Rheumatoid Arthritis
Questions and Answers

Information provided by:
The Information was kindly provided by David Blake, Professor of Bone and Joint Medicine, University of Bath & Royal National Hospital for Rheumatic Diseases, Bath, and reviewed and updated by Robert Moots, Professor of Rheumatology, University of Liverpool.

1. **Is rheumatoid arthritis hereditary?**
In most cases it is not. In some families rheumatoid arthritis and other ‘autoimmune’ diseases appear to be passed down to some family members. The twin of an identical pair with arthritis has a much-increased risk. The twin of a non-identical pair has an increased risk. If you have a brother, sister or family member with arthritis you have a slightly increased risk. Clearly there is a hereditary component to arthritis but it is not the dominant factor for most individuals and the risk of transmitting the disease to one of your children is small.

It should not discourage anyone from having a family. If you or a member of your family has arthritis and your children get joint symptoms, you should tell your doctor who is likely then to seek specialist advice. Remember, however, that perfectly normal children complain of pains in and round the joints from time to time and this should not cause you undue concern. If a joint becomes swollen, it should, or if the child starts to complain of pains in his joints, stiffness in the morning and is easily tired or irritated.

2. **Why are some joints but not all are affected by RA, and why does it affects just a few joints in some patients but many more in others?**
Researchers have for many years been intrigued by this question. Different forms of arthritis attack different joint areas; some in a symmetrical fashion, others just on one side. It is likely that both genes and the nervous system influence these complex patterns. One intriguing observation has been that unfortunate people who have a stroke affecting one side of their body rarely get rheumatoid arthritis on the stroke side if they develop rheumatoid arthritis later.

This has suggested to many researchers that the central nervous system contributes to the pattern of the disease expression. It may also have an influence on the flare response in arthritis and other aspects. The most common joints to be affected by Rheumatoid arthritis are the 2nd, 3rd and 4th knuckles on both hands and the balls of the feet (bones in the forefoot, the metatarsals - the equivalent of the knuckles in the hands) but every joint area can be affected.

3. **I would like more information about the process that drives rheumatoid arthritis and to understand more of the jargon that experts use?**
Here is a brief description of the process and the jargon words we use:

When inflammation starts in a joint, the lining layer of the joint which is known as the synovium, swells. We call this synovitis. The ending ‘-itis’ is attached to structures to describe in shorthand inflammation of that structure. Appendicitis, pharyngitis, orchitis, conjunctivitis are examples of the same thing: inflammation in the throat, testicle, lining of the eye, respectively; but there are hundreds more examples that you can think of.

As the synovitis develops, different cells move into the joint in the same way as they would do into an infected wound. The first cells to come in are fast-acting scavenger cells - these are white blood
cells called polymorphs. Soon after more long-lasting cells arrive which are cells that orchestrate our immune response. The immune response is an extremely complicated process, of which we know a lot, which leads to the production of amongst other things, cytokines, antibodies and other substances which are primarily designed to kill any infective agent.

As we have discussed, we know of no infective agent that causes rheumatoid arthritis so why they are there and what triggers their coming remains a mystery. The cells tend not to disappear. It is as if they are constantly looking for some infection that they don't find. However, they continue to release their toxic products which then start to damage the joints. As the joints get damaged various bits of material from bone and cartilage are released and in their turn they cause more cells to come in to clear away the damage and so the process continues.

This has been called an autoimmune reaction describing a long-term and self-perpetuating destructive process. Over time the synovial cells become more and more organised into a tissue that we describe as callus and in the rather strange environment of a joint, this starts to eat away at the bone and cartilage surface almost like a tumour though the cells do not turn malignant. This process occurs at different rates in different people. As we have discussed, it is controlled to a greater or less extent by our disease-modifying anti-rheumatic drugs (DMARDs).

Whilst arthritis is a disease that for the most part just attacks joints, other tissues in the body can also be affected. These include some tissues in the eye, the lining layer of the lung (pleura) causing pleuritis; occasionally the lining layer of the heart (pericardium) causing pericarditis and small blood vessels (the vascular system) causing vasculitis. These are known as systemic complications of arthritis. Another systemic complication is anaemia, meaning less blood than normal and this contributes to the tiredness that comes with arthritis.

A mild anaemia is very common; the other complications much less common but your doctors and consultants will be on the look out for them each time you come to the clinic. Another fairly common complication is little bumps or nodules that occur over the elbows or points of pressure. These are called rheumatoid nodules. We do not know what causes these and they are difficult to stop with DMARD therapy, indeed methotrexate may make them slightly worse. Whilst they are disfiguring and sometimes uncomfortable, they are of themselves not too much of a worry. For those anxious to know more of the science of rheumatoid arthritis, the following websites are helpful….

4. Are viruses a possible cause for arthritis?
Potential links between viral diseases including German measles have been researched quite thoroughly over the years and as new tests are developed to make viral diagnoses more precise, they are regularly applied to patients with arthritis. To date no link has been established. However, as we have discussed, certain viruses including German measles, parvovirus, Coxsackie virus and the Echo virus can cause a short-lived arthritis, particularly in adults. Some patients develop a short-lived arthritis after German measles vaccination. This is not common.

5. What is the relationship between arthritis and stress?
It is now quite clear that stress can affect our immune systems and it is likely that sufferers living under stressful conditions find that the body's natural ability to help limit arthritis is worsened. Stress, of course, means different things to different people and therefore measuring its affects absolutely is complicated and difficult. Many find challenging situations a positive benefit if they are able to deal with them.
However a constantly stressful environment over which you have little control and when there is inadequate time to deal adequately with problems is the sort of stress that causes most difficulties. Doctors suffer from this in busy over-booked clinics! The kind of stress that comes after bereavement sets up a whole battery of chemical responses and it does appear that this kind of stress event does trigger the flares of arthritis that we have discussed in some people.

6. **Why does rheumatoid arthritis strike people at different times?**

We do not know the answer to this important question. It is much more common in women than men and by and large attacks most people in their late thirties through to their late fifties, but it can attack at all times and the patterns of rheumatoid arthritis are slightly different in different age groups.

7. **What is the 'rhyme or reason' to it all?**

Well, we don't know that either but this is an important comment. A very wise investigator of rheumatoid arthritis once made the important quote 'that physiology begets pathology' and that we will never understand pathological processes until we know what is the physiological process behind them. Translating this into more common use of English, it means that reaction sequences such as the inflammatory cascade have evolved for a reason and the genes behind them are maintained in society for a purpose. When we consider inflammation as a physiological process we are describing the body's reaction primarily to infection or damage.

There are very many infective agents that we can be exposed to. It would appear that we all have our genes set at slightly different thresholds so that if an unknown and truly nasty infective agent comes, such as the AIDS virus, some people will respond extraordinarily dramatically to it and be able to eradicate it. Now imagine if in creating this massive anti-infective response there was a downside that allowed the inflammatory reaction to be set off by a very trivial event.

It would do the bulk of people a lot of damage but if, there were a few who would survive the insult, for example the AIDS virus this would allow our species to continue. We have a variety of genes not for the benefit of any one individual, but for mankind as a whole. In some situations an individual is a winner and in others, a loser. Rheumatoid arthritis may be an example of this phenomenon where some people's genes for a chronic, inflammatory response are set to be too sensitive and they run the risk of a disease. In an evolutionary sense there is, however, likely to be a benefit to this process and the benefit is likely to be your ability to respond to certain unpleasant infections that would be damaging to the rest of us.

At the moment we don't know first of all whether this far-reaching idea is true and we don't know what the infective advantage might be. If we go back to discovering AIDS, however, we do know that some people who have certain genes are better able to fight this frightening disease than others and the same gene puts them at risk of developing certain different autoimmune diseases. This suggests that this theoretical model is helpful.

The practice side of this is that when your consultant says to you that he wants to start you on disease-modifying drugs which are immune-suppressing agents, it does not mean that he wants to suppress your immune system below that of normal but to lower it down to a normal level. A better and less frightening way of describing this are the words 'immune normalisation' which is a kind of averaging out of the situation. So when well-meaning but slightly misguided colleagues say, 'I wouldn't want to be taking those immune-suppressive agents', they are right, they don't need to because their immune system isn't super-charged and they would suffer more side effects than someone with a super-charged system. Asthma is an example of a super-charged system controlled
by genes that affect our earliest responses to inflammation.

We undertake regular blood tests on most disease-modifying drugs to make sure that we have achieved immune normalisation and not gone a step too far with immune suppression. When your doctor asks for regular blood tests it is very important that you understand their importance. The blood tests also help us to see if your disease is changing in its activity.

8. **What is the association between rheumatoid arthritis and hormones?**
There is likely to be a connection here but it is far from being fully understood. Firstly RA usually dramatically gets better during pregnancy and the symptoms, though not always the signs, can almost disappear completely. Secondly, a common time for arthritis to develop is around the time of the menopause. We do not however know of any hormonal replacement therapy that influences the onset or the outcome of arthritis.

9. **What might have triggered my rheumatoid arthritis?**
All patients try to seek an explanation from recent events. We do not know the cause of rheumatoid arthritis and there may be more than one cause. We do know that in some families rheumatoid arthritis appears to be handed down from one generation to another. If one of a pair of identical twins gets rheumatoid arthritis, the other is very likely to do so.

From this we know that there is a genetic influence on the process and an analysis of the genes that appear to be important show that they are genes that control our bodies' immune response. However, plenty of people have the same genes and do not develop rheumatoid arthritis so there must be other factors that come into play. This has been a subject of very intensive research, but no answer has yet emerged.

10. **What drugs are used to treat rheumatoid arthritis?**
A good source of information is the leaflet 'Drugs and Arthritis'. They also produce more specialised leaflets on non-steroidal anti-inflammatory drugs and patient information sheets on all the specific drugs. Different types of arthritis are treated with different drugs. For rheumatoid arthritis the drugs are broadly divided into drugs that help control the symptoms and those that actually slow down or stop the course of the disease. The main drugs used to control symptoms are the pain killers (analgesics) such as paracetamol. Aspirin-like drugs, also known as non-steroidal anti-inflammatory drugs, are also used to control pain. These also reduce stiffness in joints - but do not affect the disease itself. The disease-modifying anti-rheumatic drugs (DMARDs) are sometimes referred to as second-line drugs. These suppress the inflammation that causes rheumatoid arthritis, reduce disease activity and thereby relieve pain. People sometimes refer to a third group, corticosteroids or steroids which also are able to reduce inflammation. Finally, we have biologic drugs such as the TNF inhibitors, which act against a key molecule that drives inflammation and causes fatigue.

Examples of painkillers include paracetamol, di-hydrocodeine, co-proxamol and paracetamol/codeine combinations. Examples of non-steroidal anti-inflammatory drugs are aspirin, ibuprofen, naproxen, diclofenac, celecoxib. Drugs that affect the disease and are called DMARDs include methotrexate, sulfasalazine, cyclosporin, penicillamine, gold, hydroxychloroquine, azathioprine, leflunomide. The biologic drugs available today include the TNF inhibitors etanercept (Enbrel), Adalimumab (Humira), infliximab (Remicaide), certolizumab (Cimzia) and golimumab (Simponi); the B-cell depletory rituximab (MabThera) the anti-costimulatory drug abatacept (orencia) and the IL-6 inhibitor tocilizumab (RoActemra).

Steroids are very effective in controlling inflammation but are very prone to produce unpleasant side
effects in high dose and when given for more than a month or two.

Medicines are only one aspect of the treatment for arthritis. Here are a few general points to remember about them:

- Always try to bring a list of all the medicines that you take with you, including those bought from the pharmacist or an alternative prescriber so that you can tell your doctor at each clinic visit.
- Follow the instructions that come with the tablets carefully. Some should be taken with food, some after food. Make sure you are certain.
- Study the side effects list that is always included in each packet. Don't be overwhelmed by the great lengths of these lists, but do keep a careful eye out and tell your doctor if you are troubled by side effects. It is very easy to be overwhelmed by concern of side effects. The doctor writing this is on four tablets for his blood pressure which makes him eligible for two hundred different side effects. Your first thought is, they must be mad, but they are rare and rarely troublesome.
- If you are asked to have regular urine or blood tests and this is common with DMARDs, it is important that you do so. It is important that the results are checked and ideally held on a shared doctor/patient information record.
- If you are on a steroid you should carry with you in wallet or purse a steroid card and be aware of the warnings within it. Cards can be obtained from your doctor or pharmacist and should be given to you at the time of the first prescription. If you are receiving a steroid by joint injection, you do not need to carry a card.

11. Does arthritis come in different forms and has it many causes?
There are over 200 different causes of arthritis and for many we have a very clear understanding of what causes the disease. Many forms of arthritis are treatable. Unfortunately, two of the commonest, rheumatoid arthritis and osteoarthritis, are more difficult to control and we have a poorer grasp of the complex factors that cause them. Research, however, is very active in these areas and the Arthritis Research UK details research activities in this country.

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12. Why are people so poorly informed about arthritis when it is so common?
Rheumatoid arthritis certainly is a common disease affecting a little less than 1 in 100 adults at some time. It is more common in women and often starts in their early middle years when they are trying to bring up their children. Arthritis is never welcome at any time but at this time it causes particular difficulties.

It can cause special problems in people whose joints are very painful but to an outsider they look nearly normal or only slightly inflamed and this creates enormous frustration, particularly for women when her family may not show the tolerance that is needed or the assistance. Children often do not appreciate the great difficulties that their mothers face. Most consultants welcome the opportunity to speak to family members under circumstances like this, as support from partners is crucial at all stages of the disease and a well-informed partner is a useful ally.

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13. Is arthritis caused by a virus?
A lot of viruses can cause arthritis. The arthritis can be quite extraordinarily painful. If only a few joints are involved, they will usually settle quickly – often without special treatment but sometimes requiring a steroid injection. There is no evidence, at present, that a virus causes rheumatoid
arthritis. One particular virus, 'the parvovirus', can cause an arthritis that may last up to a year in adults and look quite similar to rheumatoid arthritis as it attacks joints evenly on both sides of the body. In this condition, which is usually caught from a child, the rheumatoid factor test may be positive and this can cause diagnostic confusion.

14. Why do people think the outlook for patients with rheumatoid arthritis is so full of doom and gloom?
Although there is a generally held view that you can't do much to treat arthritis. This is most definitely not the case. Treatment of rheumatoid arthritis has undergone a revolution over recent years. We now aim to induce remission of disease (the absence of any symptoms or features) by suppressing the inflammation that causes it. Once in remission, the job is to maintain it. With our modern rheumatology units, the early use of drugs that suppress rheumatoid disease, and careful use of biologic drugs, this is achievable in a large proportion of patients. There still remains a need to take medicines, though the hope is that, in the future, drug-free remission will be possible. However, developing rheumatoid arthritis can certainly be a frightening experience and, in the early days, it can be very hard to be positive when you feel so ill, sore and tired.

14. Can arthritis affect all age groups?
Most people think of arthritis affecting older people but it can occur in children though it is rare. It is about as common as childhood diabetes. It often may start before the age of five. Arthritis causes particularly difficulties in children and enormous problems for their families.

All regional centres now have access to a paediatric rheumatologist who needs to be consulted early and they are well trained to deal with the problems in a family setting. Again, Arthritis Research UK produce a useful series of booklets written for children, for parents and for teachers and these should be consulted. Arthritis Care has a specific helpline for parents, children and young people and useful addresses and links can be found via this website. See also Healthtalkonline’s section on young people’s experiences of arthritis.

15. Why can it take so long to diagnose rheumatoid arthritis?
It does not need to take long to diagnose rheumatoid arthritis today. However, RA can start in many different ways. Sometimes just one joint is involved and it then settles, only to come back elsewhere in one or more joints. It may then vanish again for some time. In others a more widespread arthritis creeps in over time and then explodes in lots of joints simultaneously. In some, it is limited to just one area. The hands are a common place for it to start but in others, just the feet.

Whilst there is no absolute diagnostic test for rheumatoid arthritis, the combination of signs, symptoms and blood tests helps general practitioners think about the condition and refer rapidly to rheumatologists, who can make the diagnosis definitely. Doctors work to well-defined criteria that were specified internationally by experts and published jointly by European League Against Rheumatism and the American College of Rheumatology as diagnostic criteria. Research is being undertaken to find a more reliable blood test that can predict this clinical state early. As treatment for many people is lifelong, it is very important that the original diagnosis is accurate.

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16. Is rheumatoid arthritis a particularly 'English' condition?
It is true that rheumatic diseases generally were called the English disease and it was thought that the rather changeable and often damp environment that we lived in was a cause of rheumatics. This was a view widely held in the 18th and 19 century. It is very common observed in patients with
rheumatic complaints that when they visit warmer countries their symptoms are relieved. I believe it to be accepted that generalised joint aches and pains are improved by warmth and conversely cold and damp conditions generally make pain states linked to rheumatic diseases more troublesome.

However, there is no evidence that rheumatoid arthritis is any less frequent in any part of the world and indeed this area has been very well researched. Whilst some research suggested that in South Africa a rural population had a lower incidence than an urban population, this research has never been repeated though it is extremely intriguing. We need to distinguish in relation to rheumatic problems whether we are talking about rheumatoid arthritis a very specific condition, other forms of arthritis or generalised musculoskeletal aches and pains, often described as being arthritic.

Rheumatoid arthritis can be affected by changes in barometric pressure and humidity in the weather but, 'It is probably better to live with a happy family in a warm, dry house in the Thames Valley than alone in sunny Spain amongst strangers'. It is probably better still if you can combine the best of both weather and environment in your living conditions and daily activities.

Should you find yourself in council housing that is neither warm nor dry, your doctors can write in support to your council explaining the importance of stable environments and rheumatic symptoms. It is important particularly in the winter to keep yourself warm and to make use of all resources that the State provides to help with this.

17. I was told that it was possible that I might end up in a wheelchair within three years? This would be a very unlikely consequence of arthritis. In the days before our modern medications, this was a common scenario, but it most certainly is not now.

18. Why do I feel so angry and frustrated? This response is very similar psychologically to those that occur after the death of a loved one and are known as the 'grief response'. She is right that this issue is rarely raised in consultations but it is much better faced openly and with sympathy, bringing one's partner to the clinic and discussing these difficulties with the consultant.

19. Why in some cases is the diagnosis of rheumatoid arthritis so difficult? There are over two hundred forms of arthritis. Arthritis means nothing more than inflammation in a joint and at its earliest stages one form of arthritis can look similar to another. The investigating doctor or consultant needs to ask many questions to try to narrow the situation down and may need to perform special investigations such as blood tests and ultrasound or MRI scans to see clearly what is happening around the sore joints. Rarely, only the passage of time helps clarify the situation. One of the earliest forms of rheumatoid arthritis that occurs in only a minority of people is palindromic rheumatoid arthritis. The word palindromic is used to illustrate how the problem comes and goes. Attacks may last hours or days and in a proportion the frequency of attacks increases until a more persistent form of arthritis settles in. In other patients the initial problem may be stiffness with little in the way of joint swelling. This particularly occurs in elderly people. The difficulties arise because we have no absolute diagnostic test. The pattern of presentation is, as you can see, very variable and the differential diagnostic possibilities are large.

Viral or bacterial infections can produce a disease that looks like rheumatoid arthritis for a short while but is not. The parvovirus, which often goes through the country in epidemics, can cause a disease that looks very much like rheumatoid arthritis and the blood test for rheumatoid arthritis is weakly positive (rheumatoid factor). The disease, however, usually gets better quite quickly. Adults
who have caught a parvovirus infection have usually done so from a child who has a characteristic rash on his face that looks a little like his or her cheeks have been slapped. Parvovirus infection in children is sometimes called 'slapped cheek disease'.

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20. How good are tests at diagnosing and predicting how rheumatoid arthritis will progress?

One of the standard blood tests to see if you have rheumatoid arthritis is to measure 'rheumatoid factor'. This is a test that measures a protein in your body called an immunoglobulin. Immunoglobulins are also known as antibodies and we produce many antibodies to any foreign material or infective agents. When the antibody sticks to say a bug, the body then sends cells that target the antibody that kills the bug.

Rheumatoid factor is an antibody that appears to be targeted against another perfectly normal immunoglobulin and therefore we call this an autoantibody. It seems odd that the body would want to attack itself but this appears to be the case. There have been many hypotheses put forward as to why this might happen but the answer is far from certain. If you have high levels of rheumatoid factor it is likely that your arthritis will be more troublesome than if you have low levels. However, it is also true that you can have rheumatoid arthritis without having this antibody so it is not a foolproof diagnostic test.

There are other antibodies (ant-citrullinated peptide antibodies: ACPA) which have been more recently discovered. These are more reliable than rheumatoid factor as they correlate much more closely with a diagnosis of rheumatoid arthritis. In some rare situations, they are present before the disease develops. One of the blood tests that we use to measure how active the disease is at that moment in time is called the ESR. Another similar test is called the CRP. Both these tests are indirect measures of how many small proteins (cytokines) are active in your joints. If we see that these tests are rising, this suggests a rocky period which may lead a specialist to increase your tablets.

The ESR and CRP are, however, not specific and a simple infection, say a urinary infection which is common in women, may increase this blood marker but not indicate that the disease is worsening. The doctor uses the blood tests and all the things you tell him in response to our simple questions, to work out the best approach. Researchers are actively studying other markers that may be helpful, both to make the diagnosis accurately and to predict its outcome. When we have a fuller understanding of the complex inherited genes that contribute to this process, which we should have soon, now the human genome project is completed, our tests both for arthritis and for many other poorly understood diseases should improve.

21. Does the German measles virus cause rheumatoid arthritis?

Viruses can cause arthritis but to date is there is no evidence that this virus, Rubella, or any other, causes rheumatoid arthritis. Nor is there evidence that bacteria, years, fungi or other microbes can cause this disease. But researchers are still actively looking for a possible infective trigger, so far without success.

A lot of viruses and some bacteria can cause an arthritis that looks very similar to some of the earliest types of rheumatoid arthritis. These viral forms of arthritis usually settle within three months but occasionally the arthritis may last for a year. Doctors when they see patients with an early form of arthritis that may prove to be rheumatoid arthritis check for known viral causes that can look similar.
Of course, rheumatoid arthritis can strike at any time and everyone relates what has just happened to them to their arthritis in order to make some sense of it. It can be difficult or impossible to distinguish what is likely to be a causative link from one that is just a coincidence. Common associations suggested by patients are stress, often a bereavement, trauma, infection, surgery and heavy exercise. Whilst there is no evidence that any of these on their own cause arthritis, it is well known that such things may change the way our body responds to another insult and they therefore may all indirectly have an influence.

22. Why do we use drugs in certain orders?
It is now routine experience when someone develops rheumatoid arthritis and the diagnosis is clear to start methotrexate, which is taken weekly or sometimes sulphasalazine or leflunomide, which are taken daily. These drugs may be given in combination in severe disease, as they work well together. They have slightly different side effects and this occasionally influences which is offered in the first place.

Over time, some of these drugs may lose effect and require either the dose to be increased or another added. If patients do not respond well to these agents they may become eligible for a biologic medication. The latter is, however, very much more expensive. Doctors are guided by government medical agencies as to when it is appropriate to add these medications. If, however, you still have active disease despite taking an appropriate dose of methotrexate and/or sulphasalazine, you should be offered a biologic drug, usually a TNF inhibitor. In situations where a TNF inhibitor does not work, other biologic drugs such as rituximab, adalimumab or tocilizumab are used.

23. What side effects do steroids have?
Steroids are extremely effective in suppressing arthritis in the short-term. When they were invented in the 1950s they were hailed as a cure for arthritis and the inventor received a Nobel Prize for the discovery. It wasn’t long before the serious side effects of steroids emerged and bruising, though unsightly, is in many ways the most trivial. Steroids at high doses when given for some time cause many problems including high blood pressure, diabetes and bone thinning (osteoporosis). They also suppress the adrenal glands’ ability to produce normal steroids.

Steroids are almost never prescribed as the main drug for a treatment programme but are often used for an acute flare and are given very frequently as injections into the joint where they act locally. Anybody on steroids for more than a day or two must carry a blue steroid card which is available from all hospitals or pharmacies and they warn of their dangers and in particular, the danger of abruptly stopping the drug. If you are on steroids for your arthritis it is essential that your doctor and pharmacist advise you of their potential hazards.

24. Why do so many so-called experts keep popping up announcing that a cure is just around the corner?
This is unfortunately true and it is not much helped by the fact that the press sell newspapers by exaggerating already exaggerated claims. Having been in rheumatology for thirty years, I have probably been offered by patients close on a thousand cuttings from newspapers, usually not very clever ones, or from women’s magazines describing the cure for rheumatoid arthritis.

This unnecessarily raises expectations, causes disappointment and can drive people to seeking unhelpful medications. Many complementary medicines, unproven and unlicensed, are often massively exaggerated in this way, appearing as news when they are nothing but adverts in disguise. TENS machines which are quite helpful, are one of the many products for which claims are made
that are fantastically exaggerated when compared with the benefits that have been observed in studies.

Before spending money on these products, feel free to discuss the evidence with your doctors. For the most part I advise my patients when faced with these near-illegal claims, that a nice meal out with a good friend might be a better investment of the money.

25. What are anti-TNF drugs?
Information about the five approved anti-TNF therapies etanercept, infliximab, adalimumab, certolizumab and golimumab are available from the Arthritis Research UK as a leaflet and further information is available on their website and on the website of the National Rheumatoid Arthritis Society (NRAS). TNF is a small protein that accumulates in the blood and the joints in large amounts where it causes inflammation. It is also responsible for causing much of the tiredness that patients experience.

Infliximab is given as slow infusion into the vein, in hospital, usually every 2 months after an induction course of three injections over eight weeks. The other TNF inhibitors are given by the patient or their carer as an injection under the skin, at home. Etanercept is usually taken once a week, adalimumab and certolizumab once a fortnight and golimumab once a month. Whilst these drugs work very well in many patients, they do not work in everyone. The most important side effect is a risk of infection. You may not be given these drugs if you have had tuberculosis in the past, unless we are confident it has been completely removed, if you are getting infections often, if you have had a recent cancer or if you have symptoms suggestive of multiple sclerosis.

These side effects relate to the fact that inflammation is a means of dealing with infection and TNF itself is one of a large number of self-made anti-cancer molecules. However, long-term trials of anti-TNF drugs have not shown a worrying increase in cancer, but this is being constantly monitored by organisations such as the British Society of Rheumatology. Anti-TNF drugs are now well reported to have a substantial effect in many people and benefit may be seen as early as a few weeks. Tiredness often disappears first.

26. What is b-cell therapy rituximab?
Rituximab is a drug that depletes a certain type of white blood cell, the B-cell, that eventually becomes a cell producing antibodies. This drug is given as a cycle of two infusions, given slowly into a vein. Each infusion is given in hospital. There is a gap of two weeks between each infusion. After a cycle of rituximab, patients that respond can experience a reduction in activity of their disease for many months. When the disease flares up again, it usually responds to another cycle of the drug.

27. Where can I find information about problems with hands and wrists?
Arthritis Research UK provide a very good information booklet on this subject entitled 'Hand and Wrist Surgery for Arthritis' which describes carpal tunnel syndrome, when a nerve (the median nerve in the wrist) is blocked and your thumb, index and part of your middle finger start to tingle. It describes trigger finger when there is a swelling in the tendons which are guiders that run over the joints.

These are often painful and fingers can stick. Local injections or a small operation help. The booklet describes ganglions which are cysts, sometimes soft, sometimes hard which form on joints or tendons and most commonly found on the back of the wrist.

Some get better on their own, some need to be drained and minor surgery may be needed. The
knuckles, also called the MCP joints, may become deformed in arthritis with a sideways drift of the fingers. This can make the hand weak. Slightly more difficult surgery is needed here and outpatient physiotherapy or occupational therapy treatment is needed after to help maintain mobility of the hands.

Occupational therapists can recommend exercises and splints that help slow down the problems. Occasionally, tendons over the hands rupture and there is a sudden loss of movement in any of the fingers, most often the thumb, little and ring fingers. Early surgical treatment is needed and you should seek immediate advice if this happens. Repaired tendons need six weeks to heal.

A common problem that can occur with or without rheumatoid arthritis is a Dupuytren's contracture. This describes scar tissue in the palm of the hand and fingers, sometimes in nodules and sometimes in bands that may make the fingers curl down. Surgery may be needed but the condition is painless and may progress only very slowly. Surgery is not necessary for most people with arthritis in their hands, but when it is, it is useful for reducing pain and improving function.

Foot problems are also common in arthritis. The foot is a complex structure with more than thirty joints and one hundred muscles and all of our feet are a little different. Some people's feet that are rather flat called pes planus; others have higher arched feet called pes cavus and some normal people develop other problems if the arches are too flat or too high such as hammer toes, bunions, corns and calluses. Many women who have worn high heels and/or pointed shoes in their teens or as young adults are troubled by a bent big toe called hallux valgus, and corns.

When rheumatoid arthritis affects the feet these problems are more likely to develop as the foot architecture is disturbed. It is important to get good attention to your feet as painful feet rapidly lead to a loss of mobility and fitness which, as we have discussed, causes its own problems.

A very useful source of information is the booklet on 'Feet, Footwear and Arthritis' and it teaches sensible, practical things such as what you need to do when buying shoes, how to deal with difficult fastenings on shoes, what to do if you can’t buy shoes that are correct for you. The booklet describes the role of chiropodists and orthotists and informs you about functional orthoses which are inserts that can be put into shoes to help maintain correct position. All the many jargon words used to describe feet and associated problems are nicely described.

28. I would like to know more about neck problems?
As we grow older many of us and particularly women, suffer from wear and tear in their neck, also known as cervical spondylosis and this is the commonest problem that affects patients with rheumatoid arthritis. It can cause considerable pain as when the discs wear as they do with age or over-use, the vertebrae above and below them sink down and the nerve which leaves between each pair of vertebrae can be pinched. You then feel the pain in the area that that nerve supplies - so for instance, many people who complain of pain around their shoulder going down their arm, have pain that has come from their neck.

People who get shooting pains or a dull pain that goes all the way to the fingers have trapped the nerve at the bottom of the neck. If you suffer from pain which is going round the back of your head, it is possible that you have trapped the nerve between your first and second cervical vertebra. These changes can usually be seen on x-rays and they are present in almost everyone by the age of 65 though in many cases, despite quite considerable wear, there isn't much pain. If there is a lot of damage, the spinal cord which runs just behind the main vertebrae can get pinched or squeezed and this causes weakness and numbness in the arms and the legs.
This is serious and needs immediate medical/surgical attention. Much more common but very rarely serious are the clicking and grating noises that most of us get when we move our heads. The jargon word to describe this is crepitus. Whilst they can be upsetting, they rarely matter.

However, occasionally one of the arteries that supplies your brain which runs up the side of the vertebrae can be pinched and this pinching of the vertebral artery can make you feel dizzy when you look up and occasionally black out. This does require attention. Longstanding neck pains and stiffness often disturb sleep making sufferers tired and depressed. There is much to be done to help ranging from simple painkiller and anti-inflammatory drugs to massage, exercise, relaxation and collars. Acupuncture does help; reflexology does not and no change in diet is of benefit.

Techniques such as yoga, the Alexander technique and Pilates may all assist but sitting correctly at a desk with a chair at the right height and your neck position correctly is very helpful as is avoiding carrying even slightly heavy objects in just one hand. A woman's handbag held over a shoulder for a lifetime is a common cause for premature neck problems. The strap should go over the head to help distribute the weight and the contents of the handbag which, to the doctor who is writing these notes, are often fantastically excessive, can usually be left at home. One of my patients carried two spanners and a hammer at the request of her husband for over thirty years and continued to do so after his death!

Rheumatoid arthritis, however, may affect the 1st and 2nd neck bones in a way that is different from simple wear and tear. The joint between the 1st and 2nd vertebrae is what lets us rotate our head from side to side and is held together in a different way to the other joints with a little peg that comes out from the 2nd vertebra called the atlas and is held by a ligament at the back of the 1st vertebra called the axis. This ligament is covered by a special membrane (synovial) which we have described before in the joints.

If the membrane becomes inflamed there then the ligament weakens and the atlas and axis move apart. This is called atlantoaxial subluxation and is potentially serious. It is serious because the spinal cord runs just in front of the peg which may slip into it and cause pressure on the cord with weakness of the arms and legs. This requires urgent attention from your doctor or surgeon. The neck may need to be stabilised by an operation or supported with a collar. People are at particular risk from injury to a weakened cervical cord if their head moves forward suddenly not properly controlled by the muscles. This occurs most commonly in a car when the driver brakes suddenly and hard and whereas this may not trouble a normal individual, it can be enough to unsettle a loose rheumatoid spine. Collars are often advised for patients when driving.

29. What new research is being done on rheumatoid arthritis?
This is an extremely active field and for a comprehensive review of the area Arthritis Research UK website should be accessed. In brief, there is considerable research studying the genes that we inherit that control both the onset and the progress of the disease. There remains a lot of interest in the chemicals, of which there are many, that drive this destructive process. From Arthritis Research UK-sponsored work, researchers identified the small protein known as TNF (tumour necrosis factor) which plays an important part in perpetuating rheumatoid arthritis.

Both academic and commercial researchers worked hard to find strategies for blocking TNF and they are now used extensively in the clinic for patients whose disease is poorly controlled on other therapies. Researchers are now actively looking for less expensive ways of achieving TNF blockage with chemicals that can be taken by mouth. TNF is however only one of many small proteins that
contribute to the complex process and other researchers are working hard to find out if blocking these will have the same beneficial effects or other advantages. We are still some way from finding the cause, if indeed there is only one cause, of rheumatoid arthritis, but other researchers continue to look for a possible infective cause for this disease.

30. Are complementary approaches helpful for arthritis?
Yoga, pilates and the Alexander technique are excellent exercise regimens for patients with arthritis and professional instructors are very tolerant of the needs of people with difficulties. Simple relaxation and exercises can help maintain joint suppleness and the more generalised exercise benefits almost certainly have an effect via the brain on the immune system that also helps. Stress or perhaps more importantly, pressure that is difficult to live up to, does appear to have a negative impact on the development of arthritis and a positive attitude is clearly beneficial. It is much easier to be positive when you are well informed and therefore feel in some kind of control.

31. What alternative remedies can I use for rheumatoid arthritis?
Alternative remedies have been scrutinised by a committee formed by AR UK, who prepared a helpful report (available as a leaflet or by download from the AR UK website). In short, we know of no complementary medicine or diet that significantly alters the course of rheumatoid arthritis. Aspirin, after all, was the mainstay of our treatment and it was, of course, derived from the bark of the willow tree. We could still prescribe willow tree bark but purity, dosing, etc., is very difficult. Orthodox doctors have no difficulty in embracing the basic concept that herbal remedies may be found that can influence the disease but at present we know of none that do.

Relaxation exercises often prescribed by complementary physicians are very helpful to patients with arthritis and many are adopted within physiotherapy departments. Orthodox drugs do of course have side effects and it is hard to imagine that drugs that control inflammation will not have some side effects because the inflammatory process that attacks the joint is exactly the same complicated process that we use to fight infection. Over many years drugs have been screened to make sure that for the vast majority of people the potential benefits very significantly outweigh the dangers.

Uncontrolled rheumatoid arthritis not only destroys joints but also damages the body's blood supply and causes premature atherosclerosis. It is against the certain knowledge of the seriousness of these problems that you have to make a judgement. It is a personal matter and no doctor will coerce you into taking medication against your wishes even if he believes it is in your best interests to do it. You have total control. It is often, however, very dispiriting for the specialist when he knows that he could substantially improve someone, when they are warned off treatment by a complementary physician who has no training in the seriousness of the problem and very little idea of the nature of the drugs we use.

This happens regrettably rather frequently and is a cause of considerable concern. New legislation is being passed to ensure that complementary practitioners receive some professional training and work to an acceptable standard.

32. Why is there very considerable variation between one patient with rheumatoid arthritis and another?
That is to say if 95 per cent of people respond reasonably or well to a treatment and the risks are slight in all but a small minority, then a drug is recommended. However, it can be very difficult to predict, indeed for the most part impossible, whether any individual will respond well or the opposite, whether they will develop significant side effects and of course these are precisely the questions that are important to the patient.
33. Is there any link between osteoporosis and rheumatoid arthritis?
Osteoporosis describes the thinning of bones and commonly affects women particularly in areas of
the back and around the hips which can lead to fractures. Rheumatoid arthritis has been found to be
associated with osteoporosis, not just because treatment with steroids at high dose can weaken
bones – but the generalised inflammation in rheumatoid arthritis itself can add to the risk of
developing osteoporosis.

The most commonly used drugs to help strengthen the bone are known as bisphosphonates.
Hormone replacement therapy is occasionally advised but much less so, now we have
bisphosphonates. When synovitis develops and becomes persistent, then the bones around the
joints become thinned and we refer to this as localised secondary osteoporosis. This process can
make joint replacement more difficult as there is less high quality bone to hold the prosthesis.

34. Is there anything else that could be done to make life easier for RA sufferers?
One of the major problems of rheumatoid arthritis is pain. Doctors, for the most part, knowing that
the pain comes as a consequence of the inflammation, aim to treat the inflammation and anticipate
that the pain will settle. This is successful up to a point. In some people the disease continues to
progress when the inflammation settles but the joint is damaged beyond repair and is then painful
for different reasons that relate to it being out of place and other factors.

It is important with rheumatoid arthritis to keep going and you should not be nervous about taking
painkillers that are not anti-inflammatory to keep you mobile. We have discussed the relationship
with rheumatoid arthritis and osteoporosis above, but one sure-fire way of getting osteoporosis is to
be a woman who is elderly and then to be immobile. It is very important to make sure that your
doctors suppress your pain sufficiently for you to take regular exercise which helps strengthen your
muscles, your ligaments and your bones and improves your cardiovascular health.

35. Is there a connection between rheumatoid arthritis and other immune disorders, multiple
sclerosis or cancer?
Generally there is not, but unfortunately the answer does not end there. In some families certain
autoimmune diseases seem to cluster together such as autoimmune liver disease, rheumatoid
arthritis and thyroid disease. For the most part individual family members usually only have the one.

There is no link between rheumatoid arthritis and multiple sclerosis but interestingly, some TNF
inhibitors can create, in a very few patients, multiple sclerosis-like symptoms and therefore you
should not take these drugs if you have had any such symptoms previously. Rheumatoid arthritis is
associated with a slightly increased risk of developing a somewhat uncommon cancer called
lymphoma which is a malignant (cancerous) transformation of the lymph glands. This is more
common in people who have the complication of Sjogren’s syndrome described above.

36. Is it inevitably that the disease will cause severe disability and handicaps that might lead
me to be wheelchair-bound?
Rheumatoid arthritis is very variable in the way it progresses. With modern medications taken
regularly and good support from the whole rheumatological team the outcome is usually very good.
To keep people active and at work is a team effort with the patient being the most important part of
the team.

37. Why is rheumatoid arthritis so persistent?
Rheumatoid arthritis normally persists but in a few people it may disappear and disappear completely. This, however, is rare and often raises the question in retrospect, whether a viral cause for the arthritis was missed. Despite the persistence however, and with good attention from medical staff and a positive frame of mind, most people's disabilities can be kept to a minimum and many people with rheumatoid arthritis lead very active and fulfilled lives.

38. What is Sjogren's syndrome and what are its long-term effects?
A good source of information about this uncommon condition, a fairly rare complication of rheumatoid arthritis, is the British Sjogren's Syndrome Association. Arthritis Research UK has also produced an excellent patient leaflet. The syndrome is named after a Swedish ophthalmologist, Henrik Sjogren, (pronounced Showgren). The symptoms caused by this autoimmune disease are dry eyes, a dry mouth, feeling tired and generally achy. It is much more common in women than men and usually starts after the age of forty. We don't know the cause but there appears to be a genetic influence and possibly a viral trigger.

The most common problems which are often the most troublesome are dry eyes and dry mouth and this comes about because immune cells similar, but slightly different from those that infiltrate the synovial membrane, invade the tear glands around the eyes and the salivary glands around the mouth.

This disease can occur with rheumatoid arthritis and it can also occur with certain other known as autoimmune diseases affecting the skin, the liver and the thyroid gland. It may occur on its own. It is diagnosed by testing the amount of tear production in the eyes. This is a simple test consisting of inserting a little bit of blotting paper into the eye and is called the Shirmer test.

A specialised examination of the eye may also be needed with a special lamp referred to as a slit lamp that allows us to see if the conjunctiva, the lining of the eye, is damaged. Very occasionally we need to measure production of saliva in the mouth or undertake a lip biopsy. More commonly a blood test is taken as certain antibodies are generated in this condition and can be tested for in the blood.

The treatment for straightforward Sjogren's syndrome is to provide artificial tears and saliva of which there are a variety of products. Patients with Sjogren's syndrome need to make sure they visit their dentist regularly as drying of the mouth can cause problems to the gums, either gingivitis (the surface structures) or periodontitis (around the tooth root). Good oral hygiene is essential.

The salivary glands may occasionally become swollen giving an impression a little bit like early mumps as the parotid glands on the side of the face are often involved. Patients with Sjogren's syndrome are slightly more likely to be allergic to drugs, particularly antibiotics. If there is severe involvement of the parotid gland with a very dry and possibly ulcerated mouth, a secondary fungal infection can arise requiring an anti-fungal treatment.

This is easily overlooked as there may be very little to see or the fungus may hide in dentures. A rarer problem is the complication of a dry vagina causing painful intercourse. The jargon name for this is dyspareunia. A variety of vaginal lubricants are available which are very helpful but if pain persists, discuss with your doctor the possibility of a superimposed fungal infection as discussed above.

39. Is there anything else that can be done to help me live with my arthritis?
This is a very important question and not one that is dealt with well in a busy NHS clinic where basic medical, surgical and drug-related matters take up all the time that we are allocated. This is completely unsatisfactory for all parties. Arthritis Research UK produce a large series of leaflets that deal with issues that relate to this broad question.

They are entitled ‘Are you sitting comfortably?’, ‘Choosing shoes’, ‘Diet and arthritis’, ‘Driving and your arthritis’, ‘Exercise and arthritis’, ‘Gardening with arthritis’, ‘Rheumatism and the weather’, ‘Sexual aspects and parenthood’, ‘Sexuality and arthritis’, ‘Stairlifts and home lifts’, ‘Your home and your rheumatism’ and ‘Caring for a person with arthritis’. Arthritis Care also offers useful booklets including a guide to safe exercise, and a guide to living at home. They also provide sources of information and contact telephone numbers for benefit enquiries, disablement information and advice lines and access to the NHS Waiting List helpline.

So there is a lot of useful and practical advice about which is well worth reading. One of the greatest difficulties, particularly facing women with arthritis, is difficulty generated between them and their partner, some of which relates to sexuality. In this area good communication is vital and mutual respect and understanding essential. You may well wish to take your partner along with you to the clinic or the physiotherapy department to discuss these matters and your local rheumatology centre may well hold group sessions so that such things can be discussed as couples and in the company of others.

40. What are flare ups?
Rheumatoid arthritis is not a consistent problem. Even without treatment there are periods when the disease appears to be dormant only to explode over a very short period in a very large number of joints which sometimes leads the patient to be bed- or chair-bound for a few days. We do not understand what causes these flares - a short course of steroids often settles them. We do know that regular use of disease-modifying anti-rheumatic drugs reduces the frequency of attacks and sometimes stops them.

Often when people are stable they ask to stop or reduce their DMARDs. This usually is a mistake with a flare occurring very rapidly afterwards. We then usually need to raise the dose even further to get back to the previous situation. Whilst it is quite reasonable to take a non-steroidal anti-inflammatory drug as and when you need it, dependent on your symptoms, DMARDs cannot be treated in this way and it is not sensible to stop them abruptly when everything feels much better.

41. Why do I feel so tired and depressed?
This is extremely common, indeed almost invariable, when people develop arthritis and is extremely hard to deal with, not least because you look well when you feel completely drained. This occurs because the inflamed joint produces small bits of protein which can act on centres in the brain to cause these overwhelming feelings of tiredness.

The closest a normal person comes to feel like this is when a bad attack of flu is starting. You are faced with an overwhelming desire to rest and often the smallest exertion causes severe tiredness. Whilst most patients in a hospital clinic complain of pain, this very common feeling is often not spoken about.

As the disease modifying drugs work this sensation progressively wears off. It is one of the great advantages of anticytokine medication. It is common for people to tell us that they hadn’t realised just how tired they were until the feeling settled with their anticytokine drug. Some people find that they often burst into tears for no apparent reason or following a very trivial upset.
This occurs in both men and women and it is extremely important that partners and relatives are aware of this feeling and respond appropriately. It is during these periods that people can take themselves to bed and then develop problems associated with not using their joints. Steroids, though rarely advisable for prolonged use, are helpful when there are extreme fatigue episodes.

42. What will happen to me in the future?
It is true that we have considerable difficulty in saying with certainty what the outcome will be. Some of the blood tests undertaken by your doctor help give us a general idea. These tests are the rheumatoid factor and ACPA levels and a general test of inflammatory activity, the ESR or CRP. Patients sometimes react badly to being told that their arthritis is early and is mild. They respond by thinking, well I feel absolutely awful, tired and depressed and my joints hurt like mad. If this is early and mild, what does the future hold? Arthritis in its first stages is often at its most disabling even though there may be little or no damage to the joints. This is because, as we have discussed before, a burst of small proteins from the joints stimulates the brain in a negative way. This will settle with appropriate treatment and the very sharp pains that are throbbing and characterise rheumatoid arthritis at its early stages usually settle.

43. Why is rheumatoid arthritis associated with an increased chance of dying of heart or blood vessel disease known as premature atherosclerosis?
This is unfortunately the case. Inflammation appears to increase the risk of atherosclerosis, which is why controlling inflammation as quickly and effectively as possible is very important. The good news is that modern management of rheumatoid arthritis, with appropriate use of biologic drugs, can not only improve symptoms dramatically, but also reduce the risk of cardiovascular disease. In addition, general practitioners are advised by rheumatologists to have a lower threshold to treat possible hypertension or high cholesterol in patients with rheumatoid arthritis compared to others. Steroid drugs, which do control inflammation well do, however, increase your risk of atherosclerosis by different mechanisms. Nobody is advised to smoke but rheumatoid patients put themselves at a particular risk of getting smoking induced heart disease because of the generalised inflammation that occurs.

This is also another reason why it is so important to maintain your fitness levels and to eat a sensible, heart-protective diet. We know of no diets that influence the course of rheumatoid disease but a diet low in saturated fatty acids, that is supplemented with fresh fruits and vegetables, will limit your risk or suffering the accelerated atherosclerosis that unfortunately accompanies uncontrolled rheumatoid arthritis. It is for this reason that doctors by and large do not encourage patients to take unusual diets for which excessive claims have been made that they influence rheumatoid arthritis. Essential fatty acids (EFAs) omega-3 and omega-6 include, see Arthritis Research UK booklet.

44. Why didn’t I have more input from social workers, occupational therapists and physiotherapists at an earlier stage in my disease?
Patients with rheumatoid arthritis are best managed by a team of professionals as many issues of concern are not adequately dealt with in a short doctor-patient consultation. Social and occupational health professionals can provide a lot of help with benefits and occupational issues. Occupational therapists can also advise here but have special skills in appropriate appliances that can make life much more comfortable.

Rheumatology-trained physiotherapists have special expertise with helping to maintain joint
function and are always on the look out for small problems that can add to the difficulties of rheumatoid arthritis.

These include problems when the nerves become entrapped by swollen tissue. This is quite common in the wrist and can cause a carpal tunnel syndrome due to trapping the nerve that supplies your thumb, index and middle fingers. There are many other examples. A team approach is needed for keeping on top of the multiple problems that appear small to a doctor but can have major consequences for the patient.

A good source of information that relates to the support you can expect from allied health professionals is your patient liaison officer at your local hospital. Another useful source of information is the Arthritis Research Campaign leaflets which cover all of the issues I have mentioned and many more. Arthritis Care is also an excellent source of information.

45. Why did I develop an explosive form of arthritis?
Unfortunately, this is very common and some people, they go to bed perfectly well and awake with multiple stiff and painful joints and find it very difficult to move. This is a very frightening experience not just for the patient but also for their relatives. With fear, almost invariably comes a rather ill-defined sense of resentment and occasionally blame.

The enormous frustration of being deprived of your mobility can often be vented in inappropriate anger towards relatives and health professionals. This is made much worse if there is any delay in getting good advice.

Government health organisations give priority to diseases that are life-threatening and this unintentionally can cause problems to those who have extremely disabling conditions but not an immediate threat to life. Anyone who has had rheumatoid arthritis knows that this is more than just a touch of arthritis, doctor.

If you believe that your local service is failing you, it is appropriate to be persistent and appropriate to be vocal to your local health providers on behalf of yourself and others to help remedy the situation.

Mr RA30 also raises the important problem that arthritis can cause to normal marital relationships. The tiredness that comes with arthritis makes normal relationships difficult and partners resent as much as sufferers the enormous intrusion of this disease in their family lives.

Problems at work generated by ill-health may of course cause financial difficulties - though many couples find their relationship becomes stronger as a consequence of the support that is needed. A useful booklet on sexuality and arthritis is produced by the Arthritis Research Campaign which also lists a series of useful addresses including SPOD, an association that aids sexual and personal relationships for people with a disability.

46. What is the systemic side of the illness?
The description of the strange 'unwellness' that accompanies arthritis cannot be bettered. There are other 'systemic' problems associated with arthritis. The word systemic is used to describe problems outside of the joints of a more widespread nature and it is important for sufferers to be aware of these. It is common with any longstanding inflammatory disease to develop an anaemia and this is caused because iron is locked away in the body and less accessible to blood cells.
Some patients become anaemic because non-steroidals can cause small amounts of bleeding from the stomach and your doctor will monitor you for this. Anaemia itself contributes to the tiredness and fatigue and can cause memory disturbances. A more worrying systemic complication that is really quite rare is an inflammation of the blood vessels called vasculitis (-itis meaning inflammation of). Patients may get very small haemorrhages at the sides of the nails or more blotchy rashes often of the feet. Though rare it is important to look out for these as your consultant is likely to advise a change in therapy in the short-term.

47. Why was I not put in contact with fellow sufferers early on so that I could get a much better idea of what lay ahead?
There are now a fair number of local self-care groups and Arthritis Care are a good place to start if you think this would benefit you. Clearly this site is also meant to provide the kind of support that Miss RA32 requests and having accessed it and hopefully found it helpful, please make sure that your local rheumatology department advertises this facility to others. Many other diseases are also being placed on the Healthtalkonline website and the response has been excellent.

48. I would have like to have been able to contact and discuss my disease with people in a similar situation?
This is a common request and most rheumatological centres can assist here via the patient liaison offices who can advise on patient partners or local groups. Both Arthritis Care and Arthritis Research UK help considerably in organising contacts.

49. Why do hospital consultants and their teams to approach in such numbers (eighteen)?
Yes, I can fully sympathise with your situation, having recently been in the same situation myself. One of the problems with multi-disciplinary approaches to care, which is essential for best treatment, is that many people can approach the bedside simultaneously, though eighteen can only be said to be excessive or ridiculous. Qualified doctors and medical students and allied health professionals accessing the site and reading these words may wish to consider their own service and rectify this problem.

50. Why do I feel so socially isolated?
This is a real problem that affects all age groups - it is easy to withdraw when you feel tired. People are often embarrassed by their joint deformities and don't like to expose themselves in public. Holidays can be difficult.

51. I would like to know more about joint replacements?
Most people who have arthritis will never need surgery. The Arthritis Care charity produces an excellent guide on surgery and arthritis and the has two guides entitled 'A new Hip Joint' and 'A New Knee Joint'. The hip and knee and the most common joints to be replaced and the operations now are remarkably successful. The shoulder joint is also quite commonly replaced. Joint replacements usually last about fifteen years but can be replaced. Joint replacement is usually remarkably successful and almost immediately relieves pain and very rapidly improves function. People are of course concerned about potential problems.

These are now rare but do include a risk of infection. Occasionally a blood clot (a venous thrombosis) may occur and rarely some of this may break off and end up in the lungs (pulmonary embolus). This is now an uncommon problem and is prevented by early mobilisation, appropriate leg stockings and mild thinning of the blood with an aspirin-type drug or occasionally full anticoagulation.

After surgery you will be referred for physiotherapy. The exercises that you are taught are extremely
important. You may also need the assistance of your local occupational therapy to make sure your home is suitable when you return from surgery. You may need a slightly higher chair or raised toilet seat, special handrail for the stairs or the shower. You have a right to be properly assessed under the NHS and Community Care Act of 1990. There may be a delay in obtaining this assessment as indeed there often is for surgery. It is sensible to plan well in advance.

Many orthopaedic centres will assess you in a pre-admission clinic when there is plenty of opportunity to ask questions. Some may well be able to provide you with video material that illustrates the ward aspects of the procedure and exercises to do afterwards. These are very helpful and reassuring. Ask your local orthopaedic surgeon if they provide this facility and if they don’t, encourage them to do so.

52. Why do joints need replacing?
If rheumatoid arthritis is not fully controlled then it is likely that the joint itself will become damaged. The first event in rheumatoid arthritis is inflammation of the lining layer of the joint which is called the synovium. Over time the synovium reorganises into a tissue that can punch small holes in bone. It also secretes small proteins that can weaken the cartilage in the joint. If this is not well controlled the joint loses its stability and as a last resort needs replacing. Fortunately, orthopaedic surgery is now a very advanced specialty and many joints can be successfully replaced with an artificial joint. The most successful joint replacements are to the hip and to the knee but other joints can be tackled, either by replacement or by other procedures. Joint replacement is not an invariable consequence of having rheumatoid arthritis.

53. Why it is that professional don’t sort out properly each patient’s individual needs and give us so little time for a problem that can cause a lifetime of difficulties?
It is clearly impossible to deal with such complex problems in the 15 minutes that our Health Service allocates to doctor-patient consultation. Both sides feel let down. It is for this reason that most of us work in teams with assistance from nurses, physiotherapists, occupational therapists and other health workers so that we can approach these complex problems on a broader front. However, even that often doesn’t work as well as it might.

It is for this reason that we have launched this DIPEx site in order that patients can get a much better feel of the disease, its problems and frustrations. Clinic appointments make most patients nervous as they are peculiar environments. They are stressful, and often too much is going on for them to make sense of the information at that time. This site has links to the Arthritis Research Campaign, Arthritis Care and other places of information that help—let us have your views. Everyone is different.

54. Why is it so difficult to finding a specialist in rheumatology?
Rheumatology is a relatively new specialty and has really only existed for forty years. Many district hospitals had no rheumatology service and patients were managed by a general physician. The situation is now considerably different and every patient should be able to access a specialist in this area and through their consultant, the allied professional team. Within rheumatology departments there may be even further specialism, some consultants dealing with some forms of arthritis such as rheumatoid arthritis and others dealing with complex pain states, connective tissue disorders and rehabilitative matters.

55. Why are health care professionals so negative in their approach, particularly when talking about drugs and their side effects?
This is a common concern and it is often hard to strike the right balance between warning people about possible side effects yet advising them at the same time of the benefits. It is all about relative risk for an individual. Most of the drugs used in arthritis have few side effects, they are for the most part mild. If side effects occur and they are troublesome, they usually stop when the drug is withdrawn.

As is well known, aspirin and drugs like it known as non-steroidal anti-inflammatory drugs, (NSAIDs), can cause stomach ulcers which may bleed and sometimes perforate. The risk is relatively small but very real. Drug risk is defined as a probability for a group as a whole but is borne by an individual. The same, in reverse is true of our National Lottery. There is not much chance but most of us risk it hoping this time it will be you. Of course, it rarely is.

All the drugs approved for arthritis are effective but to variable extents. They work in different ways. NSAIDs help reduce the pain and stiffness and they work fast. They do not in any way stop the disease progressing. Other drugs often referred to as disease-modifying anti-rheumatic drugs (DMARDs), have little effect on the symptoms to start with, but over a few months slow down the inflammatory process considerably, and with that comes symptom relief.

We now have new drugs called anticytokines, for example TNF and IL-6 inhibitors, which show the most promise for stopping the disease or dramatically slowing it down, particularly if given early. Both the DMARDs and anti-TNF drugs do have side effects and require all patients who receive them to be monitored regularly. For the most part the benefits are much greater than the risks.

**56. Why was my disease not treated much more aggressively and early on, before joint damage had set in?**
Because of the difficulties in making an early diagnosis, treatment is sometimes delayed too long. In the past when the drugs were used were more dangerous than today, and the harms appeared to outweigh the benefits, it was common to delay some while and use low doses that might have been safer – yet were less effective. With the newer DMARDs and the anticytokines we are much more likely to advise early and dynamic treatment as the benefits outweigh the harms.

There is no known complementary medicine or diet that has been proven to significantly affect the progression of arthritis despite claims to the contrary.

**57. Why did the doctor speak to my relative as if I wasn't present in the room?**
Doctors vary considerably in their ability to communicate clearly with their patients. Certainly younger doctors are now much better trained than their older counterparts, though with age comes experience. Faced with difficulties like this it is often better to take control though this can seem very difficult in a strange clinic setting.

It is much easier to communicate with patients after you have met then a few times and both have got to know each other a little bit. Doctors also pass information over in little parcels. It is often as much as most people can cope with to be given the diagnosis and a brief explanation of the initial treatment plan.

In a good clinical setting you would be followed up quite quickly after having had the chance to read any printed material that the clinic has available. The Arthritis Research Campaign booklets are very helpful here. At the second and third visits when hopefully the disease is settling, the doctor can then tackle the very many different questions that arise in your personal circumstances.
When parents attend clinics with their children, the parent often takes control as arthritis occurring in one’s child is a very frightening experience and their fears are often greater than the young person’s. Paediatric rheumatologists now work in all the major centres in the United Kingdom and are specially trained to deal with children, adolescents and their families in these very difficult circumstances. If you are a young person with arthritis a variety of different information sites are available to help you with your specific problem.

58. **What are the benefits or possible dangers of exercise?**

This is one of the commonest questions we are asked in the clinic. It is a simple enough question - should I keep going or will this damage my joints more? But it is not easily answered. We are back to risk and benefits and striking a sensible balance. A lack of exercise rapidly causes you to lose fitness which in turn makes your health deteriorate more generally. People who keep themselves very immobile very soon lose bone strength as they use calcium out of their bones. This is immobility causing osteoporosis.

Patients who don’t move their joints soon find that though the inflammation settles a little, they become extremely stiff. The sensible answer is to keep going as much as possible but not to over-stress any joint. For instance, if you have rheumatoid arthritis affecting your wrists, if it was active it would be foolish to play badminton or tennis. This would almost certainly make the condition worse and cause further damage to the bones and ligaments.

It is however, sensible to keep them gently moving and to take as much general exercise as is possible. When arthritis affects your feet, this can be quite difficult because the pain usually comes from the balls of the feet. Soft and well-supported shoes help a lot. Keep going but don’t over do it and try to keep your general fitness level as much as possible.

59. **I wish I'd exercised properly in the early days of my arthritis. Could I have avoided what doctors refer to as fixed deformities of the joints?**

It is essential when your arthritis is first diagnosed that you are assessed by a chartered physiotherapist who is part of the rheumatological team and can help you in maintaining an active, independent life at home and at work. Fixed deformities can come on quite quickly and the mobilising, stretching and strengthening exercises that they advise help enormously. They can also provide assistance in many other ways including hydrotherapy, relaxation exercises, walking training and occasionally splinting.

Many physiotherapy departments run group sessions which have the added advantage of allowing you to discuss your problems with others. Physiotherapists often have more time for consultations and are a useful source of professional information.

Occupational therapists also provide assistance with splinting and will also help provide advice on strength movements and simple, practical techniques to help cope with the pain. The Arthritis Research Campaign provides three information sheets entitled 'Physiotherapy and Arthritis', 'Occupational Therapy and Arthritis' and Hydrotherapy and Arthritis'. They are well worth reading at any stage of your disease.

60. **Is hydrotherapy good for arthritis?**

Hydrotherapy is extremely useful for patients with arthritis as it allows them to exercise their joints without having to bear their full weight. This improves muscle and tendon strength and helps to keep joints aligned. Whilst much benefit can be obtained from heated local baths, specialised hydrotherapists can give good initial advice on the most appropriate exercise regimens.
61. I would like more information that is suitable for a people whose arthritis has progressed to a disability and handicap?

Hospital-based occupational therapists are the best local source of information about suitable aids and liaise closely with social workers to assist with other matters. It is very helpful to be assessed by an occupational therapy unit early in the course of your disease so that you are aware of the many gadgets that can make life easier for you or for a carer. Many centres are also linked to local engineering units which can provide tailor-made adaptations that can assist in unusual circumstances. It is sensible to be reviewed fairly regularly by the occupational therapy team as technological advances are considerable and the amount of support constantly expands. The local Red Cross usually best accessed by your local district nurse also can provide, free of charge, more substantial bits of equipment that are occasionally required.

62. What triggers my flare-ups?

We do not know what triggers flare-ups. Sufferers of rheumatoid arthritis can have long periods when the disease seems very well controlled, when for no obvious reason it explodes all over again. People seek explanations for this in things that have just happened and it would appear that emotional or physical stress can induce flare-ups but sometimes there is no explanation. We do know that with regular use of disease-modifying agents the frequency of flares is reduced and the intervals between them extended. Rheumatologists occasionally prescribe very short courses of steroids to help with these often extremely painful episodes.

Some people get a warning of a flare before it occurs when they start to feel extremely tired and it is believed that this is due to an increase in some of the chemicals in the joints spilling over into the blood and causing these flu-like fatigue symptoms. A very brief course of a steroid at this time does appear to stop the flare in some people and is certainly something to discuss with your doctor if you are troubled by lightning attacks of this kind. Multiple flares are an indication that the amount of disease-modifying therapy is too low. They often occur in patients who feel great and then suddenly reduce or abandon their treatment. These can be the hardest to put right quickly and you should not lower your disease-modifying therapy without consulting your consultant advisor.

63. What research into complementary therapies and rheumatoid arthritis is being done?

There have been relatively few formal studies undertaken by complementary therapists to assess the usefulness of the remedies prescribed. Professor E Ernst, Professor of Complementary Medicine, has undertaken systematic reviews of the limited number of research studies in this area. In his review entitled Musculoskeletal Conditions and Complementary/Alternative Medicine he reminds us that these therapies sometimes abbreviated to CAMs are 'immensely popular'.

His conclusion is that 'collectively that some of these treatments show promise but none of the treatments are devoid of risk' and 'that by and large the data are not compelling.' He is right to point out that CAMs are not without risk and he ends by suggesting to complementary practitioners that 'efforts must be directed towards defining which form of CAM generates more good than harm for which condition.'

It is possible to be more encouraging about the various complementary approaches that are physical in nature and I believe that most orthodox physicians accept that those treatments such as yoga, pilates and acupuncture which help with movement and coordination, whilst linked to relaxation, have benefits in rheumatoid arthritis and other pain states. It is difficult to find evidence that one is superior to another but all orthodox physicians fully accept that a holistic approach to health care is ideal but is not so easily delivered within the time constraints imposed by busy National Health Service clinics.
The Arthritis Research UK provide a booklet on complementary therapies and arthritis which is helpful and in a series of brief statements describe 'what is... acupuncture, Alexander technique, aromatherapy, chiropractic, copper bangles, a good diet, dietary supplements, healing, herbal medicine, homeopathy, magnetic therapy, manipulation, massage, osteopathy and reflexology. Listed are all the useful addressed that relate to practitioners in this area and their web addresses.

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