





Early Inflammatory Arthritis/Rheumatoid Arthritis (RA) Videos in Punjabi (and English)

Video 1 – GP Consultation between Dr. Faika Usman (GP) and Mrs. Fozia Hussain (patient with Rheumatoid Arthritis).

This video has a very short intro in English by Ailsa Bosworth explaining that this is a face-to-face consultation between Dr. Faika Usman who is a GP at the Bellevue Medical Centre and her patient, Mrs. Fozia Hussain, who lives with Rheumatoid Arthritis and explores her investigations and experience being referred to the rheumatology team.

Video 2 – RA - RA Diagnosis, Early Journey and Information from and about members of the Rheumatology Multi-Disciplinary Team Involved

Dr. Kanta Kumar, Associate Professor, University of Birmingham presents the consultant rheumatologist perspective

Rheumatoid arthritis (RA) is a long-term autoimmune condition that can cause pain, swelling and stiffness in the joints, where the immune system which normally protects us from infection, virus, etc. is triggered into going wrong and attacking healthy tissue in the joints.

The resulting pain, swelling and stiffness affects our ability to carry out our day to day tasks and impacts people's emotional as well as physical wellbeing.

We do not know the cause of RA but we know that factors such as smoking, having a family history of RA/inflammatory arthritis can pre-dispose an individual to developing the condition. We also know that women are 3x more likely than men to get the condition. RA affects approximately 1 in 100 people in the UK.

There is no cure for RA, however, there are many effective treatments to control the condition. We also know that the sooner we diagnose someone and get them started on medication to reduce and stop the inflammation, thereby minimising damage to the joints, and improving outcomes.

Diagnosis:

The key symptoms of RA as already mentioned are pain, swelling and stiffness of the joints. RA can affect any joint but typically tends to affect the small joints of the hands, wrists and feet. Feeling a bit 'flu' like and experiencing fatigue are also important symptoms associated with the disease.

If you develop such symptoms, we recommend you arrange to see your GP immediately.

Your GP will assess your joints and may also do some blood tests and X-rays.

If you have swelling of the joints, and your GP suspects this is RA or another type of inflammatory arthritis, they will refer you urgently to be seen by a specialist doctor who treats this condition. They are known as Consultant Rheumatologists.

Rheumatology doctors will work alongside nurse specialists and other health professionals to help manage and treat your arthritis as part of a team in a hospital setting.

Our team approach:

The range of treatments developed over the years to manage RA is now considerable and medication is vitally important in order to help slow down and control the condition. In addition to the consultants and specialist nurses, input from the therapy teams, ie physiotherapy, occupational therapy, podiatry, orthotics and in some units there is health psychology support will be available as needed. A referral will be made to these services on your behalf when necessary. The National Rheumatoid Arthritis Society, NRAS are also available to provide education, information and support about your disease and provide free access to video information in Hindi. It's also possible to convert their website into Hindi at the click of a button. (Scroll down to Site Tools at the bottom of the home page on their website <u>www.nras.org.uk</u> and you will see an image of an Indian flag, click on this and the site will automatically be converted to Hindi. The translation is not perfect, but it is good enough to be able to provide key articles in the Hindi language.)

Physiotherapy

Keeping physically active and incorporating exercise into your routine is very beneficial in RA and physiotherapists can offer advice and support to help improve your fitness. Your physiotherapist can teach you exercises to help make your joints more flexible and increase muscle strength.

Occupational Therapy

Occupational therapists offer advice and support if your RA affects your hands or is causing difficulties doing everyday tasks. Occupational therapy helps you to carry out everyday tasks and activities on your own, at home and at work, by informing you how to look after your joints and through using special equipment or tools (such as a device that helps you unscrew jar lids). Occupational therapists can also help you to adjust to living with your condition by, for example, offering to show you relaxation and stress-management techniques.

Podiatry and Orthotics

Podiatrists offer advice and support if your RA affects your feet. You may be provided with orthotics (insoles) to help relieve your symptoms. Some patients experience difficulty in finding comfortable footwear; the orthotist and podiatrist work together and advice is given on the suitability of a wide range of shoes.

Health Psychology

Health psychologists work with people who have physical health problems like RA. We understand that living with a long-term condition like rheumatoid arthritis can be challenging. You may be referred to see a health psychologist if appropriate.

Having a condition like RA can affect your mood and emotional wellbeing and this is quite normal, especially in the early stages of the condition. Once the medication brings your disease under control you will generally find that things improve. However, should you feel that low mood, anxiety or depression persists, talk to your rheumatology team. Some rheumatology teams have access to a health psychologist but you are more likely to be able to access 'talking therapies' through your GP.

What about medication?

Early drug treatment in RA is important to minimise joint damage. There are several different types of medication available. Some control the disease itself, and some help to ease symptoms. Drugs used to treat the progress of the disease are called 'disease-modifying anti-rheumatic drugs' (DMARDs).

These include methotrexate, sulphasalazine and hydroxychloroquine. Research studies suggest that combinations of drugs often work best (and don't cause additional side effects) so you may be offered more than one drug for your initial treatment.

There are another group of drugs known as 'biological therapies.' These drugs are given by injection or as an infusion. They are often used after DMARDs if the DMARDs don't start to control your disease adequately. Not everyone reacts to the drugs in the same way and sometimes in can take a little while to find the right combination of medications to suit you and your disease.

Drugs to control symptoms include non-steroidal anti-inflammatory drugs, which are commonly referred to as NSAIDs (such as ibuprofen or naproxen). These drugs are not appropriate for every person and alternative pain relieving medications such as paracetamol or cocodamol may be advised.

In the next section, Dr. Kumar further discusses medications used to treat RA.

There are a variety of very useful medicines that can help bring the condition under control. For many patients, there is a very positive outlook to life and they carry on functioning every day as normal. In your journey you will find that we might change your medication sometimes, for example we might increase the dose of a particular drug and possibly add in another drug. We take these decisions on the basis of how well your symptoms are controlled. Also, because sometimes the medicines are associated with problems like side-effects or the medication given doesn't do the job in controlling the condition as it should.

We are aware that people may choose to experiment with their medications but this is not recommended as it can cause a lot of extra problems. In some cases, the problem is that a few people believe that taking long term western medications is harmful and toxic for their health and they fear the risk of side effects from long term medication more than the risk of serious complications from the arthritis. It's important to understand that the harm that you can get from uncontrolled disease is worse than a side-effect from a medication which can be dealt with in a number of ways.

People sometimes think once their symptoms are controlled, they can stop their medication and may prefer to try herbal or ayurvedic remedies to control their condition. However, we know from research that herbal or ayurvedic medications have shown less benefit in controlling arthritis symptoms. If you are thinking of using ayurvedic treatments then it is okay to discuss these thoughts with your clinician and to discuss the evidence and options. Having an autoimmune disease requires strong medication that can stop the disease progressing and causing damage to your joints which can't be reversed.

You will find that being on hospital medication is very closely monitored through regular blood tests so there is always someone who you can talk to and together we can work out a plan and treatment can be adjusted to suit you. From our research we also understand that people don't want to disclose taking medication to their families. We would suggest that when you go to the hospital appointment please do discuss any of these issues that you might be having. Sometimes taking long term medication is a family decision so we also understand that you may wish to take family members with you to the clinic appointments so that they can help you ask questions and remember the answers from the clinician and so your family member or friend can support and help you.

Dr. Parbir Jagpal BEM – Associate Professor (Pharmacist), University of Birmingham

Pharmacists are experts in medicines and can provide a lot of support and advice to help you to understand and manage your arthritis better. If you are having pain or have noticed swelling around your joints you may have already taken painkillers that you have bought or received from friends or family. It's really important to check before you take any medicines to make sure that they are right for you so it's good to talk to your Pharmacist if you have any concerns with your medications.

Pharmacists advise on why your medicines have been prescribed, how they work, how they are monitored and checked, any side effects and what to do if you are unsure about anything. If you have other medical conditions e.g. high blood pressure, diabetes, heart disease, they will also check and review these medicines to make sure that everything is safe and appropriate for you to take.

They also provide other health advice including information about vitamins, supplements, diet, exercise, smoking, mental health and well-being, aids to help with your mobility. They work as part of a wider team of health and care professionals so can point you in the right direction if you need more specific information. If you have any worries about your treatment, want to check before starting something new, or just want a general chat about your condition they are there to help.

Your local community Pharmacist is easy to access, you can walk in and have a chat or book an appointment for a review. They can provide advice when you collect your prescription. If you are thinking about taking something to help with your arthritis that hasn't been prescribed, always check with the Pharmacist first to see if this is right for you.

There are now Practice Pharmacists working in GP surgeries who can view your treatment and management information from the hospital as well as your GP so they can review the various elements of your care. You can book an appointment for a structured medication review, speak on the phone, have a video consultation or visit the surgery.

Many Pharmacists now prescribe medicines and specialise in the care of arthritis. They work in community Pharmacy, GP surgeries and in hospitals. They may be directly involved in the treatment and management of your arthritis or support the care you are provided with by the hospital team. They will also review all the medicines that you are taking and communicate with everyone involved in the treatment and management or your arthritis.

Dr. Ruman Tiwana, Health Psychologist, University of Birmingham - Reactions to Diagnosis with a long-term condition like RA

People react to the diagnosis of a chronic illness in many ways. For some people, the diagnosis is a relief, because it provides answers, enables you to identify specific symptoms and allows you to start making sense of your experiences leading up to the diagnosis. However, for others a diagnosis of a chronic illness like rheumatoid arthritis is very stressful and can become distressing. It can cause you

to ask many questions about your condition, your body and your future. Typically, people ask questions such as

- What symptoms will I experience (putting an identify to symptoms)?
- Will I be able to work? Will I be able to look after my family? What does the future hold (consequences)?
- Will this last forever (timeline)?
- Can this be cured? Can I control this condition (cure/control)
- What caused this condition (cause)?

The answers to these questions can come from multiple sources. We may seek information on the Internet, we may talk to friends and family. We may know of somebody from our past who's had a similar illness and we may think about what happened to them to form our ideas about what rheumatoid arthritis means to us. Our own communities have ideas about arthritis which can influence the way we think, for example our community may have ideas about what the cause of arthritis may be, and what potential cures are out there for us to try. Our community may also think that with the right cures, rheumatoid arthritis can be a temporary condition which will not last forever.

It is important for you to make sense of your illness. The ideas that you form about your illness may be different to the ideas that your doctor or nurse has about rheumatoid arthritis. And it's okay to have different ideas. The most important thing is that you share your thoughts about your illness with your doctor or nurse. It's really important that they know what you're thinking. If healthcare professionals can understand your beliefs about your illness they can perhaps understand why you may be feeling particularly sad or distressed by your diagnosis. They will be able to understand the origins of your concerns about treatments. They may try to provide you with some information to help you form more helpful beliefs, or they may ask you to speak to somebody such as a friend, somebody from your community who has experience of this illness , or even a psychologist if your beliefs are really distressing.

Is feeling sad normal?

The diagnosis of a chronic illness is a stressful event and living with rheumatoid arthritis can bring many other stressors. Feeling sad in response to a stressor is normal, and for some people stressors can cause worries and anxieties. It's important to discuss these stressors with your healthcare professionals so that they can monitor your mood levels and provide you with advice and support. In some cases, speaking to people about your thoughts and feelings can be helpful, however, there are talking therapies, family therapies and other treatments available if your symptoms persist. If you find that you are sad or anxious for a long period of time please let your doctor or nurse know. There is no shame is speaking about your worries. Doctors and nurses will be very discrete about finding you the right type of support and help. If your symptoms get worse or start to change please make sure you speak to someone. Feeling isolated and along will make your symptoms worse, and will have a negative impact on your illness. NRAS also have trained volunteers with RA who you can speak to on the phone as they all have RA themselves and understand what it's like to live with the disease and take the medications and cope day to day. They are mostly English speaking but they do have a small number who speak Hindi or Punjabi (AB to check with Janet).

Mandeep Ubhi – Research Associate, University of Birmingham - Impact of RA on work

RA can impact on your work e.g. causing joint pain especially in the hands and feet, which may affect how you quickly you can move and carry out job tasks. However, many people with RA can continue working in a variety of jobs and sectors (cleaning, manufacturing to office work) with some changes.

You can continue to work with RA but your ability to work may be limited by your symptoms e.g. not able to work a long shift, work at a fast pace, or conduct certain tasks. Sometimes small changes at work e.g. having more rest periods, can help to improve your ability to continue working and improve your job satisfaction. It is important to think about and discuss with your employer what types of changes at work would help you. Your employer is required to make reasonable adjustments to help you stay at work. Your symptoms may change over time therefore there is a need to regularly review changes required at work with your employer. Hopefully once your disease is under control with the right medication, things at work may well return to something like normal, and this may vary between individuals. NRAS have developed two very helpful booklets available in leaflet form that can also be downloaded from the website (or email NRAS for a hard copy – enquiries@nras.org.uk), that are specifically related to work and RA. The first is a guide for employers that explains how RA can affect people at work and how employers can provide support. The other is for the employee and explains they type of support that is available to help people remain at work and minimise the impact of RA on their employment. You may find it useful to take these to your employer and discuss the points together.

Returning to work

Sometimes your symptoms may be severe and cause you stop work temporarily and you may need to take sick leave.

During recovery period it is good to start thinking about getting back to work and the type of changes at work which may help you. You should write down which parts of your jobs you may find difficult and the changes that would help you. There may also be changes to your medication and additional medical appointments for you attend. You should ask your doctors if the medication can affect the type of work you do and what to avoid at work. These aspects should be discussed with the employer before you return to work.

RA affects people differently and sometimes if you have very severe disease and should your symptoms become so severe and persistent that you are not able to work, you may qualify for a disability benefit. Most benefits are provided by the Department for Work and Pensions. NRAS has 2 booklets on Benefits and Personal Independence Payments which are available free, downloadable from the website or in hard copy.

Benefits of being in work

It is important to continue working if you can. Being at work not only provides money but can improve your health and well-being. Being at work enables you to remain physically and mentally active and gives you a sense of pride and personal achievement.

Natalie Cooper – Occupational Therapist, Royal Wolverhampton NHS Trust

When you are first diagnosed with rheumatoid arthritis, you may be referred to an occupational therapist separately, or be seen as part of the rheumatology multidisciplinary team.

We are able to provide practical advice on how to overcome problems and difficulties experienced in everyday life: be that at home, at work or during leisure activities. Our focus is on your function and looking at education and techniques that can help with self-management.

A big part of our education or advice is called joint protection principles, these are principles which can be incorporated into your daily lives.

These include trying to avoid tight or prolonged grips as these can aggravate your joints and put a lot of pressure on your small joints in your hand, such as, writing, using tools for DIY or gardening. You could instead use a larger/ chunkier handled garden trowel or use a pen grip, as having a larger handle will put less pressure and strain on your fingers.

Try to distribute the load— use stronger/ larger joints during a task instead of putting increased pressure on smaller joints. For example when carrying shopping bags try to use the crook in your arm or put the bags over your shoulder so that you do not put the heavy weight through your small finger joints.

Avoid positions that push joints towards deformity for example, twisting and maintaining a good posture during tasks.

Pacing your daily routine/ tasks helps to avoid over using your joints and can help manage joint pain and fatigue. You can do this by having frequent breaks during the day or during a certain task, can someone else help with a difficult part of the task(?), does that task need to be done today or can it be simplified into smaller more manageable tasks? A key part of pacing is to rest before your pain levels increase or feeling tired and to focus on balancing activity with rest.

Gadgets/ aids can help, again incorporating joint protection principles during daily tasks to help make these tasks easier and help maintain your independence.

For example a jar opener can help you to position your wrist and finger joints in a more stable position and take the pressure off them whilst opening a jar. (demonstrate a jar opener) or if you struggle with holding mobile phone or tablet then you can get a case that's got a stand or a hand strap attached to it which stops you having to tightly grip it for prolonged periods.

Or if you struggle with bending down when washing or dressing yourself you may find a long handled sponge or a long handled shoe horn beneficial as again helps to avoid aggravating your joints if you struggle with bending. (Natalie demonstrates a long handled sponge)

Daily simple hand exercises are a huge part of your self-management as these can help to improve (then maintain) a good range of movement, they can help to reduce morning stiffness and they will also help to build up the strength in your hands. Therefore they will help overall to improve your hand function and over time you will be able to tolerate doing certain tasks for a longer period of time. So if you complete regular exercises, your hands and wrists will be stronger so then when you complete a task in the kitchen for example using a rolling pin it will be easier as it will not aggravate your wrists as much as they would get stronger and they will be more flexible to be able to shape dough, or knead or lift heavy saucepans.

Dr. Ruman Tiwana, Health Psychologist, University of Birmingham - Smoking

Smoking can have a negative impact on rheumatoid arthritis. Studies have linked smoking to arthritis and smoking can make your experience of symptoms worse and reduce the effectiveness of your medications. We also now know from a recent study that second-hand smoke exposure in both childhood and adulthood is associated with an increased risk of rheumatoid arthritis in women. Smoking can also make exercise difficult; It can have a negative impact on other aspects of your health. If you do smoke, it's important to share this information with your doctor so that they can provide you with some appropriate advice. Even if you are not thinking about quitting smoking please let your doctor or nurse know that you smoke so that they can monitor your symptoms more accurately. If you've never given any consideration to quitting smoking, you may want to think about the benefits and losses that may occur if you decide to quit. It is important to give some consideration to why it makes sense for you to quit so you can think about the benefits for you, your health, your illness management and your family. Making a list may help you decide whether this is a journey that you want to embark on now or whether you want to set quitting smoking as a goal for the future.

When you feel you've come to a decision, it is always helpful to let people know, this includes your family, your friends and your healthcare professional team. Telling other people about your plans and goal will ensure that you have the maximum amount of support around you. These people can help you to monitor your goals.

Some people find it helpful to set a time and date for you to give up smoking. Having a goal, which has a time associated with it may be helpful. It can really help to be goal orientated. Make sure you reward yourself when you achieve your goals. Use the money you've saved on cigarettes to buy yourself a treat, it's important to review your achievements and let others know about your successes.

It is perfectly normal to fail a few times before you succeed, therefore, do not be disheartened if you start smoking again - its ok. At least you know you can stop, you have the ability, you just need to keep trying until you can make this a long-term change.

Key message

It is important to get the help and support you need in order to live well with Rheumatoid Arthritis. As your time with the doctor and nurse is limited. It is important you look after your own health and try to manage your condition as best as possible between consultations with the right support. Do it for yourself.

National Rheumatoid Arthritis Society

Contacts:

Enquiries@nras.org.uk Phone: General Enquiries: 01628 823524

NRAS National Free Helpline: 0800 298 7650 – available Mon – Fri 09.30 – 16.30

NRAS website : <u>www.nras.org.uk</u>

NRAS e-learning programme for people with RA : <u>www.nras.org.uk/smile</u>