

# The Arthritis Helpbook

A Tested Self-Management Program for  
Coping with Arthritis and Fibromyalgia

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*Living a Healthy Life with Long Term Conditions* by Kate Lorig, Halsted Holman, David Sobel, Diana Laurent, Virginia González, and Marian Minor

*Living Well: A Take Care of Yourself Health Guide for the Middle and Later Years* by James F. Fries

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## A Note to Readers

This book is not meant to replace medical care. Rather, it is a supplement to that care. Most doctors do not have the time or take the time to explain exercises or pain-management techniques to you with enough detail to help you very much. Therefore, we hope this book will assist both you and your physician. All of the advice and activities that we describe have been reviewed by many, many doctors, physical therapists, occupational therapists, nutritionists, and nurses, including the entire staff of the Stanford Arthritis Center. They represent a sound program essentially the same as that recommended by most health authorities today. If you have particular questions please talk them over with your doctor.

We would like you to feel that you are part of our cast of thousands. If you have comments or suggestions please send them to us by writing:

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Your suggestions will be reviewed and considered for our next edition.

To all of you who helped in the past and whom we couldn't name, many thanks, and to those of you who are just joining, a hearty welcome.

K. L.  
J. F. F.  
*Stanford, California*  
*January 2006*

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## **Part I**

# **Understanding Those Aches and Pains**

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# Chapter 1

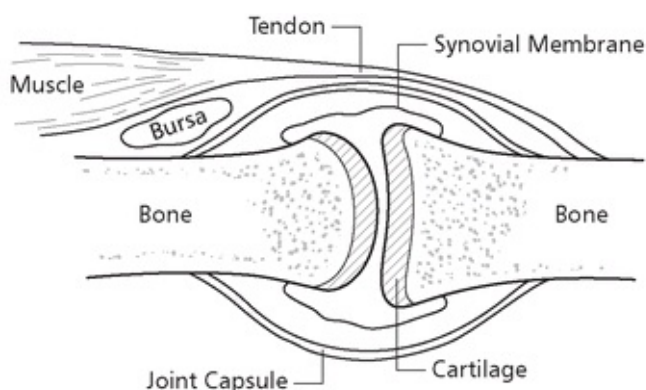
## *Arthritis: What Is It?*

Arthritis. Fibromyalgia. The very words evoke a specter of fear and pain. People think of getting old, being unable to get around, and of becoming more dependent upon others. The terms carry with them a sense of hopelessness and futility. But the very opposite should be true. All arthritis and fibromyalgia can be helped.

In order to understand how to work with your condition, it is necessary to know a little about it. In fact, arthritis is not just a single disease. There are over 120 kinds of arthritis, all of which have something to do with one or more joints in the body. Even the word *arthritis* is misleading. The *arthr* part comes from the Greek word meaning “joint,” while *-itis* means “inflammation or infection.” Thus, the word *arthritis* means “inflammation of the joint.” The problem is that, in many kinds of arthritis, the joint is not inflamed. A better definition might be “problems with the joint, or the ligaments, tendons, and muscles near the joint.” “Rheumatism” is a broader term that encompasses a variety of kinds of pain and stiffness in the muscles and joints.

Now that you understand what *arthritis* means, the next step is to understand what a joint looks like and what the various parts do.

A joint is a meeting of two bones for the purpose of allowing movement. It has the following parts.



### ***Where arthritis attacks.***

1. **Cartilage.** The end of each bone is covered with cartilage, a tough material that cushions and protects the ends of the bone. To get some idea of what cartilage is like, feel the middle of your nose or your ears. These are also made of cartilage. Cartilage in meat is gristle.
2. **Synovial membrane (synovial sac).** Around each joint is the synovial sac, which protects the joint and also secretes the synovial fluid, which oils the joint. In fact, this fluid has many times the lubricating power of oil. Synovial fluid is a little like egg white.

3. **Bursa.** A bursa is a small sac that is not part of the joint but is near the joint. It contains a fluid that lubricates the movement of muscles: muscle across muscle and muscle across bones. In some ways, it is similar to the synovial sac.
4. **Muscle.** The muscles are elastic tissues that, by becoming shorter and longer, move the bones and thus move you.
5. **Tendon.** The tendons are fibrous cords that attach the muscles to the bones. You can feel them on the back of your hand or in the back of your knee.
6. **Ligament.** The ligaments are fibrous cords, much shorter than tendons, that attach bone to bone and make up the joint capsules.

When someone says, “I have arthritis or fibromyalgia,” it means that something is wrong with one or more of these parts. For example, when the synovial membrane becomes inflamed, this is true arthritis. The joint is inflamed. However, if the muscle becomes stretched from overexercise or injured, this is not arthritis. The joint itself is not affected.

In each major kind of arthritis, a different joint part is involved. In *rheumatoid arthritis*, the problem is chiefly *synovitis*, an inflammation of the synovial membrane. This inflammation must be reduced with medication in addition to your self-management program. In *ankylosing spondylitis*, the problem is an *enthesopathy*, an inflammation where the ligaments attach to the bone. This inflammation also needs to be suppressed by medication, and the affected joints need to be regularly exercised and vigorously stretched. In *osteoarthritis*, the problem is a breakdown of the joint cartilage, but it can be helped by exercise and proper use of your joints. In *gout*, the problem is crystals in the joint space that cause inflammation and pain. In *fibromyalgia*, the problem is not the joint, but the muscles and ligaments. Each kind of arthritis is different and requires different medical treatment. However, the self-management techniques are very similar for most types of arthritis.

The table on pages 6-7 gives a quick overview of the three most common types of arthritis: rheumatoid arthritis, osteoarthritis, and fibromyalgia.

If you are interested in knowing more about these and other types of arthritis, read *Arthritis: A Take Care of Yourself Health Guide*, by Dr. James F. Fries (Cambridge, Mass.: Da Capo Press, 1999), or contact your local Arthritis Foundation or Arthritis Society for information.

## **Types of Arthritis**

Pathology	Rheumatoid arthritis	Osteoarthritis	Fibromyalgia
What happens	Inflammation of synovial membrane, bone destruction, damage to ligaments, tendons, cartilage, joint capsule.	Cartilage degeneration; bone regeneration (growth) may result in bone spurs.	Unknown. Accompanied by sleep disturbance and prolonged muscle contraction.
Joints affected	Symmetrical: wrists, knees, knuckles (both sides of body).	Hands, spine, knees, hips. May be one-sided.	Joints not affected. Certain tender points. Muscles, ligaments, tendons may be affected.
Features and symptoms	Swelling, redness, warmth, pain, tenderness, nodules, fatigue, stiffness, muscle aches fever.	Localized pain, stiffness; bony knobs of end joints of fingers; usually not much swelling.	Overall aching, morning stiffness, fatigue. Sleep disturbance.
Long-term prognosis	Less aggressive with time; deformity can often be prevented.	Less pain for some, more pain and disability for others; few severely disabled.	Usually improves slowly over time. Pain and fatigue may be disabling in some; most are not disabled.



<b>Pathology</b>	<b>Rheumatoid arthritis</b>	<b>Osteoarthritis</b>	<b>Fibromyalgia</b>
Age at onset	Adults in twenties to fifties, children approaching adolescence.	Forty-five to ninety; most of us have some features with increasing age.	Thirties to fifties.
Sex	75% female.	Males and females equally.	More frequently female.
Hereditiy	Familial tendency.	The form with knobby fingers can be familial.	Unknown at this time.
Tests	Rheumatoid factor (80%), blood tests, X-rays, examination of joint fluid.	X-rays.	Tender point exam, sometimes blood tests to exclude other conditions (thyroid tests, sedimentation rate).
Treatment	Reduce inflammation. Balanced exercise program, joint protection, weight control, relaxation, heat, sometimes medication and/or surgery.	Maintain activity level. Exercise, joint protection, weight control, relaxation, heat, sometimes medication and/or surgery.	Exercise, heat, relaxation, sometimes medication for pain and/or for enhancing sleep.

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## Chapter 2

### ***Rheumatoid Arthritis: Inflamed Joints***

Rheumatoid arthritis (RA) is more than just arthritis. Indeed, many doctors call it “rheumatoid disease” to emphasize its widespread nature. The name is trying awkwardly to say the same thing. *rheum-* refers to the stiffness, body aching, and fatigue that often accompany rheumatoid arthritis. People with RA often describe feeling much as though they have a virus, with fatigue and aching in the muscles, except that, unlike a usual viral illness, the condition may persist for many years.

About one half of one percent of the population has rheumatoid arthritis, about 20 million people around the world. Most of these people (about three-quarters) are women. The condition usually appears in middle life, in the forties or fifties, although it can begin at any age. Rheumatoid arthritis in children is quite different. Rheumatoid arthritis has been medically identified for about two hundred years, although bone changes in the skeletons of some Mexican Indian groups suggest that the disease may have been around for thousands of years.

Since RA is so common, and because it can sometimes be severe, it is a major international health problem. It can result in difficulties with employment and problems with daily activities and can put severe stress on family relationships. In its most severe forms, and without good treatment, it can result in deformities of the joints. Fortunately, most people with RA do better than this, and most can lead normal or nearly normal lives. Fear of rheumatoid arthritis, sometimes greatly exaggerated, can be as harmful as the disease itself.

In RA, the synovial membrane lining in the joint becomes inflamed. We don't have a good explanation as to why this inflammation starts, but the cells in the membrane divide and grow, and inflammatory cells come into the joint. Because of the bulk of these inflammatory cells, the joint becomes swollen and feels puffy or boggy to the touch. The increased blood flow that is a feature of the inflammation makes the joint warm. The cells release chemicals (called enzymes) into the joint space and the enzymes cause further irritation and pain. If the process continues for years, the enzymes may gradually digest the cartilage and bone of the joint, actually eating away parts of the bone.

This, then, is rheumatoid arthritis, a process in which inflammation of the joint membrane, over many years, can cause damage to the joint itself.

### **Features**

Swelling and pain in one or more joints, lasting at least six weeks, are required for a diagnosis of rheumatoid arthritis. Usually both sides of the body are affected similarly, and the arthritis is said

be “symmetrical.” Often there are slight differences between the two sides, usually the right side being slightly worse in right-handed people and vice versa. Occasionally the condition skips about in an erratic fashion. The wrists and knuckles are almost always involved. The knees and the joints of the ball of the foot are often involved as well, and any joint can be affected. Of the knuckles, those at the base of the fingers are most frequently painful, while the joints at the ends of the fingers are often normal.

Lumps, usually between the size of a pea and a moth-ball, may form beneath the skin. The *rheumatoid nodules* are most commonly located near the elbow at the place where you rest your arm on the table, but they can pop up anywhere. Each represents an inflammation of a small blood vessel. Nodules come and go during the course of the illness and usually are not a big problem. They tend to occur in people with the most severe kinds of RA. In rare cases, they become sore or infected, particularly if they are located around the ankle. Even more rarely, they form in the lungs or elsewhere inside the body.

Laboratory tests can sometimes help a doctor recognize rheumatoid arthritis. The *rheumatoid factor* or *latex fixation* is the most commonly used blood test. Although this test may be negative in the first several months, it is eventually positive in about 80% of people with RA. The rheumatoid factor is actually an antibody to certain body proteins and can sometimes be found in individuals with other diseases. Some doctors think that it is a way the body fights the disease; others think that it may play a role in causing the joint damage.

The *sed rate* is another frequently used blood test. This test’s full name is *erythrocyte sedimentation rate*; the name sometimes is abbreviated ESR. The test doesn’t help in diagnosis, but it does help to gauge the severity of the disease. A high sed rate (over 30 or so) suggests that the disease is quite active. The C-Reactive Protein (CRP) test also measures the amount of inflammation. The joint fluid is sometimes examined in rheumatoid arthritis in order to look at the inflammatory cells or to make sure that the joint is not infected with bacteria.

X-rays are not very helpful in the initial diagnosis of rheumatoid arthritis. It is unusual for changes to be seen in the bones or cartilage in the first few months of the disease, even when it is most severe. X-rays can help the doctor determine if damage to the bones or cartilage has occurred as the disease progresses. Some doctors like to get baseline X-rays to compare with later X-rays. Simple hand X-rays probably should be done in the first year of disease and every two or three years thereafter.

Most people with RA notice problems in parts of their bodies other than the joints themselves. Usually there are general problems such as muscle aches, fatigue, muscle stiffness (particularly in the morning), and even a low fever. Morning stiffness is often considered a hall-mark of RA and is sometimes termed the *gel phenomenon*. After a rest period or even after just sitting motionless for a few minutes, the whole body feels stiff and is difficult to move. After a period of loosening up, motion becomes easier and less painful. People often have problems with fluid accumulation, particularly around the ankles. Rarely, the rheumatoid disease may attack other body tissues, including the whites of the eyes, the nerves, the small arteries, and the lungs. Anemia (low red-blood-cell count) is quite common, although it is seldom severe enough to need any treatment. Some patients will develop *Sjögren’s*, or sicca syndrome, in which the tear fluids and the saliva dry up, causing dry eyes and dry mouth. This happens because the lacrimal (tear) glands and the salivary glands become involved in the rheumatoid process.

There can be unusual features that are due to the inflammation of the joint membrane. A *Baker cyst* can form behind the knees and may feel like a tumor. It is just the synovial sac full of fluid, but can extend down into the back of the calf and may cause pain. Or the fluid in the joint can become infected and require immediate treatment. Suspect infection if a single joint, usually a knee, becomes suddenly and severely worse.

Rheumatoid arthritis is one of the most complicated and mysterious diseases known. It is a challenge to patient and physician alike. Fortunately, the course of RA can be dramatically changed in most individuals. New treatment strategies are much more effective than the old ones. More so than with any other form of arthritis, RA requires you to develop an effective partnership with your doctor, as discussed in Chapter 17.

## **Prognosis (What Will Happen in the Future)**

Rheumatoid arthritis is the condition that most people think of when they hear the word *arthritis*. A common image that comes to mind is of a person in a wheelchair, with swollen knees and twisted hands. True, many such people have rheumatoid arthritis. On balance, rheumatoid arthritis is the most destructive kind of arthritis known. Erosion of the bone itself, rupture of tendons, and slippage of the joints can result in crippling. But most people with rheumatoid arthritis do very much better than this. Many of the serious problems can be prevented by good, early treatment.

Often it is hard for persons with RA and their relatives to appreciate that inflammation in even the worst forms of rheumatoid arthritis tends to lessen with time. The arthritis usually becomes less aggressive. The inflammation (synovitis) is less active and the fatigue and stiffness decrease. New joints are less likely to become involved after several years of disease. But even though the disease becomes less violent, any destruction of bones and ligaments that occurred in earlier years will persist. Thus, deformities usually will not improve, even though no new damage is occurring. Hence, it is important to treat the disease correctly in the early years so that the joints will work well after the disease inflammation subsides.

## **Treatment**

Treatment programs for RA are often complicated and can be confusing. In this section we give the broad outlines for sound management. But you need to work out with your doctor the combination of measures that is best for you. It has been said that the person who has himself for a doctor has a fool for a patient. In many areas of medicine, and for some kinds of arthritis, this is not true; you can do just as well looking out for yourself. But with rheumatoid arthritis, you do need a doctor. Indeed, with rheumatoid arthritis, we strongly believe that you should be seen early in the course of the disease by a specialist in arthritis, a rheumatologist. In this way, the critical early treatment can begin at the right time. Only rheumatologists are familiar with the latest and most effective RA treatments.

First, some common sense. Your RA may be with you, on and off, for months or years. The best

treatments are those that will help you maintain a life that is as nearly normal as possible. Often the worst treatments are those that offer immediate relief. They may allow joint damage to progress and may cause delayed side effects that ultimately make you feel worse. So you must develop some patience with the disease and with its management. You have to adjust your thinking to operate in the same slow time scale that the disease uses. You and your doctor will want to anticipate problems before they occur so that they may be avoided. The adjustment to a long-term illness, with the necessity to plan treatment programs that may take months to get results, is a difficult psychological task. This adjustment will be one of your hardest jobs in battling your arthritis.

*Synovitis* is the underlying problem. The inflammation of the joint membrane releases enzymes that very slowly damage the joint structures. Good treatment reduces this inflammation and stops the damage. Painkillers can increase comfort but do not decrease the arthritis. In fact, pain per se helps protect the joints by discouraging too much use. Therefore, in RA it is important to treat pain by treating the inflammation that causes the pain. By and large, pain relievers such as codeine, Percodan, Darvon, or Demerol must be avoided. (To learn more, read Chapter 20.)

The proper balance between rest and exercise is hard to understand. Rest reduces the inflammation and this is good. But rest also lets joints get stiff and muscles get weak. With too much rest, tendons become weaker and bones get softer. Obviously, this is bad. So moderation is the basic principle. You may help you to know that your body usually gives you the right signals about what to do and what not to do. If it hurts too much, don't do it. If you don't seem to have much problem with an activity, go ahead. As a rule, if you continue to have pain caused by exercise for more than two hours after exercising, you have done too much.

A particularly painful joint may require a splint to help it rest. Still, you will want to exercise the joint by stretching it gently in different directions to keep it from getting stiff. You will not want to use a splint for too long, or you may want to use it just at night. As the joint gets better, you will want to begin using the joint, gently at first, but slowly progressing to more and more activity. In general, favor activities that build good muscle tone, not those that build great muscle strength. Walking and swimming are better than moving furniture and lifting heavy weights, since tasks requiring a lot of strength put a lot of stress across the joint. And regular exercises done daily are better than occasional spurts of activity that stress joints that are not ready for so much exertion.

Common sense and a regular, long-term program are the keys to success. Should you take a nap after lunch? Yes, if you're tired. Should you undertake some particular outing? Go on a trip? You know your regular daily activity level. Common sense will help you answer most such questions. Full normal activity should be approached gradually, with a long-term conditioning program that includes rest when needed and gradual increases in activity during nonresting periods.

Physical therapists and occupational therapists can often help with specific advice and helpful hints. The best therapists will help you develop your own program for home exercise and will teach you the exercises and activities that will help your joints. However, don't expect the therapist to do your program for you. Your rest and exercise program cannot consist solely of formal sessions at a rehabilitation facility. You must take the responsibility to build the habits that will, on a daily basis, protect and strengthen your joints. It is important to start exercise and proper use of your joints before you have problems. These are good preventive measures.

Medications are required by almost all patients with rheumatoid arthritis, and often must be

continued for years. Great progress has been made recently with disease-modifying antirheumatic drugs (DMARDs), causing a virtual revolution in the treatment of rheumatoid arthritis (see Chapter 19). These crucial drugs should be prescribed early in the course of the disease. The most important rule now is “Don’t do too little, too late.” At present, the DMARD drugs are Plaquenil, Azulfidine, gold shots, oral gold (Ridaura), penicillamine, methotrexate, Imuran, leflunomide, minocycline, cyclosporin, and the cytokine treatments. More are under development. The great majority of patients with RA should be taking a DMARD or a combination of DMARDs at all times.

Less powerful anti-inflammatory drugs are similar to aspirin. Aspirin is a valuable drug when used as detailed in Chapter 18. Every patient with RA should become familiar with the uses of aspirin, which, used correctly, can be a good analgesic drug with an acceptable level of side effects. Aspirin variants, such as Disalcid and Trilisate, may better protect the stomach lining. Drugs roughly similar to aspirin are called *nonsteroidal anti-inflammatory drugs* (NSAIDs) and are also frequently used. Examples of such drugs are Lodine, Relafen, Motrin, Voltaren, Naprosyn, Indocin, and Feldene. The new COX-2 selective inhibitors are among the least toxic drugs on the stomach but may pose risks to the heart. There is increasing use of acetaminophen (Tylenol), which is not an anti-inflammatory drug but helps with pain and is quite safe. For more information on these drugs, see Chapter 18.

Drugs such as sulfasalazine (Azulfidine), auranofin (Ridaura), or hydroxychloroquine (Plaquenil) (page 298) are often used as the first DMARDs. Gold injections (page 295) are often very helpful and sometimes result in complete disappearance of the arthritis if used early enough. Methotrexate has become the most frequently used, and probably the best, DMARD. Penicillamine can also result in dramatic improvement. Azathioprine (Imuran), leflunomide (Arava), minocycline, and the cytokine treatments are also in this category.

Corticosteroids, most frequently prednisone, are strong hormones with formidable long-term side effects. Their use is controversial in rheumatoid arthritis; some physicians feel that they should almost never be used, while others use them only in very small doses, except in unusual circumstances.

See chapters 18, 19, and 20 for detailed discussions of individual drugs.

Surgery sometimes can restore the function of a damaged joint. Hip replacement, knee replacement, shoulder replacement, synovectomy of the knee, metatarsal head resection, and synovectomy of the knuckles are among the most frequent operations. These are discussed in Chapter 21.

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## Chapter 3

### *Osteoarthritis: Worn Cartilage*

Osteoarthritis (OA), also known as osteoarthrosis or degenerative joint disease (DJD), is the kind of arthritis that almost everybody gets. It is increasingly common with age, and, because of its relationship to the aging process, it is not as responsive to medical treatment as we might like. However, there are many things you can do for yourself to alleviate this disease. Fortunately, osteoarthritis is usually a much less severe form of arthritis than rheumatoid arthritis. The changes in the skeleton that occur with age are inevitable, and they cause symptoms in many people but severe symptoms in very few.

Osteoarthritis used to be thought of as the inevitable result of “wear and tear.” In fact, most activities with a lot of “wear” don’t seem to cause much “tear,” and authorities now recognize the need for exercise to strengthen the joints, both before and after signs of arthritis have developed. Exercise will very seldom harm someone with OA. On the other hand, being inactive can cause a great deal of harm.

The tissue involved in osteoarthritis is the cartilage. This gristle material faces the ends of the bones and forms the surface of the joint on both sides. Our ears and nose are also made of cartilage. Gristle is tough, somewhat elastic, and very durable. The cartilage, or gristle, does not have a blood supply, so it gets its oxygen and nutrition from the surrounding joint fluid. In this it is aided by being elastic and able to absorb fluid. When we use a joint, the pressure squeezes fluid and waste products out of the cartilage, and when the pressure is relieved, the fluid seeps back, together with oxygen and nutrients. Hence, the health of the cartilage depends on use of the joint. Over many years, the cartilage may become frayed and may even wear away entirely. When this happens, the bone surface on one side of the joint grates against the bone on the other side of the joint, providing a much less elastic joint surface. With time, the opposing bony surfaces may become polished, a process called *eburnation*. As this happens, the joint may again move more smoothly and cause less discomfort. This is one of the reasons it is important to continue to use painful joints.

The difference between the terms *osteoarthritis* and *osteoarthrosis* has to do with the question of inflammation. The suffix *-itis* denotes inflammation, and with osteoarthritis very little inflammation is to be found. Hence, some experts prefer the term osteoarthrosis, which does not imply inflammation. Otherwise, both words mean the same.

There are three common types of osteoarthritis. The first and mildest causes knobby enlargement of the finger joints. The end joints of the fingers become bony and the hands begin to assume the appearance we associate with old age. The other joints of the fingers may also be involved. This kind of arthritis (or arthrosis) usually causes little difficulty beyond the cosmetic. There may be some stiffness, and there can be some pain, particularly when the bony knobs are growing.

The second form of osteoarthritis involves the spine and is sometimes called *degenerative joint*

*disease*. Bony growths (spurs) appear on the spine in the neck region or in the lower back. Usually the bony growths are associated with some narrowing of the space between the vertebrae. This time the disk, rather than cartilage, is the material that becomes frayed. Changes in the spine begin early in life in almost all of us but cause long-term symptoms relatively seldom.

The third form of osteoarthritis involves the weight-bearing joints, almost always the hips or the knees. These problems can be quite severe.

It is possible to have all three kinds of osteoarthritis or any two of them, but often a person will have only one.

Individuals who have had fractures near a joint or have a congenital malformation at a joint seem to develop osteoarthritis in those joints at an earlier age. But, as noted, the usual description of the arthritis as “wear and tear” is not accurate. While excessive wear and tear on the joint can theoretically result in damage, activity helps the joint remain supple and lubricated, and this tends to cancel out the theoretically bad effects.

Careful studies of people who regularly put a lot of stress on joints (such as individuals who operate pneumatic drills or run long distances on hard paved surfaces) have been unable to show a relationship between these activities and the development of arthritis. Hence, intensive activity does not predispose you to arthritis any more than intensive activity predisposes you to heart disease. In fact, the very opposite may be true. On the other hand, injury to the joint, as in knee injuries in football players, may lead to osteoarthritis in the injured joint. Excess body weight can lead to OA of the hip and knee.

## Features

The bony knobs that form around the end joints of the fingers are called *Heberden's nodes*, after the British doctor who first described them. Similar knobs can be found in the middle joints of the fingers. Usually, the bony enlargement occurs slowly over a period of years and is not even noticed. In most cases, all of the fingers are involved more or less equally.

There is an interesting variation of osteoarthritis in which the bony swelling occurs over only three or four weeks in a single finger joint. The sudden swelling causes redness and soreness until the process is complete; then it stops hurting altogether. This syndrome is seen in women in their forties, earlier than the more usual form of osteoarthritis. These patients frequently have other family members with the same problem. This “familial” form of osteoarthritis doesn't really seem very much worse over the long run, but one joint after another may suddenly develop a bony knob over a short period.

Osteoarthritis of the spine does not cause symptoms unless there is pressure on one of the nerves or irritation of some of the other structures of the back. If a doctor tells you that you have arthritis of your spine, do not assume that any pain you feel is necessarily related to that arthritis. Most people with X-rays showing arthritis of the spine do not have any problem at all from the bone spurs seen on the X-ray; the pain is from some nearby structure such as a ligament or muscle.



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