

Therapy-led Ankylosing Spondylitis Clinic

Abertawe Bro Morgannwg University Local Health Board

What is it and what makes it different?

Ankylosing spondylitis is a chronic and painful, progressive form of inflammatory arthritis, which mainly affects the spine but can also affect other joints, tendons and ligaments. The condition is diagnosed by combining the clinical criteria of inflammatory back pain with enthesitis - inflammation at the site of bone insertion of ligaments and tendons - or arthritis with radiological findings.

The prevalence of ankylosing spondylitis is between 0.1% and 2% of the population; its peak onset is between 15 and 25 years of age and it affects three times as many men as women. Many patients with mild disease may remain undiagnosed. Currently, there is an unacceptably long delay of between five and 10 years, between the first occurrence of symptoms and diagnosis of ankylosing spondylitis. AS (*J Sieper - Arthritis Research & Therapy 2009, 11:208*)

The management of ankylosing spondylitis has been revolutionised by the development of biologic agents - anti-TNF drugs. The use of these effective but expensive and potentially toxic agents in the NHS is controlled by National Institute for Health and Care Excellence (NICE) guidelines.

These include minimum criteria, including specific disease activity scores (Bath Ankylosing Spondylitis Disease Activity Index or BASDAI), which have to be met before treatment can be started, as well as regular monitoring of disease activity to ensure continued treatment is warranted. This has occurred against a background of evolving advances in the imaging investigations for ankylosing spondylitis and the development of new diagnostic criteria.

Successful management of ankylosing spondylitis requires a multidisciplinary approach involving physiotherapists, occupational therapists and other clinicians with specialist understanding of the condition and its impact. If not appropriately treated, ankylosing spondylitis results in major functional impairment and disability.

In Abertawe Bro Morgannwg University Health Board, ankylosing spondylitis patients were seen in busy general rheumatology outpatient clinics as part of a diverse patient mix, dominated by rheumatoid arthritis and other more common conditions.

Ankylosing spondylitis is also frequently associated with inflammation of other organs, including bowel (colitis) and eyes (uveitis) for which patients require referral to appropriate specialists. Physiotherapy and, when required, surgery in ankylosing spondylitis are also specialised and differ from that required by other patients with back pain or arthritis.

There was no clear local pathway for patients to be seen by appropriate physiotherapists, occupational therapists or other specialists and they frequently required several onward referrals before eventually being seen by the correct person.

Furthermore, the ankylosing spondylitis scores and assessments performed by the physiotherapists were not available to the clinicians when patients were seen in rheumatology clinic. The current service for ankylosing spondylitis patients was disjointed and no longer fit for purpose in the era of biologic therapies. The evolving imaging and diagnostic developments also demanded that patients have access to specialists with up-to-date expertise in this area.

In 2013, the physiotherapists and occupational therapist with a specialist interest in ankylosing spondylitis, decided to establish an allied health professional-led service and created a multidisciplinary team clinic for these patients. It is held fortnightly, initially at Neath Port Talbot Hospital, and now at the Port Talbot Resource Centre.

This clinic sees patients who have been referred by rheumatologists with a diagnosis of ankylosing spondylitis. The clinic currently has a capacity of roughly 100 patients per year.

At their first visit, all patients have full baseline assessments, including a full review of their diagnostic imaging and treatment, including self management techniques to manage the physical and psycho-social impact of this long-term condition. All patients have an annual review with an open door policy so that they are able to speak to a clinician if their symptoms require. There is fast track access back to the rheumatology consultant if required.

In addition, all patients complete a BASDAI (consisting of a 1 - 10 scale measuring discomfort, pain, and fatigue -1 being no problem and 10 being the worst problem - in response to six questions asked of the patient pertaining to the five major symptoms of ankylosing spondylitis) and related questionnaires before the appointment and a quality-of-life impact questionnaire via *Talking AS*, an online programme which they can access anytime and provide an accurate record of their scores. This ensures disease activity is monitored more closely and it identifies patients whose disease is rapidly deteriorating, requiring more urgent review to allow timely intervention and prevention of complications.

Disease activity scores and reports generated are integrated into the clinical notes, via CELLMA (integrated software which designed to help enable the provision of a patient centric service), and are available when the patient is seen in any rheumatology clinic. Robust data is therefore captured to allow assessment of disease activity and response to treatment, facilitating evaluation of these clinics and outcomes. This also enables regular audit and ensures compliance with NICE guidelines.

What impact has it had?

Regular systematic assessment in this multidisciplinary specialist ankylosing spondylitis clinic helps ensure patients receive the best possible treatment for their condition. Separating these patients from the general rheumatology clinics ensures regular assessment of disease activity, pain and function, resulting in appropriate and timely investigation and treatment in accordance with current best practice and NICE requirements.

Patients who require anti-TNF therapy or specific physiotherapy/OT input receive these in a timely manner, while patients not meeting the NICE response criteria for anti-TNF therapy have this treatment stopped, avoiding unnecessary exposure to treatment and the associated risks.

Adverse events from therapy and disease complications can also be detected and managed in a timely manner, minimising the impact on the patient. There is good evidence that appropriate treatment with anti-TNF agents results in improved function and work productivity, as well as reducing complications, disability and the need for surgery.

Patients attending the clinic benefit from a holistic approach of managing the condition, with treatment and advice given by physiotherapist and occupational therapist. The clinics are also provided in a community setting away from the hospital.

What makes it prudent?

Specialty ankylosing spondylitis clinics deliver improved quality care to patients with this condition. In addition to the clinical and safety benefits, these focused clinics and the associated structures, ensure optimal use of resources in terms of drugs, imaging, physiotherapy, occupational therapy and specialist referrals.

- Patients are seen by appropriately-trained physiotherapists and occupational therapists, freeing up other physiotherapists and occupational therapists to see people with different conditions more appropriate to their skills. As patients attend this clinic, consultant appointments are freed up to see new patients and address the five to 10-year discrepancy for diagnosis; an example of the only do what only you can do principle at work;
- Complications and adverse events are detected and treated early, minimising their impact on both the patient and the health service and reducing the risk of harm to individuals; As per the idea of minimum appropriate intervention, patients are only referred on when required as many expected complications of ankylosing spondylitis and its treatment can be managed by the multidisciplinary team clinic; When required, referral is directly to the appropriate specialist or surgeon, avoiding duplication and numerous onward referrals.

The dedicated ankylosing spondylitis clinics ensure the routine capture of the high-quality and robust data required for NICE guideline, audit and outcome

purposes. The outcomes of the clinics are readily available to the rheumatology consultants, thus improving patient management.

Dedicated ankylosing spondylitis clinics and clearly defined referral pathways also deliver an exceptional learning environment. Improved training of allied health professionals will benefit both the patients and NHS by facilitating earlier diagnosis of patients with ankylosing spondylitis (patients often first present to physiotherapists) and enable the establishment of further multidisciplinary team-led ankylosing spondylitis clinics in the future.

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