British Sjögren's Syndrome Association

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How the rheumatologists approaches a patient with Sjögren's and arthritis

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The aim of this article is to give the reader some insights into the way the doctor thinks in the rheumatology clinic. I should acknowledge that this may be the way one doctor, the author, works in his clinic and it may not represent the views of every rheumatologist but I hope it will allow the reader to understand a little better what's going on when they attend a clinic for their joints.

Basic steps

The principles in looking after joint disease can be summarised in a series of steps. The first is to establish the process that is going on - ideally one makes a precise diagnosis but sometimes this can be difficult and observation over time can make a difference. Having made a diagnosis one wants to try and assess how bad the problem is, as clearly this is going to govern the risks that are taken with interventions. Having decided that treatment is needed, treatment can be divided into symptom relieving measures, prevention, dealing with problems outside the joints and in some cases there is specific treatment. Sadly however there are rarely cures that we can find in the rheumatology clinic though some problems do go away of their own accord.

Inflammation and wear

When assessing an arthritis usually the rheumatologist will want to try primarily to differentiate between an inflammatory process and a process which is more characterised by wear (often with associated attempts at repair – but unfortunately the human body is not very good at repairing damaged joints). The commonest type of inflammatory arthritis is rheumatoid disease (fig 1) and wear is referred to as osteoarthritis (fig 2) in the joints and spondylosis in the spine. Sometimes more than one type of arthritis will occur together. The wear and repair process is readily understood when one thinks of irregularities in the joint surface that might occur when a bone is broken and the fracture involves the joint surface. After such a fracture taking load through the joint can be unevenly distributed and because of higher pressures at one area often wear will occur. So osteoarthritis often occurs after a fracture through the joint line. Similarly inflammatory arthritis which erodes or eats away at the joint surface will leave less of the cartilage to take the load and again a secondary attempt at repair will result in the appearances of osteoarthritis complicating the inflammatory process. In Sjögren's Syndrome there is an increased incidence of osteoarthritis (not usually related to any previous injury). Patients with primary Sjögren's Syndrome often develop an inflammatory arthritis which may resemble rheumatoid arthritis in the pattern of pain and stiffness but is not usually associated with the same damage. The third but unusual possibility is that the symptoms of Sjögren's initially dominate, but the joint problem ultimately proves to be rheumatoid arthritis associated with secondary Sjögren's Syndrome. Alternatively secondary Sjögren's Syndrome develops some time after the diagnosis of rheumatoid arthritis has been established. (Secondary Sjögren's Syndrome sometimes develops after another diagnosis such as scleroderma or systemic lupus erythematosus - SLE, but under these circumstances the pattern of arthritis is mainly determined by the primary diagnosis.) The rheumatologist will try to sort out what is going on using the history, examination and blood tests.

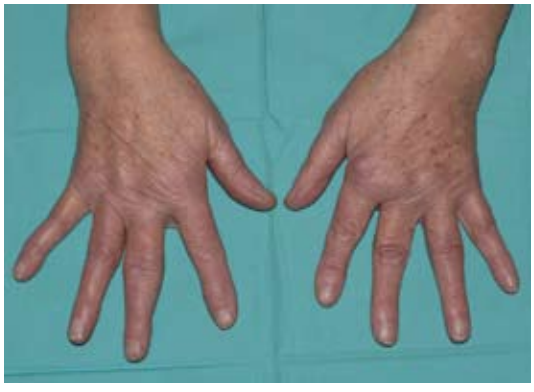

FIG 1. Rheumatoid arthritis in the hands. The swelling is spongy – except in the places where normal hands are bony hard. As the joint capsule stretches the ligaments may stretch allowing the joints to loosen and change position.

Sorting out inflammation and wear

Always the rheumatologist will be trying to find out at the clinic as far as possible whether the problem relates to inflammation or wear in the joints.

To some extent the pattern of pain is different. In inflammation pain is dominant at rest and tends to ease off with mobility. Some patients with inflammation feel worst in the mornings alone but often it is worse in the mornings and evenings; and sometimes pain will waken the patient from their sleep at night. Similarly the stiffness tends to be worst in the morning. With wear related pain people tend to get increased problems either during periods of increased activity or they will pay for the increased activity afterwards when they get more pain. They may be stiff in the morning but quite often they are just as stiff or even more stiff after they've sat down for a while, for instance, after a long car journey.

When the doctor examines the joints he will look for swelling and whether this is softer and related to the capsule or lining of the joint or whether it is related to the bone. Bony hard swelling tends to be a feature of the load being spread over a larger area in the joint and this characterises part of the repair process when wear has been a problem.

Again which joints are bothering the patient can be a guide as to whether the problem is more likely to be inflammatory or wear and in the hands, for instance, the bony swelling at the joints

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furthest along the fingers tends to suggest a wear process. It is strange that often these joints although swollen are not a source of symptoms.

Blood results may show clear features of inflammation but if the amount of inflammation is modest or if it is largely in peripheral joints sometimes the markers for inflammation in the blood can be completely normal.

How bad is that arthritis?

So once the diagnosis has been clarified the next step is to assess the severity of the problem. One would never wish to institute a treatment which might cause more problems to the patient's health than the problems they present with and these days we have some quite potent and sometimes hazardous treatments to manage joint disease. Clearly we are guided by the pain and the stiffness that the patient suffers but the other aspect is how much the problems with the joints limit day to day activities. It's therefore important that the patient is asked about aspects of life (which may be quite personal) where they depend on other people at home to help them out. Often these are activities which we normally all take for granted. In the clinic you may find that you are asked about difficulties you may have with personal hygiene in the bathroom. Clearly if you have something that is causing pain but it isn't stopping you from doing anything you don't want to take the same risks as if you have so much pain that you depend on a wheelchair to get around. There are other aspects about limitations of day to day activities which might suggest an occupational therapist may help somebody and the degree to which a patient depends on others for help is an important factor in awards for disability living allowance.

Finally the blood tests and imaging tests (like x-rays and scans) have some capacity to identify patients who are likely to have more damage to the joints in future, and of course, limitations in day to day activities because of the damage done.

Treating the symptons

The next step of course is treatment. Patients usually come to us looking for relief of symptoms so this is always a priority. Often they will already be on some treatment, even if it's simply something they have bought at the supermarket or at the local pharmacy. This can include the simple pain killers like Paracetamol or Co-codamol, or they may have gone as far as anti-inflammatories. Usually anti-inflammatories will have rather more impact on stiffness than the simple pain killers and it's a paradox that although anti-inflammatory drugs do have actions on the chemicals that are involved in the process of inflammation, they don't appear to have any effect on slowing down damage done by inflammation.

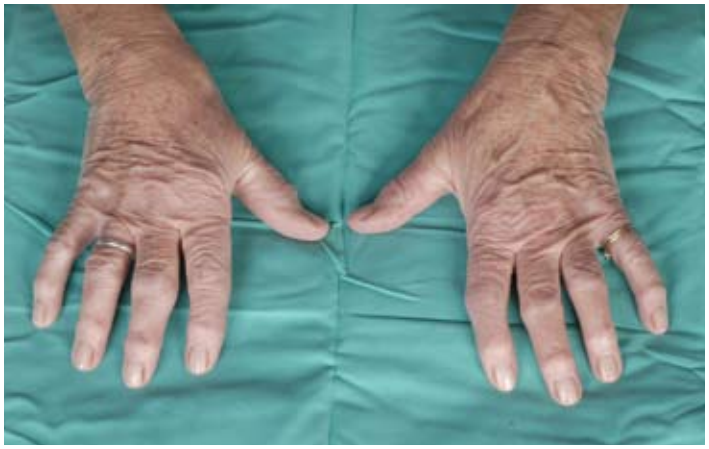

FIG 2. Osteoarthritis in the hands. The swelling is in most of the small joints of the fingers is bony hard and similar swelling is often present at the base of the thumb just beyond the wrist.

Simple pain killers like Paracetamol are much safer than anti-inflammatories, particularly in the long run so if the patient can manage with Paracetamol alone without undue upset we will avoid anti-inflammatory drugs like Ibuprofen, Diclofenac or Naproxen even though it means the patient often takes a large number of tablets in the day.

Sometimes pain can be very difficult to manage and it may originate from pressure on a nerve around a joint as in sciatica or carpal tunnel syndrome. Where pain is widespread or there's an obvious problem with nerve involvement contributing to pain, drugs like Amitriptyline, Nortriptyline, Gabapentin or Carbamazepine maybe used, but side effects are quite common with these drugs. In some ways this is not surprising as our nerve endings are most concentrated in our brains and our brains control everything we do; so the side effects can be very variable. Nevertheless, the addition of these drugs can be a real advantage for some patients.

Relief of pain and stiffness may not just be achieved though using tablets. It maybe that, where a particular area is causing discomfort, a support will help, such as a wrist splint for an inflamed wrist or a splint for wear and tear at the base of the thumb. Sometimes changing the way we bear weight through our feet can help with pain involving the toes or the heel. Often the Podiatrist or an Orthotist will advise on this. Again, if one joint is causing a lot more trouble than others it maybe possible to inject the joint, usually with steroid and often patients will get a good response to this particularly where inflammation is an issue.

Prevention

Another aspect of treatment is prevention. There are things people can do to try and help keep their joints good. Exercise to maintain joint movement and muscle strength will stand any arthritic patient in good stead. With a sore shoulder it is easy to move things about the work surfaces and forget about the high shelves, but in time most will regret not being able to use the space on the upper shelves. In addition one of the best predictors of the range of movement after joint replacement is the range of movement immediately beforehand, so keeping joints moving throughout the course of an arthritis makes good sense. (Here the term "arthritis" is simply used to describe some degree of inflammation in joints – it does not necessarily imply joint surface damage.)

Similarly keeping good posture takes the strain off joints. Probably this is most important in the spine. The Physiotherapists tend to cover the area of exercises and the Occupational Therapists teach patients about joint protection techniques. These are probably most easily understood in rheumatoid arthritis where there is a tendency for the fingers to drift off to the side. In many respects this is a natural response to using the hand's grip and activities such as removing the top of a jar will tend to put pressure on the fingers to encourage loosening of the joints where the fingers join the hand. Joint protection may reduce the deformity and will almost certainly reduce the pain

Sometimes of course there are problems outside the joints and these may also require management. Fatigue may respond to gradually increasing exercise and often this is facilitated by supervision from a Physiotherapist. Sometimes fatigue is the consequence of anaemia and sorting out anaemia and treating it appropriately can be quite a challenge. Sometimes anaemia is due to blood loss related to anti-inflammatory drugs; sometimes it can be due to dietary problems as having arthritis can make you less enthusiastic about a good balanced diet or indeed pain and stiffness can make you less interested in preparing nutritious food because of the discomfort involved in using the hands.

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Sometimes the anaemia is simply a function of the marrow being slowed down in the presence of inflammation elsewhere, and under these circumstances treatment is the treatment of the underlying problem or if necessary, blood transfusion, but transfusion isn't risk free.

Patients with rheumatoid arthritis quite often develop nodules and the best success at keeping nodules at bay relate to keeping the pressure off those points at which the nodules form.

Not surprisingly depression can be a feature of patients with arthritic problems but the evidence suggests that depression should be treated and will respond to treatment in much the same way as in a patient who becomes depressed who doesn't have arthritis, so it's wise to allow your doctor to help.

Specific treatment

Specific treatment is difficult. There are no cures yet. In Primary Sjögren's where the problem is inflammatory but not destructive usually drug therapy revolves around symptom relief and use of hydroxychloroquine. This drug helps the arthritis in rheumatoid and in SLE so where there's uncertainty in diagnosis you may well find your rheumatologist will suggest it as a good starting point. It is generally well tolerated and the concerns that have existed in the past about deteriorating vision in patients on hydroxychloroquine are perhaps less as increasing audit data suggests that this is exceptionally rare.

A few people are allergic to hydroxychloroquine like many other drugs, but there is the possibility of using tiny doses of chloroquine, a similar drug, built up on a very gradual basis to desensitise people should they prove to be allergic. Most studies on arthritis and hydroxychloroquine suggest that at the end of 6 months patients may well find that their pain is reduced to about half the level it was before treatment and the period of stiffness in the morning is also substantially reduced.

The swelling may settle down but there isn't a lot of evidence that hydroxychloroquine reduces joint damage in those patients who have Sjögren's secondary to rheumatoid arthritis. For these patients there are many other options including methotrexate, sulphasalazine, gold injections, leflunomide and the new biologic therapies including anti-TNF agents, rituximab and tocilizumab. This range is quite an advance on the range of treatments that were available in the past and we are beginning to get to the stage in those people who have destructive arthritis that we can anticipate that drugs will actually halt the damage and increasingly, if you have been diagnosed as having rheumatoid accompanying Sjögren's, you will find that your doctor will try to inhibit as much inflammation as possible by adding drugs as the evidence suggests that this is best way to ensure future well being. Certainly we see far fewer patients who have reached the stage of requiring several joint operations in succession at the clinic. You will find now that there is increasing interest in trying to induce remission (getting rid of signs and symptoms) in inflammatory joint disease at an early stage and perhaps we are beginning to get the drugs that will achieve this. However, managing these different approaches to treatment and all the different areas that might help is always a matter of negotiation and you should consider yourself as the person at the centre of all the decisions. You should always consider the balance of risks and benefits and seek as much information as you feel you need to help you make decisions about your treatment. Make sure too that you get help from all the quarters available as generally 2 heads (or more) are better than 1! So feel free to take a trusted family member or a friend with you when you attend the clinic.

Conclusion

I hope this article has given you some insight as to what might happen at a rheumatology clinic and how people might make decisions about your care. Often there are grey areas, and difficult decisions to be made so please have patience with your doctors, but don't hesitate to ask searching questions. It's those searching questions that have often provoked discovery when there is an enquiring mind in a budding researcher at the clinic! It may even be a student who is sitting in who will be the person to make the important discovery in a few years' time.