



# Ankylosing Spondylitis (Axial Spondyloarthritis) (AS)

A guide to anti TNF therapy

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## Who is this guide for?

It's for anyone with ankylosing spondylitis (axial spondyloarthritis) (AS) who wants to find out more about anti TNF therapy

## What is anti TNF therapy?

Anti TNF therapy, also known as biologic therapy, is used to treat a range of conditions including ankylosing spondylitis (axial spondyloarthritis) (AS).

Anti TNF therapy interferes with the action of a protein called tumour necrosis factor (TNF) which is over-active in the body in people with inflammatory arthritis.

This causes inflammation and damage to bones, cartilage and tissue.

Anti TNF therapy blocks the action of TNF and can reduce inflammation.

## Who can be offered anti TNF therapy?

Many people with AS do not need anti TNF therapy because they can manage their condition well with a combination of physiotherapy and non steroidal anti inflammatories (NSAIDs) such as ibuprofen or naproxen.

Your rheumatology consultant might talk to you about anti TNF therapy if:

- You have tried at least two different NSAIDs but you feel they aren't helping.
- You are not able to take NSAIDs because they cause you problems with your stomach or other medical conditions.
- You have high pain levels.
- Your AS is having a big impact on your life. It might be affecting your ability to work or have a good quality of life.

Anti TNF therapy can only be prescribed by a consultant rheumatologist. Your GP cannot offer it to you. So if you are not under the care of a rheumatologist do ask your GP to refer you.

The National Institute for Health and Care Excellence (NICE) have produced written guidelines about prescribing anti TNF therapy that must be followed. Your rheumatologist will advise you if you meet the criteria for anti TNF therapy.

You may not be suitable for anti TNF therapy if:

- You have had tuberculosis (TB) in the past.
- You have had other repeated / serious infections.
- You have multiple sclerosis (MS).
- You have had cancer in the past 10 years.
- You have a serious heart condition.

## How can anti TNF therapy help?

The evidence shows that anti TNF therapy works for around 8 in 10 AS patients and, if taken continuously, the benefits you gain from the medication do not seem to wear off over time.

Anti TNF therapy works to reduce inflammation in your body and that means you should get less pain, less stiffness and more movement. Hopefully this will mean you can get moving more quickly in the morning, find it easier to carry out your daily activities, be able to exercise more and sleep better. In short, anti TNF therapy should give you a better quality of life.

There is currently no proof that anti TNF therapy has a positive impact on radiographic (x-ray) progression of the condition or that it can prevent new bone formation.

*People get best results from anti TNF therapy when they use it alongside a daily stretching and exercise routine.*

## What are the side effects?

Anti TNF therapy has relatively few day to day side effects.

The most common are:

- injection site reactions where reddening and irritation of the skin at the injection site is seen.
- upper respiratory tract infections where a normal cold might last longer or need antibiotics.

You should bear in mind that the long term side effects of anti TNF therapy are not fully understood because they are still a relatively new treatment.

These treatments have been used in patients with AS and other types of arthritis for over 10 years now and no pattern of serious long term side effects is currently emerging. Safety data is being collected by large registries around the world, principally the UK (British Society for Rheumatology Biologics Register), mainland Europe and Scandinavia.

## What are the risks?

All medications come with risk. It's important to understand the risks and to balance these against the possible benefits for you of taking the medication. These risks will always be fully discussed with you by your consultant and the team who assess your suitability for anti-TNF therapy.

Theoretically, there may be a slightly increased risk of cancer with anti TNF therapy as it interferes with the immune system. This is possible because the immune system is involved in recognising and killing cancerous cells. It's important to bear in mind that, for most types of cancer, this link hasn't been proven and is still being extensively researched.

A review in 2012 of studies involving over 25,000 patients found no increase in the incidence of cancer above what was expected in the general population - with the exception of certain types of skin cancer which can be readily treated when diagnosed early.

People on anti TNF are asked to keep a close eye out for any suspicious skin moles, lumps or bumps that develop once treatment has started and see their GP for a review if necessary.

Very rarely, people taking anti TNF therapy may develop a condition called drug induced lupus. This is usually mild and can be diagnosed by a blood test. Symptoms include a rash, fever and increased joint pain. If you develop drug-induced lupus, the anti TNF therapy will be stopped and the condition then usually disappears.

## How do I decide if anti TNF therapy is for me?

- Talk to your rheumatologist, specialist nurse and physiotherapist.
- Read through all the information in this guide and any other leaflets given to you.
- Get your family and friends to look through the information.
- Have a chat with someone else taking anti TNF therapy. A third of NASS members are now taking anti TNF therapy.
- Call for a chat on the NASS Helpline (020 8741 1515).

Then use the following pages to write down your hopes and worries about anti TNF therapy. Take it to your next appointment and talk them through with your rheumatology team.



# Getting started on anti TNF therapy

Anti TNF therapy is a long term treatment rather than a short term option so your rheumatologist will want to be sure it's right for you. Checks that may be carried out include:

**Blood tests** to check your inflammatory markers. If you have inflammation in a part of your body then extra protein can be released from the site of inflammation and circulates in the bloodstream. Erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) blood tests are used to detect this increase in protein, and so are markers of inflammation. Remember though, not all AS patients have raised inflammatory markers.

**X-rays** to see if there has been any changes to your spine or involved joints.

**MRI** to see if there is any inflammation around your sacroiliac joints.

## **Bath Ankylosing Spondylitis Disease Activity Index (BASDAI)**

asks a number of questions about your AS symptoms including fatigue, back pain and morning stiffness. You rate your symptoms using a 1 to 10 scale. A higher score means your symptoms are worse.

**Spinal pain** asks you to assess your back pain. You score higher the worse your back pain is.

**Checks for active and latent tuberculosis (TB).** TB is caused by a bacteria picked up by exposure to someone with the illness. In most people, the immune system kills the bacteria and you have no further symptoms. Sometimes the immune system cannot kill the bacteria, but manages to prevent it from spreading in the body. This means you will not have any symptoms, but the bacteria will remain in your body. This is known as latent TB.

Latent TB could develop into active TB infection if your immune system becomes weakened by a medication such as anti TNF. If you are found to have latent TB you may need treatment with antibiotics before starting anti TNF.

# Choices, choices, choices...

A number of anti TNF drugs have been licensed by the European Medicines Agency for the treatment of AS.

Your consultant may have a particular anti TNF in mind for you given your past medical history or current AS state. Ultimately though the choice of medication should be yours with guidance from your rheumatology team.

Often your rheumatology nurse or physiotherapist will take you through your choices. They will highlight the main differences between the different anti TNFs to help you make your choice.

Some things you should consider when making your choice include:

- How often will I have to inject?
- Is there an injection device I prefer or find easier?

- How long does the drug stay in your system? This could be important if you develop an infection.
- What other conditions related to my AS will the anti TNF help? Some also help with uveitis (iritis), inflammatory bowel disease or psoriasis.

*There is no evidence to show that any one of the anti TNF therapies works better than the others.*

Choices, choices, choices... continued

**ADALIMUMAB (HUMIRA)**

- Self administered by an injection pen device
- Once fortnightly dosing

**CERTOLIZUMAB PEGOL (CIMZIA)**

- Self administered by a pre-filled syringe
- When you start certolizumab pegol you need to do two injections every 2 weeks for the first 6 weeks and then you move to one injection every 2 weeks, or 2 injections every 4 weeks

**ETANERCEPT (BENEPALI, ENBREL)**

- Self administered by an injection device or a pre-filled syringe
- Once or twice a week dosing

**GOLIMUMAB (SIMPONI)**

- Self administered by an injection device
- Once monthly dosing

**INFLIXIMAB (INFLECTRA, REMICADE, REMSIMA)**

- Administered in an out patients clinic by an infusion (drip)
- The infusion is given over two hours (this may change to one hour later on in treatment) and you'll have to wait for another 1-2 hours afterwards before you can go home in case you develop any side effects such as an allergic reaction.
- After the first infusion you may well have another two weeks later and then again four weeks after that. Once your treatment is established you usually have an infusion every eight weeks.

Use this page to write notes on what factors are important to you when choosing an anti TNF therapy and then have a chat with your rheumatology team about the best options for you.

( NOTES )

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## What next?

Once you have been fully assessed for anti TNF therapy and you and your rheumatology team have decided which anti TNF you want to use, then you will be given training on how to do the injections and all the information you need.

## How long does treatment last?

Once you start on anti TNF therapy you will be assessed after 12 weeks to see if it is working for you. If it is helping with your AS symptoms and you are happy with it then you will stay on it for the long term. You will have regular checks.

Anti TNF therapy usually stops working when you stop taking it. On average people relapse within 14 weeks of stopping therapy. If you stop anti TNF therapy for any length of time then you may develop antibodies which mean that it won't work as well when you start taking it again.

The main reasons for having to stop therapy are:

- Deciding to start a family – this is something you should discuss with your rheumatology team well in advance
- Surgery – it can be started again after surgery
- Serious infections

If you need or plan to stop treatment temporarily for any reason, it is important to plan and discuss this with your rheumatology team well in advance.

## Attending regular check ups

Check-ups should take place every 3 to 6 months to ensure that you remain healthy and well. You will need regular blood tests to monitor inflammation and general blood levels.

Any medical changes or changes in your health will be discussed to ensure that it is still appropriate that you take your anti TNF medication.

You will also need to complete simple questionnaires to assess whether you are still getting a good response and improvement from the anti TNF medication.

Monitoring your response to treatment and your health whilst on anti TNF therapy is extremely important. If you fail to attend your checkups for some time it is possible that your drug prescription will be stopped.

*It's really important you attend all you check-ups while you are on anti TNF therapy.*



# Day to day living with anti TNF therapy

## EATING AND COOKING

Visit the NHS Choices website at [www.nhs.uk/Livewell/homehygiene/Pages/Homehygienehub.aspx](http://www.nhs.uk/Livewell/homehygiene/Pages/Homehygienehub.aspx) for information on reducing your risk of infection from foods.

## VACCINATIONS

If you're taking anti TNF therapy it's recommended that you avoid live vaccines. If you do need a live vaccine do discuss all the possible risks and benefits of the vaccination with your doctor.

If you're in your 70s your doctor may advise you to have the shingles vaccination (Zostavax) before starting anti TNF therapy. This vaccination is not recommended for people who are already on anti TNF therapy.

*The Pneumovax (pneumonia) vaccine is recommended for people starting on anti TNF along with annual flu vaccines*

## OTHER MEDICINES

Anti TNF therapy may be prescribed along with other medicines. Do discuss any new medications with your doctor before starting them, and always tell any doctor treating you that you are on anti TNF therapy.

If you develop any kind of infection and are prescribed antibiotics you should not take your anti TNF therapy again until the infection has cleared.

Anti TNF therapy is not a painkiller. If you are already on a non-steroidal anti inflammatory drug (NSAID) or painkillers you can carry on taking these as well as your anti TNF therapy, unless your doctor advises otherwise.

Do not take over-the-counter preparations or herbal remedies without discussing this first with your doctor, rheumatology nurse or pharmacist.

## ALCOHOL

There is no known interaction between anti TNF therapy and alcohol.

## SURGERY

If you are going to have an operation please inform your doctor, as you are likely to be advised to temporarily stop anti TNF therapy before and after surgery.

## PLANNING A FAMILY

If you are planning a family we would strongly advise you discuss this with your rheumatologist well in advance.

## TRAVELLING

If you are travelling abroad and taking your anti TNF therapy with you, it's important to make plans to keep it at the correct temperature during the journey and at your destination. You can buy special cool bags and even travel fridges. A useful company for purchasing these products is MedActiv.

Another option is to use a Frio wallet or carry case. These are designed to keep insulin cool but work well for anti TNF. You can buy these through Amazon.

In addition to your anti TNF medication you may require a travel size sharps box. Do discuss this with your Clinical Nurse Specialist or your delivery team.

Ask for a letter confirming you have been prescribed anti TNF from your rheumatologist and keep a copy in your hand luggage. Some people find it helpful to scan a copy of the letter and email it to themselves so they have an electronic copy. This is also a handy tip for passports.

If you are travelling somewhere warm and sunny do remember that you should use a high factor sunscreen when on anti TNF therapy.

# NASS resources

## **NASS GUIDEBOOK**

A practical introduction to the treatment and management of ankylosing spondylitis with useful advice on living and working with AS.

## **GUIDE TO MANAGING YOUR AS AT WORK**

Includes how AS can affect your work, communicating about your condition, staying well at work and your rights.

## **GUIDE TO MANAGING YOUR AS FLARES**

Practical information to help you manage your AS flares.

## **LEAFLETS**

### **Axial spondyloarthritis**

An understanding of axial spondyloarthritis and how it fits with ankylosing spondylitis.

### **Driving and AS**

Safe driving, the DVLA, Forum of Mobility Centres, the Motability scheme and the Blue Badge scheme.

### **Fatigue and AS**

What causes fatigue in AS and how it can be managed.

### **Uveitis and AS**

Symptoms of uveitis and treatments.

## **EXERCISE FOR AS**

Exercise is not just a useful addition to the management of AS. It is one of the cornerstones of treatment. Exercise helps in the maintenance of flexibility and

good posture and also assists with pain management and wellbeing.

## **Back to Action**

A guide to exercising safely in the gym (pdf version). You can also buy a printed, spiral bound version in the NASS shop.

## **Back to Action App**

We have now been able to produce an App for iPhones and android phones which you can download completely free of charge from iTunes and Google Play.

## **Fight Back**

Our exercise DVD aimed at people with more advanced AS who want to exercise at home. It includes 6 exercise programmes with 35 individual exercises and contains hip safe exercises.

## **NASS BRANCH NETWORK FOR HYDROTHERAPY AND PHYSIOTHERAPY**

There are 90 NASS branches providing regular physiotherapy and hydrotherapy sessions throughout the UK. Call NASS or check on our website under NASS Near You.

# NASS

**NASS is a charity which provides support, advice and information for people with AS and their families.**

Membership of NASS can go a long way towards improving your health and your life.

You'll benefit from up-to-date information on treatment, as well as support with information on benefits and work. You'll also connect with others in a similar situation.

Not only will you feel less alone, you'll be able to share solutions.

Here are some reasons why you should become a NASS member today!

- Access to our 90 regional branches offering regular physiotherapy and hydrotherapy sessions.
- Use our Exclusive NASS members' forum.
- Twice-yearly magazine, AS News.
- Free entry to our annual Members' Day.

## **GET INVOLVED AND SUPPORT RESEARCH INTO AS**

- Support other people affected by AS.
- Support our five year plan to focus on early diagnosis, patient empowerment and self management, access to physiotherapy and exercise and awareness.

## **TO JOIN NASS**

If you'd like to join online please go to our website at [www.nass.co.uk](http://www.nass.co.uk) and choose your membership in the NASS Shop.

If you'd like to pay by credit card and over the telephone please call **020 8741 1515**.

NATIONAL ANKYLOSING SPONDYLITIS SOCIETY

Supported by UCB Pharma through an educational grant. UCB has no editorial control on the contents.



Thanks to the Rheumatology team at Queen Alexandra Hospital, Portsmouth NHS Trust for all their help in with this guide

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