Improving the treatment of ankylosing spondylitis in the UK

This editorial refers to ‘Looking Ahead: Best Practice for the Care of People with Ankylosing Spondylitis (AS)’, published by the National Ankylosing Spondylitis Society. The conclusions are underlined by the accompanying paper, ‘Services for people with ankylosing spondylitis in the UK—a survey of rheumatologists and patients’, by Louise Hamilton et al., doi:10.1093/rheumatology/ker013, on pages 1991–1998.

There is wide variation in the quality of care that people with ankylosing spondylitis (AS) receive. This is reflected in patient experiences and by the activities of patient support groups in the UK and elsewhere in the world. Experience in the UK is likely to be essentially similar to that in the rest of the Western world, so the conclusions of a British working group on the treatment of people with AS [1] are likely to be of wide relevance. Some background to the group’s report is provided by a recent survey of members of the National Ankylosing Spondylitis Society (NASS): this indicated that only 68% attend rheumatology clinics. A parallel survey of UK rheumatology departments identified that 55% had a clinician with a declared interest in AS, but most do not run dedicated AS or SpA clinics [2]. There may be understandable reasons for these observations, but in the light of major advances in the management of patients with AS this situation cannot be allowed to persist. It is time to close the service gaps and for health services to provide a uniformly high level of service for people with AS.

July 2010 saw the launch of ‘Looking Ahead: Best Practice for the Care of People with Ankylosing Spondylitis (AS)’ (hereafter ‘Looking Ahead’). This document, produced by a panel of British clinicians under the auspices of the NASS, identifies the major obstacles to good care of AS in the UK and offers solutions to them [1]. It is intended to facilitate the development and standardization of clinical services nationwide and represents a benchmark against which patients and their advocates will be able to judge clinical services.

‘Looking Ahead’ identifies seven major problems that are responsible for the suboptimal care received by so many patients. These and the appropriate remedies are summarized in Table 1. Underpinning these problems is the relatively low profile of AS among both medical professionals and the general public. Sufferers have no familiarity with the disease, medical professionals often do not consider it as a possible diagnosis and the processes of connecting possible sufferers with appropriate professionals are often ineffectual.

Delayed diagnosis is a fundamental issue. Reports that the average time from symptom onset to diagnosis is between 8.5 and 11 years [3, 4] may be outdated, but it is clear that even those whose disease begins now will likely have a long wait before their symptoms are explained and effectively treated. This is important as AS typically begins during a formative phase of young adult life, when symptoms may interfere critically with education, job prospects and social relationships. Diagnostic delay may allow irreversible structural and social changes to occur that might have been averted had the diagnosis been made sooner. The relative rarity of AS, compared with the commonness of mechanical back disorders makes diagnosis of all but the most typical cases challenging, especially in primary care. Around 30% of general practitioner (GP) consultations in the UK are for musculoskeletal conditions [5], with low back pain being second only to respiratory problems as the most common reason for consulting a GP [6]. Moreover, the emphasis in managing back pain in primary care is on physical treatment of mechanical pain and identifying red flag conditions. This may represent a reasonable response to a huge problem, but systems that fail even to look for AS, a treatable cause of serious lifelong disabling disease, are inadequate and need changing. ‘Looking Ahead’ calls for new back pain assessment pathways that allow identification of inflammatory spinal pain alongside the other major back pain categories. When the diagnosis of AS is even considered, referral to a rheumatologist should be de rigueur.

The difficulty of making an early diagnosis even when AS is suspected is also a major problem. This is partly because the modified New York criteria require radiographic changes of sacroiliitis [7]: these changes are known to develop slowly, however, with only 70% of sufferers fulfilling these diagnostic criteria after 5 years of symptoms [4]. MRI, on the other hand, can identify inflammatory changes in the SI joints and spine at a much earlier, pre-radiographic, stage and the recently proposed Assessments in Ankylosing Spondylitis International society (ASAS) classification criteria incorporate MRI as the method of choice for imaging the SI joint [8]. ‘Looking Ahead’ advocates adoption of the new ASAS criteria for identifying early AS/axial spondyloarthritis (ASpA) with use of MRI imaging as the key to early diagnosis.

Much of the morbidity of AS is established in the early years of the disease. Conventional anti-inflammatory and physical treatments managed by a skilled multidisciplinary team remain important, but the benefits of TNF blockade treatment on symptoms, quality of life and work
### TABLE 1 Key conclusions of ‘Looking Ahead’

<table>
<thead>
<tr>
<th>No.</th>
<th>Problem</th>
<th>Recommendation</th>
<th>Action</th>
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<tbody>
<tr>
<td>1</td>
<td>The diagnosis of AS is considered too late</td>
<td>Back pain assessment pathways should include a system for recognition of inflammatory back pain</td>
<td>Inflammatory spinal pain should be considered in all patients presenting with chronic back pain of &gt;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.</td>
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<td>2</td>
<td>Getting to the right expert is important</td>
<td>People with suspected AS should be referred to a rheumatologist</td>
<td>Individuals who have inflammatory back pain and/or features suggestive of AS should be referred to a rheumatologist with knowledge and understanding of AS and access to a multidisciplinary team. Referral to an orthopaedic surgeon or physiotherapist as a first choice is usually inappropriate.</td>
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<td>3</td>
<td>The criteria for early diagnosis are inadequate</td>
<td>The diagnosis of early AS should be made without waiting for X-ray changes; MRI is the investigation of choice</td>
<td>The diagnosis of early AS/axial SpA should be based on current ASAS criteria. HLA-B27 testing is diagnostically valuable in individuals with inflammatory spinal pain (see ASAS criteria). MRI of the whole spine as opposed to SI joints only may sometimes be diagnostically helpful. Dedicated SI joint sequences should be undertaken and interpreted by an expert musculoskeletal radiologist. Optimal care is that provided by expert multidisciplinary teams with easy access to relevant specialists experienced in managing AS and its comorbidities. Rheumatologist treating people with AS should have access to a multidisciplinary team comprising a: physiotherapist, nurse specialist, musculoskeletal radiologist, ophthalmologist, dermatologist, gastrointestinalist, specialist orthopaedic/spinal surgeon, occupational therapist and employment/benefit adviser. All patients should have access to specialist physiotherapy, including hydrotherapy and, when necessary, hospital or community-based exercise programmes. Patients should have easy access to telephone advice and/or early clinical review if required to manage flares or complications, e.g. iritis.</td>
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<td>4</td>
<td>There are inequalities in access to optimal care</td>
<td>People with AS should have access to all appropriate specialists and treatments</td>
<td>All patients with active disease, despite conventional treatment, should be evaluated for anti-TNF treatment. Treatment decisions should be guided by the National Institute for Health and Clinical Excellence (NICE).</td>
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<td>5</td>
<td>Access to effective drug treatments</td>
<td>Patients should be made aware of the availability of anti-TNF therapy and offered treatment if eligible</td>
<td>All patients with active disease, despite conventional treatment, should be evaluated for anti-TNF treatment. Treatment decisions should be guided by the National Institute for Health and Clinical Excellence (NICE).</td>
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<td>6</td>
<td>Many people with severe spinal deformity can benefit from spinal surgery, but are not offered surgical treatment</td>
<td>People with severe spinal deformity should have access to expert surgical assessment and treatment</td>
<td>Units involved in the treatment of people with AS should have links to a specialist spinal unit 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 option further should be appropriately assessed both medically and psychologically before a decision to proceed or not is made.</td>
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<td>7</td>
<td>There is inconsistent monitoring for people with AS</td>
<td>People with AS should be followed up regularly and have ready access to expert reassessment</td>
<td>At initial assessment, all patients should have a comprehensive clinical assessment to include DASs, 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 upon the activity and severity of their disease. Regular evaluation should include the need for changes in physical, pharmacological or surgical treatment. Periodic assessments of bone health/osteoporosis, comorbidities, renal function and cardiovascular risk should also be undertaken.</td>
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capacity in both early and late disease are well recognized. Having access to such treatments whenever they are appropriate, therefore, is critical to minimize skeletal and lifestyle damage irrespective of whether skeletal disease modification can be achieved. Such benefits apply beyond the individual and his/her family to society at large, which otherwise has to pick up much of the cost of illness and impairment; the earlier the treatment, the greater will be the returns for the outlay on treatment. Thus, early diagnosis, access to expert assessment and appropriate availability of biologic therapies are crucial elements of successful lifelong management of people with AS.

‘Looking Ahead’ also advocates universal access to regular maintenance treatments including hydrotherapy and physiotherapy when needed along with long-term surveillance. With functional disability, the most important predictor of the total cost associated with this disease [9, 10], emerging insidiously over many years even despite apparently stable disease activity [11], expert long-term follow-up has real value even in the face of financial pressures to reduce secondary care involvement. Similarly, many lives are still damaged by untreated spinal deformity; despite the humiliating and disabling aspects of severe deformity on one hand and impressive surgical outcomes on the other, many patients never have the chance to consider spinal surgery. Hence, ‘Looking Ahead’ stresses the importance of access for people with AS to all appropriate specialists and treatments and to long-term specialist monitoring.

‘Looking Ahead’ aims to improve the lives of people with AS by promoting good practice throughout the UK through altering service frameworks and by empowering patients to press for access to excellent services. These recommendations are now all achievable; it would be a sad reflection on health care in the UK if these simple, but vital steps cannot now be speedily adopted.

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