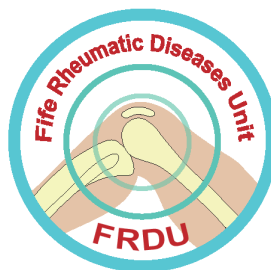




Fife Rheumatic Diseases Unit

Service User Information Leaflet



If you require the information in this leaflet in a community language or alternative format e.g. Braille, easy read, audio please contact the Equality and Human Rights Department at: Fife.EqualityandHumanRights@nhs.scot or phone 01592 729130

YOUR RHEUMATOLOGY CLINIC APPOINTMENT

This leaflet will remind you of some of the things that we have talked about during your clinic appointment.

Information about your condition

Your doctor will have diagnosed your condition and answered any questions you have. Where possible, you will have been given written information about the condition. There are many leaflets available. Please ask if there is something you would like information on. There are also websites where you can get more detailed information. These are listed at the end of this leaflet.

Your treatment

The doctor will have discussed the best ways to treat your condition. They will have answered your questions about the medicines and possible side effects. In most cases you will be given an **information sheet about your medicine**. This sheet tells you how and when to take your medicine. Please read this carefully and keep it in a safe place.

The doctor in clinic will give you a letter to take to your GP. This is **the GP prescription advice letter**. It tells the GP what drug/s to prescribe. You must **hand this letter in** to your GP practice reception as soon as possible. The GP will then write out the prescription, which may take a few days.

Blood tests

Many medications require regular blood tests. Your **drug information sheet** will tell you if you **need to have blood tests**. Your blood tests will be done at your GP practice. When you hand in the letter for your GP, please **make an appointment** with your practice to start having your blood tests. The sheet will tell you how often you need to have your blood tests. It is your responsibility to make sure that you have your blood tests at the right times. It is for your own safety. If you do not have your blood tests you will **no longer be given your drugs**.

Rheumatology Team

The Rheumatology Service works together as a team of health professionals. You may be referred to see one or more of the team members, as well as a self management group, depending on what you need. **The team will contact you to arrange an appointment. We have included a list of these team members and what they do.**

If you have any further questions please phone the Rheumatology Department on **01592 648193**.

The Rheumatology Team

Nurse/ Pharmacist

The nurse will see you if you have been diagnosed with arthritis and starting a new drug. The nurse will either phone you or see you and give you information about your arthritis. They will talk about the treatments used to help including drug therapy. They can also help with ways to manage pain, cope with your condition and other related issues.

If your consultant has asked for you to have steroid injections, they can be given by the nurse who sees you. When your condition is stable, you may then see one of the nurses or pharmacist for your follow up appointment.

If you have problems or need advice between appointments, you can contact the nurses on the advice line. Please leave your name, date of birth and a contact number so that we can schedule an appointment for a nurse to call you.. This will be within two working days.

Nurse advice line: 01592 648065

Pharmacist: 01592 648193

Occupational Therapist

Occupational Therapists help you to be who you want to be, do the things you want to do or are expected to do. They diagnose and treat problems related to your self-care, house, work, family and hobbies. They can help you adapt your surroundings and adapt to changes in your lifestyle. The Occupational Therapist can also help you with issues at work. Finally they can improve or maintain your physical and mental wellbeing and speak to other people who may help with your care.

Routinely you will be offered a phone appointment to see if you are having problems with how you do things. Appointments are offered at home, in the work place, over the phone or as an out-patient. The Occupational Therapists also run a Fatigue Management Programme.

Tel. No: 01592 648193

Physiotherapist

The Physiotherapist will ask you questions about your symptoms and how they affect how you do things. This information is used to decide on the joints and muscles that will be assessed. The Physiotherapist may also look at your balance, walking and how well you transfer from one position to another. If you no longer have any symptoms it is still important that you see a Physiotherapist.

There are a number of treatments that the Physiotherapist can use to help you to achieve your goals. They can inject your joints, use acupuncture to help pain and apply many other useful treatments. If you are struggling to exercise due to the pain it can help to get treatment in our warm pool (hydrotherapy).

The goals of your treatment are agreed together and aim to help you achieve what is most important to you. It can help you to manage your condition by finding out what to do when

you are having a flare. Physiotherapists can see you at a health centre or hospital close to where you live. In some cases we will come out to see you at home. We can also refer you to exercise classes in your local sports centre.

Tel. No: 01592 5648193 ext. 21381

Podiatrist

People with arthritis often have problems with their feet and ankles. You may be referred to the podiatrist for an assessment of your lower limb biomechanics. A biomechanics examination is an in depth assessment of your lower limb muscle action, joint position, lower limb alignment and walking.

This is carried out in order to identify any changes in the foot that can result in injuries, pain and dysfunction. On the first visit they will ask you about your problems and assess your hips, legs and feet. A management/care plan will be agreed with you if required.

Tel. No: 01383 627088

Clinical Psychologist

You may be referred, with your consent, to the Clinical Psychologist in the team. This is offered if you are finding it difficult to cope with feelings about your diagnosis or the impact of your condition. Dealing with a new diagnosis or ill health can be a stressful process. We are available to offer you emotional support. This may be for a one off appointment, or a number of sessions, focused on helping you find ways to cope with the emotional effects of arthritis. The psychologist may suggest a referral to another service to meet all your needs.

Tel. No: 01592 648193

Self Management Programmes

We have a number of self management programmes that can really help you to cope with your condition. You can ask any member of the team to be referred to a group. The groups are:-

- Arthritis Care Scotland.
- Fatigue Management Programme.
- Hydrotherapy and dry land exercise classes.
- National Rheumatoid Arthritis Society(NRAS) –Self Management Course.

The Joint Injection Clinic

This clinic runs on alternate Monday mornings at the Victoria Hospital Kirkcaldy. If you need a joint injection you will need to be booked in by a member of the Rheumatology Team.

Help lines and support

Sometimes it helps to speak to someone else who has the same condition and is not a health professional. Here is a list of websites and phone numbers that you can use to access support and information.

- **Arthritis:** Versus Arthritis supports all people with arthritis. It provides information, a confidential help line, online forums, local courses, support group and branches. For more information contact Arthritis Care Scotland at:
Telephone-0141 954 7776, email scotland@versusarthritis.org, website <http://www.versusarthritis.org>, helpline telephone 0808 5200 520 or email helpline@versusarthritis.org
- **Arthurs's place:** Online magazine and social network for young adults with arthritis, <HTTP://www.arthursplace.co.uk>
- **Chronic Pain:** Pain Association Scotland, <http://www.painassociation.co.uk/> and Arthritis Support Group Against Pain (ASAP)
- **Joint potential:** Part of young people and families service for Scotland, is a programme of events for young people with arthritis and related conditions, <https://www.versusarthritis.org/additional-services/joint-potential/>
Please also see useful YouTube links
- **Myositis:** Myositis UK www.myositis.org.uk
- **Polymyalgia Rheumatica and Giant Cell Arteritis:** PMR and GCA Scotland, www.pmrgcscotland.com
- **Psoriatic Arthritis:** Psoriasis and Psoriatic Arthritis Alliance (PAPPA), www.papaa.org
- **Rheumatoid Arthritis:** The National Rheumatoid Arthritis Society (NRAS) can provide you with up to date information. They can also provide you with emotional support if you are going through a difficult time. NRAS can help you to understand more about your disease and the treatments.
Telephone 0800 298 7650, Monday-Friday 9.30-16.30, free from landlines or website helpline@nras.org.uk
- **Vasculitis:** Vasculitis UK, www.vasculitis.org.uk Vasculitis and Lauren Currie Twilight Foundation, www.laurencurrietwilightfoundation.org
- **Sjogren's syndrome:** British Sjogren's Syndrome Association (BSSA) <http://www.bssa.uk.net>

FREQUENTLY ASKED QUESTIONS - Rheumatology Advice Line: 01592 648065

I have got pain in my joints. What should I do?

If there is pain in your joints, without any swelling:

- increase your painkillers up to the maximum dose for a week or so. If there is no benefit from this then your GP or pharmacist may be able to change your painkillers.
- try a heat pad or ice pack.
- anti-inflammatory gels to rub in can be helpful if used as directed by the doctor or pharmacist.
- if your pain is mainly at night then a medication called Amitriptyline can help this. Speak to your GP.
- if you have a TENS machine then use this.

I have swelling in my joints (e.g. knee, wrist). What should I do?

If there is swelling that is not settling then you should contact the Rheumatology Advice Line.

My GP has asked me to have my bloods checked again because they were abnormal. What should I do?

Return to your GP as he/she has asked for repeat blood monitoring. If they remain concerned about your bloods then they will contact us letting us know of the blood abnormality and let us know if your medication has been changed or ask us if it should be changed.

I am having nausea from one of my arthritis drugs. What should I do?

Sulfasalazine: reduce your dose to what it was the previous week and remain on this dose for an extra week before trying to increase the dose again.

Methotrexate: try splitting your dose so you still take all tablets within a 24-hour period. Alternatively, you could ask your GP to give you anti-nausea tablets or you could contact us to discuss the possibility of you giving yourself your Methotrexate in an injection form.

Leflunomide: ask your GP to reduce the dose to 10 mg daily. If you are already taking 10 mg daily, please contact our Rheumatology Advice Line.

I have a skin reaction. What should I do?

If you are self-injecting your medication, make sure the injection site is rotated and use a moisturising cream to relieve itchiness. If you had an infusion (drip) in hospital, please inform us.

If you are taking tablets and have developed a rash, see your GP first to discuss whether this could be due to your medication. If your GP advises you to stop your medication, please inform our nurse via the Rheumatology Advice Line.

I have developed diarrhoea. What should I do?

Leflunomide: ask your GP to reduce your dose to 10 mg daily. If the diarrhoea persists or you are taking any other type of medication then please inform us to discuss alternative treatment.

My GP has started me on antibiotics. Do I need to change anything?

For a simple infection (e.g. treated with oral antibiotics and improving) you do not usually need to stop your arthritis medication unless you are treated with biologic drugs. For more serious infection - requiring hospitalisation/intravenous antibiotics - the following drugs should be temporarily discontinued until you recover from the infection: all biologic drugs, Methotrexate, Leflunomide, Azathioprine, Mycophenolate, Cyclosporin, or Tacrolimus. If infections develop frequently, please inform us so we can amend your medication.

You must not take Methotrexate and Trimethoprim together.

I am so tired. What should I do?

Fatigue is unfortunately a very normal symptom of arthritis. Make sure you only carry out tasks which need to be done and take frequent breaks when carrying out these physical tasks. Ask members of your family to help!

I have been in contact with someone who has chickenpox or shingles. What should I do?

You only need to take action if you have had skin contact with someone with shingles or chickenpox or someone in your household has it.

If you develop a rash which is either chickenpox or shingles then see your GP and contact our Rheumatology Advice Line for advice about your medications.

Please note that the Rheumatology Advice Line is only for patients who are known to our service. For general advice please contact your own GP or NHS24.

Shingles and Chicken Pox

If You Are Taking Drugs For Your Arthritis

In Rheumatology we use a number of drugs to control the disease process. Drugs that are used to slow down the progression of the disease are called **Disease Modifying Anti-Rheumatic Drugs (DMARD's)**. Some of these can reduce immunity to infection, particularly chickenpox and shingles.

Drugs that reduce your immunity are:

- Methotrexate
- Azathioprine (Imuran)
- Leflunomide (Arava)
- High dose steroids - prednisolone (doses over 10mg a day for > 2 weeks)
- Ciclosporin / Cyclosporin (Neoral)
- Mycophenolate mofetil / MMF (Cellcept)
- Tacrolimus (Advagraf)
- Cyclophosphamide
- Anti TNF therapy –
 - Etanercept (Enbrel)
 - Infliximab (Remicade)
 - Adalimumab (Humira)
 - Certolizumab (Cimzia)
 - Golimumab (Simponi)
- Rituximab
- Abatacept
- Tocilizumab

Other drugs used for arthritis such as Sulphasalazine (Sulfasalazine), Plaquenil, gold and anti-inflammatories do not cause this problem.

Shingles and chicken pox:

A virus called varicella zoster causes these conditions. Most people become immune to catching these conditions after they have had chickenpox, but when you are on any of the drugs listed above you can lose your immunity. Infection with this virus can then be very serious.

If you come into close contact with someone with either chickenpox or shingles, what should you do?

If you are taking any of the above listed drugs and you are in close contact with someone with chickenpox or shingles then you are at increased risk of catching it. Close contact means:

- Anyone in your household.
- Skin contact with anyone else.

If this happens:

1. Stop taking the drug listed above for a two week period (except for prednisolone which must continue and never be stopped suddenly)

2. Contact the Rheumatology Dept or your GP surgery for advice on your risks. You may need a blood test to check you have immunity.

If you blood test is positive then you have immunity and no further action needs to be taken. You will have to stay off your DMARD for 2 weeks (except for prednisolone).

After the 2 weeks you can restart your drug at the same dose.

If your blood test is negative then you have no protection against the virus.

You will need to receive treatment in the form of a single injection into muscle of varicella zoster immunoglobulin (1gm). This provides you with protection from the virus.

This can be ordered from the Pharmacy Department at either hospital (Queen Margaret in Dunfermline and Victoria in Kirkcaldy) or from your GP surgery in the same way.

If the blood test is negative then you will still have to stay off your DMARD for 2 weeks (except for prednisolone).

After the 2 weeks you can restart your drug at the same dose.

What happens if you develop chickenpox or shingles?

1. Stop your DMARD except prednisolone, for at least 2 weeks.
2. See your GP or attend Accident and Emergency as soon as possible to receive anti-viral treatment. This is usually ACICLOVIR 800mg five times a day for 10 days.
 - If you are unwell with nausea and vomiting you may need to be admitted to receive this treatment directly into a vein.
3. If you have shingles or chickenpox even while receiving treatment DO NOT come up to the Rheumatology Clinic, you may expose the patients in the waiting area to the virus. Please contact once the infection has settled and your appointment will be re-arranged.

Even without any blood checks or treatment the majority of patients on these drugs who develop chickenpox or shingles have no major problems. But rarely it can lead to bad infection. It is for this reason that everyone should be aware of the best way to protect against it.

Please keep this leaflet with your medication for future reference.

Please take it with you when you attend your GP or A&E Department because of chickenpox or shingles.

JOINT INJECTION RHEUMATOLOGY CLINIC

If you are a patient with Inflammatory Arthritis under follow up by the Rheumatology Department and develop a joint flare requiring joint injection then you can contact the Department directly to book a clinic slot.

Patients can only book in for this clinic if you have developed a joint flare (severe pain or swelling) in one or more joints requiring joint injection

All patients attending will need to bring the following:

- List of your current medication

Please remember if you need a joint injection that the joint(s) should be rested for the next 48 hours.

Patients requiring hospital transport unfortunately cannot be accommodated in this clinic at the present time.

If you wish advice on other Rheumatology problems please contact the Department directly on **01592 648193** to be forwarded to the most appropriate person to deal with your query.

Only the immediate problem i.e. joint flare will be dealt with during this visit. IT WILL NOT BE A FORMAL CLINIC REVIEW.

Fife Rheumatic Diseases Unit:

**01592 648065 - SPECIALIST NURSE ADVICE LINE
(please leave a message with contact number)**

01592 648193 – GENERAL ENQUIRIES

THE RHEUMATOLOGY TELEPHONE ADVICE LINE

TELEPHONE NUMBER: 01592 648065

Aim of the Rheumatology telephone advice line service:

The purpose of this service is to provide and support for patients with Rheumatologic conditions attending the Fife Rheumatic Disease Unit.

The Advice Line is Not an Emergency Service

If you require medical advice you must contact your GP surgery, attend your local accident and emergency department or telephone NHS 24, Tel. 111

You Should Call the Advice Line:

- If you experience a reaction to an injection given by the rheumatology clinic.
- If you have “flare up” of your condition that has not improved with your usual self-help treatments.
- If you experiencing side effects which you feel may be caused by the medications prescribed for your arthritis.

How Does the Advice Line Work?

This is a Monday to Friday service 9am - 5pm,

When you call the advice line you will be asked your name, date of birth and a brief outline of your issue. We will then make an appointment at a specific time on a specific day, usually within 2 working days for a Rheumatology nurse to call you back

If you are out when the nurse calls, no further attempts will be made to contact you. If you still require advice you will need to contact the advice line again.

Who May Use the Advice Line?

The service is available to patients who attend the Fife Rheumatic Diseases Unit. Your relatives may also call with your permission. Confidential issues will only be discussed with you. Your own Doctor and other Health Care Professional can access the advice line.



Pain Self-Management Prescription



Try to focus on 1-2 areas initially

- ❑ **Education** : Increase your knowledge about chronic pain and coping strategies through books from the library & attached websites
- ❑ **Self Management: try** heat packs, cold pack or gels, TENS, etc that may help with your pain and use them regularly (2-3 times per day to keep pain manageable).
- ❑ **“Flare Up” Plan:** when you have a bad day or a bad spell, have a plan for how to deal with it. Cut back on your daily activity but don't take to your bed.
- ❑ **Medication:** take your pain medication regularly to try to keep your pain under control. Seek advice from pharmacists/ GP on how to increase it when you have a “flare-up” or reduce it safely
- ❑ **Activity Management/ Pacing:** Look at what you are doing in a day, begin to prioritise, plan and pace yourself throughout the week. Try to space out your daily activities across the week and not all in one day.
- ❑ **Exercise:** -keep active- gentle home exercise routine, investigate suitable classes with Fife Sports & Leisure trust
- ❑ **Set Realistic Goals:** Be kind to yourself, small steps. Small changes can make big differences to your quality of life
- ❑ **Relaxation:** Try different methods of relaxation, set time aside each day.
- ❑ **Emotions:** Keep diary, reflect if your emotions can affect your pain. Understand how stress and anxiety affect your pain.
- ❑ **Communication** : It's important to talk, catch up with friends, keep your family up to date with how you feel
- ❑ **Get Involved:** Find local support groups. E.g. Pain Association Scotland

GENERAL HELP WEBSITES

- Fife Integrated Pain Management Service Website – www.nhsfife.org/chronicpain
- Chronic Pain Scotland – NHS Scotland - chronicpainscotland.org
- Pain Association Scotland - www.painassociation.com (Freephone: 0800 783 6059)
- Pain Concern - www.painconcern.org.uk
- The British Pain Society – www.britishpainsociety.org
- The Pain Toolkit – <http://www.paintoolkit.org/>
- NHS Inform (Muscle or Joint Problems) – www.nhsinform.co.uk/msk

SPECIFIC CONDITIONS & ASSOCIATED PROBLEMS

- NHS Choices – www.nhs.uk/Conditions/Back-pain/Pages/Introduction.aspx
- Back Care Charity – www.backcare.org.uk/
- Sheffield Back Pain – www.sheffieldbackpain.com/
- The Neuropathy Trust – www.neuinsight.com
- Arthritis Care – www.arthritiscare.org.uk
- Fibromyalgia Association – www.fmauk.org
- Low mood, Stress, Anxiety, Mindfulness (Moodcafé) – www.moodcafe.co.uk
- Relaxation, Sleep, Chronic pain/ fatigue (Get Self Help) – www.getselfhelp.co.uk
- Breathworks -<http://www.breathworks-mindfulness.org.uk/mindfulness-for-health-reader-resources>
- Steps for Stress - www.stepsforstress.org
- Sleep Problems – www.sleepcouncil.org.uk
- ALSO BOOK PRESCRIPTION SCHEME in local Fife Libraries – ACCESS BOOKS WHICH ARE RECOMMENDED TO HELP WITH CHRONIC PAIN

