Pfizer Malaysia Sdn Bhd
Level 3 & 4, Bangunan Palm Grove,
No 14, Jalan Glenmarie (Persiaran Kerjaya)
Section U1, 40150, Shah Alam,
Selangor Darul Ehsan,Malaysia
Tel: 03-5568 6688 Fax: 03-5569 5302

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Touchpoints in Rheumatoid Arthritis

A patient's guide to living with rheumatoid arthritis

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Welcome to **Touchpoints**

Touchpoints is a new program for people with rheumatoid arthritis (RA) that will help you:

- Better understand your condition
- Talk to your doctor about your diagnosis
- Learn about available treatments and find useful tips for living with RA

As with most other diseases, the more you know about RA, the more you can do about it.

You are not alone—and you can take action

RA is more common than you might think. It affects millions of people. The important thing to remember is that RA does not define you as a person. You have the power to take charge of your condition by learning all you can about RA and finding the treatment that works best for you. Taking action will also help you feel better about your condition and yourself.

What is RA?

RA may appear to be a joint disease. It is not. It is a disease of the immune system. RA causes your immune system to attack your joints, causing chronic pain and irreversible deterioration of the joints.

RA is a chronic disorder

Joint damage is caused by inflammation, a process that your immune system uses to fight infections and heal injuries. Normally, once your body clears out an infection, inflammation stops. In RA, however, your body's immune system mistakes some organs as foreign and attacks them. This causes damage to your joints and other organs.

Some things you should know about RA

RA damage may continue even when pain and inflammation are controlled with pain relievers. These medications do not affect the disease process that causes damage to your joints and bones. This damage is permanent. Unlike many injuries that heal over time, the deterioration of the joints, bones, and cartilage caused by RA does not go away.

RA is a disease of the immune system.

Because deterioration cannot be reversed, it is critical that you work with your physician to get an early diagnosis and begin treatment that can help to slow or stop the progression of the disease.

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RA is a progressive disease

The damage increases

If RA is left untreated, the damage can increase. It starts in the lining of your joints, then spreads to cartilage, and finally erodes the bone. Think of a river that flows through a valley. With every passing day the land erodes, worn down by the water. In the same way, if RA progresses without appropriate treatment, your joints may continue to disintegrate.

The causes are unknown

No one knows why the immune system attacks healthy joint cells in RA or what triggers the disease. Some things we do know are that:

- RA may be hereditary. RA often runs in families, but the exact genetic cause, if there is one, is unknown.
- RA is not contagious—you did not get it from contact with another person, and you cannot transmit it to anyone.
- RA is more common among women, occurring at least twice as frequently as it does in men.
- RA may be related to the aging process. The risk of developing RA increases as people get older.
- RA may be related to a number of environmental factors, including smoking. Smoking cigarettes increases the risk of developing RA.

Research is continuing into the causes of RA.

RA can affect many things

RA can affect many different aspects of your life. You have to cope not only with the physical symptoms you are experiencing and your treatment, but also with the psychological impact of the disease.

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Early diagnosis is important

Because RA gets worse over time, it is important to be diagnosed as early as possible and begin a treatment that can help stop the progression of joint damage. Research suggests this is the most effective way to fight RA.

If you have RA symptoms, do not delay seeing your doctor.

> Early treatment of RA is critical.

Evidence suggests that early treatment can greatly affect the long-term course of the disease.

When you know more, you can do more, and getting diagnosed early could be one of the most important things you can do.

Do you have these RA symptoms?

Check any symptoms that you are experiencing:

- ☐ Joint pain with warmth and swelling, especially in the small joints of the hands, wrists, and feet
- ☐ Pain in more than one joint at the same time
- ☐ Fatigue
- ☐ Morning stiffness that lasts an hour or more
- ☐ Limited movement or function of joints
- ☐ Painless lumps under the skin around your elbows and hands
- ☐ Low-grade fever
- ☐ Weakness

Please note: This checklist is not a formal diagnostic tool. It is meant to help you identify symptoms that could be caused by RA. Only your health care provider can diagnose RA. Other medical conditions can cause symptoms that are similar to those of RA. Please talk to your doctor.

Turn to pages 12 and 13 for tips on how to discuss these symptoms with your doctor.

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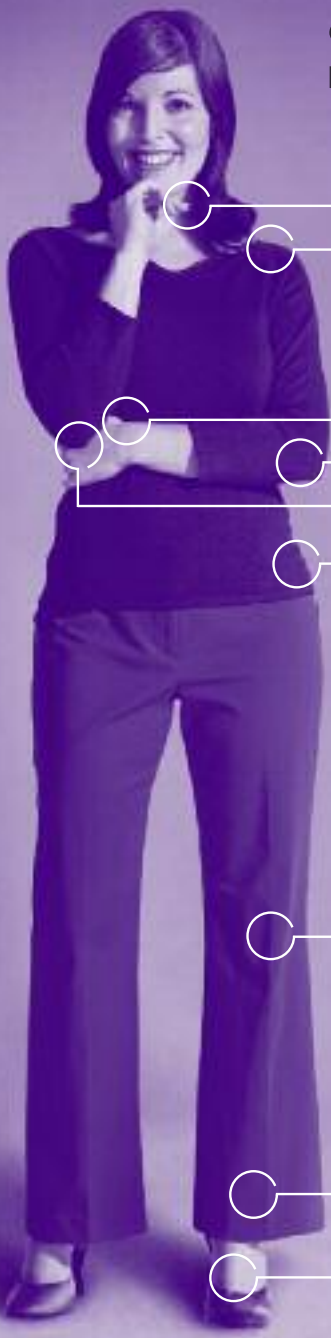
Check any areas where you have painful and swollen joints.



- Neck ☐
- Shoulders ☐
- Wrists ☐
- Elbows ☐
- Hands ☐
- Hips ☐
- Knees ☐
- Ankles ☐
- Feet ☐

Are there tests for RA?

Diagnostic tests

Although there is no single definitive test for RA, your doctor can use blood tests to look for a variety of indicators to determine whether you might have this disease.

- Rheumatoid factor is an antibody that is found in most people who have RA.
- The erythrocyte sedimentation rate (ESR) and C-reactive protein (CRP) measure the level of inflammation in your body.
- Particularly useful in detecting RA early on is a measurement of antibodies to a naturally occurring substance called cyclic citrullinated peptide (anti-CCP antibodies).

Another test involves an analysis of the synovial fluid surrounding your joints to confirm the presence of inflammatory disease.

Assessment tests

Your doctor may use other assessment tests to measure your progress against RA during treatment. For example:

- The Disease Activity Score (DAS) in RA measures disease activity in your shoulders, elbows, wrists, fingers, and knees. The DAS makes it easier for doctors to assess how active your RA is.
- The Health Assessment Questionnaire (HAQ) assesses patients' ability to function.

Some doctors conduct these tests with their patients at every visit. In addition, the ESR and/or CRP blood tests may be repeated by your doctor to see if your inflammation level has changed, and x-rays of affected joints may be taken to help determine the degree of damage and the progress of your disease.

Doctors use assessment tests to see whether your disease is progressing.

Talk to your doctor for more information about these tests.

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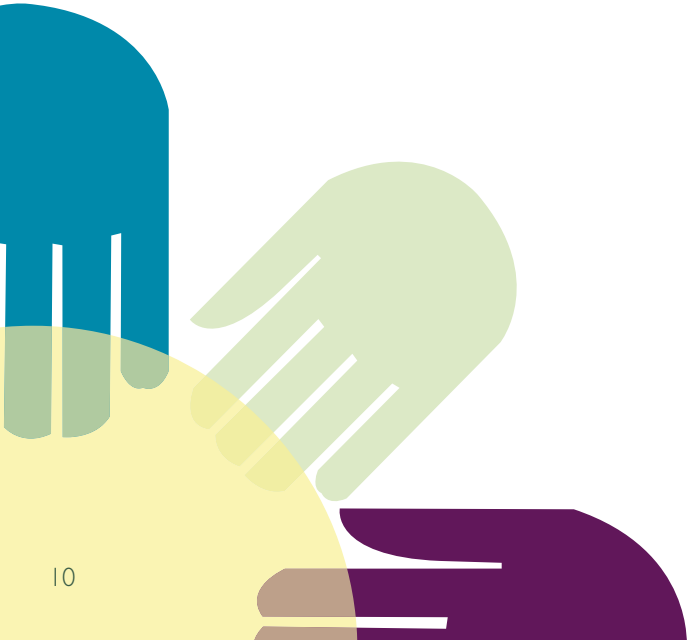
Know which treatments can help

Several studies suggest that RA responds best when it is treated early. The goal of treatment is to prevent or control joint damage and reduce symptoms. Doctors often use disease-modifying antirheumatic drugs (DMARDs) early in treatment. Your doctor will monitor symptom relief and side effects when you are taking a DMARD.

Talk to your doctor about which treatment is right for you.

There are several DMARDs that your doctor may use to treat your RA. They include:

- Sulfasalazine
- Hydroxychloroquine
- Penicillamine
- Leflunomide
- Azathioprine
- Cyclosporine
- Methotrexate



Methotrexate is a frequently prescribed DMARD that is effective in improving symptoms of RA when used alone, with other DMARDs, or with other medicines called biologic response modifiers (biologics).

Being proactive about finding a treatment that works for you may be the first step to feeling better, both emotionally and physically. If your symptoms are not improving, it is important to tell your doctor as soon as possible.

Biologic response modifiers

Biologics are established and successful option in the treatment of RA. They work in the body to reduce inflammation, relieving pain while fighting the disease. These drugs—abatacept, adalimumab, anakinra, etanercept, infliximab, and rituximab—help slow the progression of RA. They are prescribed for people who are not reaching treatment goals on a DMARD, or they are prescribed with a DMARD for additional benefit. They may help get you to your treatment goal.

> Work with your doctor to find the treatment that is best for you.

Talk to your doctor to find a treatment regimen that works for you. Your doctor can give you information about the benefits and side effects associated with all of the different treatment options.

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Suggestions for talking with your doctor

Be sure to talk to your doctor about your symptoms and progress. You and your doctor can make the appropriate treatment choices for your condition. The more information you share, the better your doctor will be able to help you.

Here are some questions that will help you prepare for your doctor visit.

- If you have any of the symptoms in the questionnaire on pages 6 and 7, when did you first experience them?
- What medications are you taking to relieve the symptoms you are experiencing?
- If you have morning stiffness, how long does it last each day?
- Is your RA affecting you emotionally?

Use the symptom checklist on pages 6 and 7 to start the conversation with your doctor.

Often, the time you spend with your doctor is limited. Make the most of your visit.

- Do not be embarrassed about asking your doctor questions. Make a list of them beforehand so you don't forget anything.
- Acknowledge your feelings and emotions about your condition. Consider communicating these to your doctor.
- Make sure you understand the information your doctor is giving you. It's all right for you to say, "I don't understand."
- Learn more about RA. This will make it easier to have a conversation with your doctor about treatment options. (See pages 18 and 19 to find organizations that may be of help.)
- Keep a diary. Write about how you feel, what you're scared of, and be sure to write about the fun times, too.
- Talk with other members of your health care team—nurses, therapists, etc.—for more help and information.
- RA, and its treatment, can be overwhelming. Learn as much as you can about it so that you can feel you are doing all you can to control it.

Do not be embarrassed about asking your doctor questions.

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Living with RA

RA, like many rheumatic disorders, is a lifelong condition. There are many things you can do to help maintain a healthy lifestyle.

Watch your weight

Extra weight can put added stress on your hips and knees, so ask your doctor if a weight-loss program is appropriate.

Exercise regularly

Exercises that improve your range of motion, strength, and endurance may be helpful. Talk to your doctor or physical therapist to determine which exercises are right for you.

Take steps to stay as healthy as you can.

Get organized

Organize your work or home so that items you use frequently are easily accessible.

Dress for success and comfort

There are simple things you can do when you get dressed to help minimize the strain on your joints:

- Put your clothes out the night before, when your joints are not as stiff.

- Pre-tie your neckties and scarves, and leave them tied. Your hands will not have to work so hard.
- Wear loose-fitting clothing with large openings so you can easily slip garments on and off.
- Choose comfortable, easy-to-fasten shoes that reduce or eliminate pressure on the foot.

Think ahead when traveling

Here are some simple tips to consider when traveling.

- Make reservations early to ensure that your needs will be met.
- Keep medications and other important items in a light carry-on bag. Remember to observe recommended storage conditions.
- Take advantage of preboarding for your flight to minimize the inconvenience of boarding.
- Pack lightly and use lightweight luggage on wheels.

Have a positive attitude

- A good attitude can improve your ability to function mentally and physically.
- Tell your doctor if your RA is affecting you emotionally. Your doctor may suggest ways to help you deal with these feelings.

Find more helpful tips on the Web sites listed on page 19.

Help others understand your RA

When you are diagnosed with RA, your family and friends may not know the best ways to help you. Here are some tips to help you explain what you are going through.

- Try to call a friend or family member regularly. Keeping in touch will allow you to discuss how your RA is affecting you.
- Learn about RA. The more you know about RA, the better you can explain it.
- Be direct. Tell your friends and family what you need.
- Tell your family and friends that the pain or stiffness you are experiencing can vary. Ask for their understanding if you need to change or postpone activities together.
- When you get together with your friends and family, plan activities that you can participate in.

Do not just cope with RA, fight it.

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- Talk openly with your partner. Expressing your true feelings will keep your relationship healthy and also allow your partner to help you.

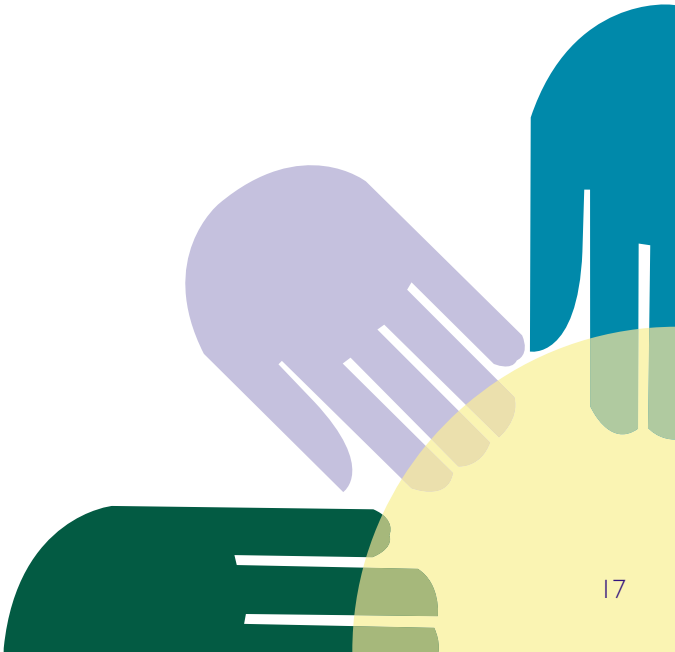
Laughter has been shown to help your immune system.

- Laugh! Laughter has been shown to relieve pain and may even help your immune system.

Moving forward

While living with RA is not easy, you should not lose your optimism about the future. You should realize that by knowing more about your condition and treatment, you may be able to enjoy your life more fully.

It is not enough just to cope with RA. By taking action, setting goals, working with your health care team, and maintaining a positive attitude, you may be able to fight back against RA.



Be well-informed

Learning as much as you can about your condition is another way to take an active role in living with RA. Knowledge gives you the confidence to talk with your health care providers about your needs and concerns.

Visit Web sites

Arthritis Foundation Malaysia
www.afm.org.my

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