

Am I likely to develop rheumatoid arthritis?

A guide for relatives of patients with rheumatoid arthritis

euroTEAM
together we'll prevent rheumatoid arthritis



At a glance

- Rheumatoid arthritis (RA) is a common disease that causes painful and swollen joints, which can lead to irreversible joint damage if untreated.
- RA can usually be treated effectively if treatment starts very soon after the symptoms start. Unfortunately, diagnosis and treatment of RA are often delayed.
- Information about your family history, your lifestyle, your symptoms, and the results of blood tests can be used to predict your risk of developing RA in the future.
- If you are at high risk of developing RA, it may be possible to reduce your risk by making changes to your lifestyle, or by taking medication.
- If you know you are at high risk of developing RA, you are more likely to be treated quickly and effectively if you do develop RA.
- Some people would rather not know their risk of developing RA, as they feel this information could have negative consequences (e.g., it might make them anxious, or more likely to have higher life insurance costs).
- If you are concerned about your risk of developing RA, or if you would like to know more, you can always ask your doctor for advice and support.

Why might I want to know more?

This booklet is for people who have a history of rheumatoid arthritis (RA) in their family. You may be reading this booklet because one of your parents, brothers, sisters or other relatives has RA and you are worried that you are at risk of developing RA yourself.

If you think that you might be at risk of developing RA, there are lots of things that you can do to reduce your risk, and to make sure you get the best possible treatment if you do get RA.

This booklet covers the following topics:

- What is RA?
- Am I at risk of RA?
- What can I do to find out more about my risk?
- Why might I want to know more about my risk?
- Why might I not want to know more about my risk?
- I am at high risk of developing RA – what can I do?
- Where can I find more information about RA?

What is rheumatoid arthritis?

There are many types of arthritis; they all affect different types of people and have different causes and treatments.

Rheumatoid arthritis (RA) is one of the more common types of arthritis, affecting about 1 in 100 people. It is twice as common in women as in men. It typically begins in people in their 40s, 50s and 60s, but it can start at much younger or at much older ages.

In patients with RA, their immune system attacks the lining of their joints, causing inflammation. Their joints become painful, swollen and stiff. In most patients, lots of joints are affected. RA often begins by affecting the joints of the hands and feet and can then spread to affect larger joints such as the knees, hips, elbows and shoulders. If untreated, the arthritis often causes irreversible damage to the joints.

Some patients can develop problems outside the joints, for example heart disease (e.g. angina and heart attacks), thinning of the bones (e.g. osteoporosis) and scarring of the lungs.

Highly effective treatments are now available for RA that control symptoms in most patients. Many patients enter a state of remission. However, these medicines do not cure RA, and patients usually need lifelong treatment.

Treatment for RA is most effective if started soon after the first symptoms of RA appear.

Am I at risk of rheumatoid arthritis?

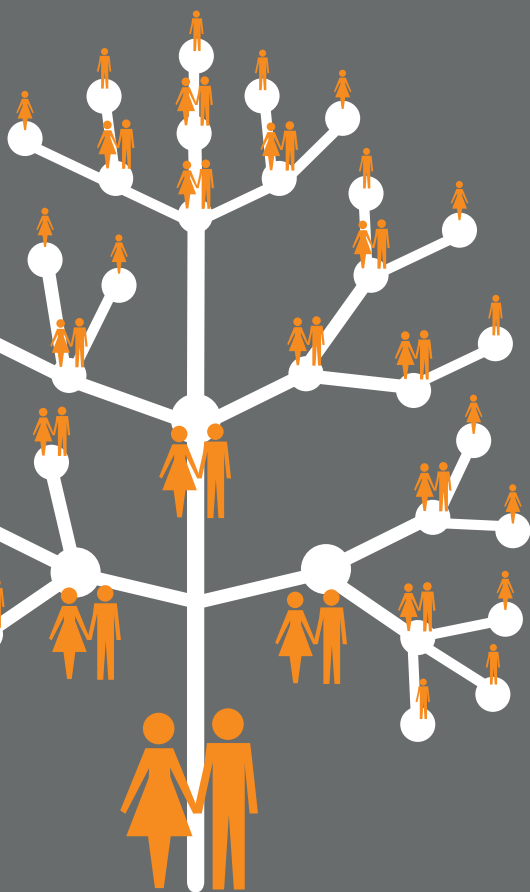
Having a history of rheumatoid arthritis (RA) in your family increases your risk of developing RA in the future.

However, many people who have a family history of RA do not develop RA themselves.

Some people who develop RA do not have a family history of the disease.

We do not know with absolute certainty why some people develop RA, but we do know that there are certain things (known as risk factors) which increase your risk of developing RA. There are also physical signs (such as swelling of the joints), and the results of tests (such as blood tests) that help us to predict how likely you are to develop RA.





Genetic risk factors

About half of your risk of getting rheumatoid arthritis (RA) is determined by your genes.

If you have a history of RA in your family, you are more likely to develop RA. The closer the person in your family who has RA is related to you, the greater your risk of developing RA.

Out of every 100 members of the general public, one person will develop RA.

However, out of every 100 people who have a parent or sibling with RA, 4 will develop RA.

Out of every 100 people who have a grandparent or uncle or aunt with RA, 2 will develop RA.

Doctors can use information about your family history to help predict your risk of developing RA. For some people, it may be useful to test for specific genes that tell us more about their risk of developing RA.

Environmental risk factors

The other half of your risk of getting rheumatoid arthritis (RA) is determined by things that you are exposed to in the environment, or due to your lifestyle.

For example, if you smoke, you are more likely to develop RA.

Other risk factors may include eating a diet high in red meat and low in vitamin C, having gum disease and being overweight.

Your genes interact with your lifestyle and environment to determine your risk.



It is important to remember that we do not fully understand why each patient develops RA. Some people develop RA who do not have a family history of RA, and who are not exposed to the environmental risk factors that we know about. Research is underway to increase our understanding of other factors that cause RA.

Smoking is one of the strongest risk factors for RA. If the whole population stopped smoking, the number of new cases of RA would reduce by about 20%. In other words, out of every 100 people that develop RA in Europe now, only 80 would develop RA if no one in the population smoked. Smoking is a particularly strong risk factor if you have a history of RA in your family.

Changes to your immune system that can be found in your blood

Some people develop changes in their blood that suggest something has gone wrong with the immune system and that they may be on their way to getting rheumatoid arthritis (RA).

These changes in the blood can be present for a long time before you develop any symptoms of RA.

Blood tests can detect an abnormality (such as an autoantibody) that is associated with RA. Doctors often test for particular autoantibodies such as rheumatoid factor (RF) and anti-cyclic citrullinated peptide (anti-CCP) antibodies.

If you have these antibodies in your blood, then your risk of developing RA in the future is increased. However, not everybody who has these antibodies will go on to develop RA.



The following diagrams illustrate the different stages people may go through in the journey from health to the development of RA.

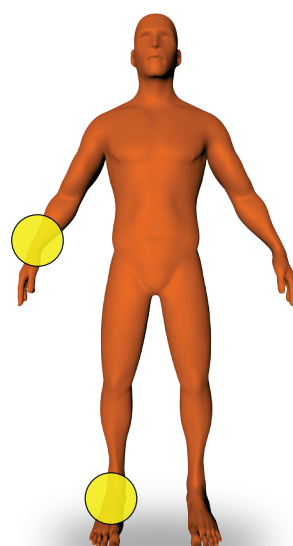
The development of joint pain

If you develop joint pain, doctors can use information about the type of symptoms you experience to help predict your risk of developing full-blown rheumatoid arthritis (RA).

This includes:

- how long you have had the symptoms for
- how much pain you experience
- how stiff you feel in the morning
- whether you have noticed swelling in your joints in the past
- which joints you have symptoms in
- whether the symptoms come and go

If your pain and morning stiffness are severe, and you have pain in joints in both the arms and legs, and you have had the symptoms on and off for less than a year, you are more likely to develop RA. However, not everybody with these symptoms will go on to develop RA.



joint pain / stiffness

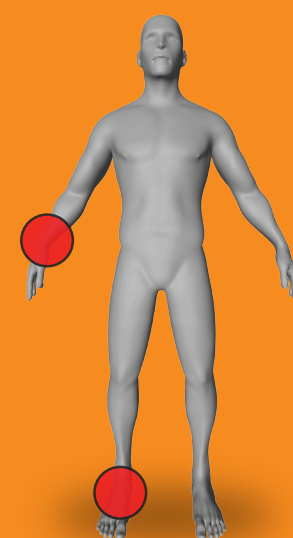
The development of joint swelling

If you develop joint swelling, doctors can use information about which joints are swollen to help predict your risk of developing full-blown rheumatoid arthritis (RA). This includes:

- which types of joints are swollen
- how many joints are swollen

If you have swelling in the joints of both your arms and your legs, or if you have swelling in lots of joints, you are more likely to develop RA.

However, not everybody with these symptoms will go on to develop RA. In fact, many people have symptoms that get better without any treatment over a few weeks or months. This is known as “self-limiting” or “resolving” arthritis.

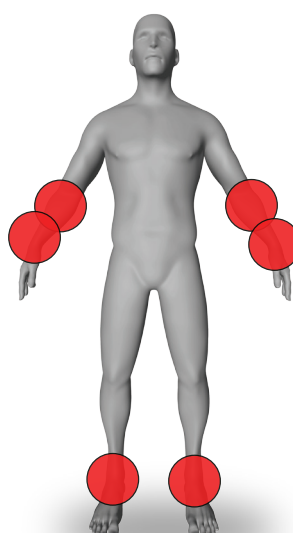


joint swelling

The development of rheumatoid arthritis

Some people go on to develop full-blown rheumatoid arthritis (RA).

It is important to realise that not all patients will pass through all of the stages above on their way to developing RA. For example, a person with a family history of RA may one day wake up with swollen joints without having any antibodies in their blood, or without any previous joint pain.



rheumatoid arthritis

What can I do to find out more about my risk?

You may be concerned about whether you will develop rheumatoid arthritis (RA) because you have already experienced some joint symptoms.

It is best to discuss the situation with your doctor or with a rheumatology specialist.

You are likely to be asked about your family history, whether you have any other ‘risk factors’ for RA (e.g. if you smoke), and about your symptoms. Depending upon your circumstances you may be offered a blood test to look for specific genes or antibodies. You may also be offered specialist scanning of the joints (e.g. by ultrasound or magnetic resonance imaging (MRI)) to see if there is any inflammation of the lining of your joints.

All of this information can be used together to predict the risk that you will develop RA in the future.

It is important to remember that there are no tests available at this time that can predict with absolute certainty that you will definitely develop RA, or that you will definitely not develop RA.

It is also important to remember that there are no tests available at this time that can give precise information about when you might develop RA in the future.

Why might I want to know more about my risk?

If your risk of developing rheumatoid arthritis (RA) is high, you may be able to do something to reduce your risk.

Lifestyle changes

If you are at risk of developing RA, it seems likely that you may be able to reduce your risk by making healthy changes to your lifestyle, especially by stopping smoking if you are a smoker. It is best to have never smoked, but if you stop smoking, your risk of developing RA will go down over time. Other lifestyle changes that may possibly reduce your risk of developing RA include changing your diet (eating less red meat and more fruit and vegetables) and maintaining a healthy weight, although more research is needed about the effect of these lifestyle changes.

We do not yet know how much you can reduce your risk of developing RA by changing your lifestyle. However, we do know that you can reduce your risk of developing many other serious diseases (e.g. cancer, heart disease) by making these healthy changes to your lifestyle. There are many good reasons to make these changes in addition to possibly reducing the risk of RA.

However, it is important to remember that though changing your lifestyle may reduce your risk of developing RA, it does not guarantee that you will not get RA.



Medication

Research studies are underway to explore the idea of giving people at high risk of developing rheumatoid arthritis (RA) a short course of medication to reduce their risk. At the moment, the results of these studies are not known, but we hope that in the future we will be able to treat people to reduce their risk of developing RA.

Early treatment

If you know your risk of developing rheumatoid arthritis (RA) is high, you are more likely to be treated quickly and effectively if you do get RA.

Treatment for RA is most successful if given within the first 3 months after RA has developed. Unfortunately, for many people with RA, treatment starts much later. This is often due to a combination of the following factors:

- i. People do not always seek help quickly from their doctor after the symptoms start. This is often because they do not understand how serious their symptoms are.
- ii. Doctors do not always refer the person to a rheumatology specialist quickly. This may be because the person's family doctor does not understand the significance of the person's symptoms.
- iii. Specialists do not always see the patient quickly after receiving the referral. This is often because the referral does not make it clear that the family doctor suspects RA.

If you know that your risk of developing RA is high, it is likely that each of these types of delay will be reduced if you do start to develop symptoms of RA. This means that you will be more likely to be treated quickly and effectively.

Why might I not want to know more about my risk?

Some people feel that they do not want to know more about their risk of developing rheumatoid arthritis (RA) in the future. Reasons for not wanting to know include:

Uncertainty about our ability to predict risk of RA.

For some people we may be able to tell them that they have a very high risk (e.g. 7 in 10, or 70%) or a very low risk (e.g. 1 in 100, or 1%) of developing RA.

However, it is impossible for us to say that a person has a 100% risk of developing RA (i.e. they will definitely develop it) or that a person has a 0% risk of developing RA (i.e. they will definitely not develop it).

Even in situations where our tests are quite good, there is still some uncertainty about whether RA will develop.

Sometimes the level of uncertainty may be even higher. For example, we may predict that your risk of developing RA in the future is 1 in 2 (or 50%). You may feel that this uncertainty is not acceptable to you.

Knowing your risk of developing RA might make you feel anxious or unhappy

You may not want to know or think about whether you might develop RA. You may feel that this information could cause unnecessary stress and anxiety for you and your family. You may prefer to wait and see if you develop symptoms, and deal with them as and when they happen.

You may feel that just by reading this leaflet you have enough of an idea about your own risk of developing RA, without the need for any specialist advice or tests. If so, the most important advice for you is to see a doctor as soon as possible if you think you've developed symptoms of rheumatoid arthritis. If you do this, and get started on treatment for RA quickly, you will be giving the treatment the best chance of working well.

Knowing your risk of developing RA might have practical or financial disadvantages

You may worry that knowing your risk of developing a disease like RA might have undesirable consequences. For example, you may feel that this information may influence life insurance premiums, or make it less likely for you to find employment.

I am at high risk of developing rheumatoid arthritis – what can I do?

If you are at high risk of developing rheumatoid arthritis (RA) there are a number of things that you can do that may reduce your risk of developing RA and may improve your outcome if you do develop RA. These include:

Changing your lifestyle:

- Avoiding or stopping smoking
- Having a healthy diet, that is high in fruit and vegetables and low in red meat
- Making sure you have an active lifestyle
- Making sure you are not overweight

Doing these things will have other health benefits.

There is no guarantee, even if you follow this advice, that you will not get RA anyway. However, if you do develop RA despite following this advice, you will make it more likely that treatment for your RA works more effectively. For example, many of the medicines we use to control RA are not as effective if you smoke.

Treatment to reduce the risk of developing rheumatoid arthritis:

At the moment, there are no medicines that have been shown to definitely reduce your risk of developing RA if you do not yet have any joint swelling. This is however a very active area of research. You may be interested in seeing if you can take part in research studies (clinical trials) in this area. You can always discuss this with your doctor.

Starting treatment quickly if rheumatoid arthritis develops:

This is one of the most important things you can do to allow your rheumatoid arthritis (RA), if you do develop it, to be treated as well as possible.

If you develop worsening of any of the following symptoms, seek help from your doctor as soon as possible:

- Joint pain (especially in the small joints of your hands and feet)
- Joint swelling
- Stiffness in and around the joints that is worse first thing in the morning

Ideally, you need to see a rheumatologist. They will carefully assess whether you have developed RA. If you have, then treatment with medication (for example with a medicine such as methotrexate), will be recommended. Also, they may recommend that you see another health professional such as a physiotherapist for advice about joint exercises and joint protection.

In some cases, your rheumatologist may advise you that you have not yet developed full-blown RA, and will suggest that they will monitor you regularly, and start treatment if RA develops at a later date.

Most people who develop RA can be treated effectively and lead full and active lives. Now that you have read this leaflet, we hope that you are better prepared to try to reduce your risk of getting RA, and to get specialist help quickly if you do develop RA.



Where can I find more information about rheumatoid arthritis?

EULAR (European League Against Rheumatism)
www.eular.org

UK Websites:
Arthritis Research UK
www.arthritisresearchuk.org

NRAS
(National Rheumatoid Arthritis Society UK)
www.nras.org.uk

NHS Choices
www.nhs.uk

Other websites relevant to countries participating in EuroTEAM:

Austrian League Against Rheumatism
www.rheumatologie.at

Dutch League Against Rheumatism
www.reumabond.nl

Estonian Rheumatism Association
www.reumaliit.ee

German League Against Rheumatism
www.rheuma-liga.de

Icelandic League Against Rheumatism
www.gigt.is

Romanian League Against Rheumatism
www.reumatism.ro

Swedish Rheumatism Association
www.reumatikerforbundet.org

Swiss League Against Rheumatism
www.rheumaliga.ch

AGORA (Platform of organisations of people with rheumatic diseases in Southern Europe)
www.agora-platform.eu

A guide for relatives of people with rheumatoid arthritis

www.team-arthritis.eu