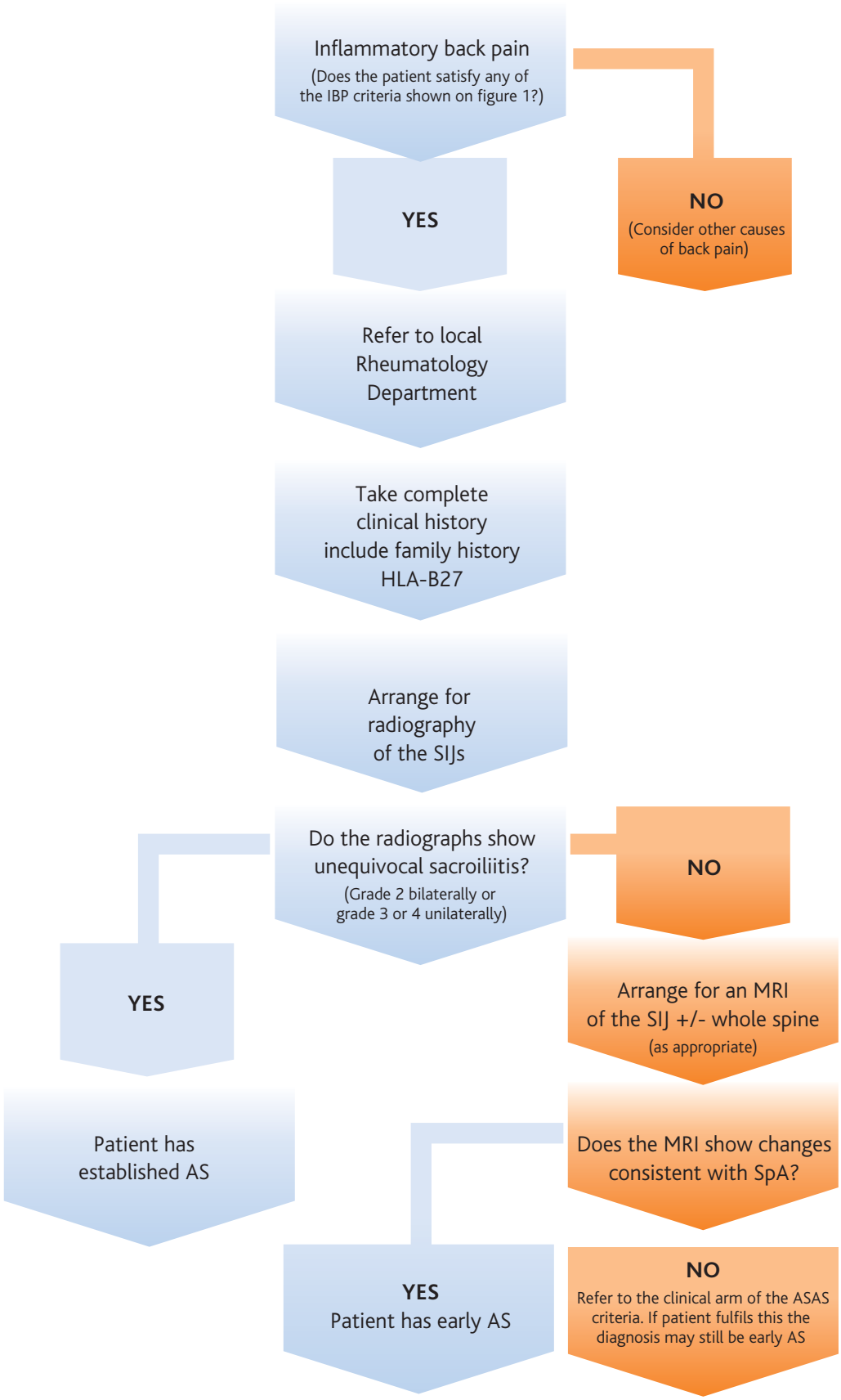
Adalimumab or etanercept are recommended as treatment options for adults with severe active ankylosing spondylitis only if all of the following criteria are fulfilled.

- The patient's disease satisfies the modified New York criteria for diagnosis of ankylosing spondylitis.
- There is confirmation of sustained active spinal disease, demonstrated by:
  - a score of at least 4 units on the Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)
  - and at least 4 cm on the 0 to 10 cm spinal pain visual analogue scale (VAS)

These should both be demonstrated on two occasions at least 12 weeks apart without any change of treatment.

- Conventional treatment with two or more non-steroidal anti-inflammatory drugs taken sequentially at maximum tolerated or recommended dosage for 4 weeks has failed to control symptoms.

Fig 5. Diagnostic algorithm for early AS



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National Ankylosing Spondylitis Society (NASS)

Unit 0.2, 1 Victoria Villas,
Richmond, Surrey TW9 2GW

Phone: 020 8948 9117

Website: www.nass.co.uk

RCN: 272258