The Arthritis Helpbook

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

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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 d not have the time or take the time to explain exercises or pain-management techniques to you enough detail to help you very much. Therefore, we hope this book will assist both you and yo physician. All of the advice and activities that we describe have been reviewed by many, mar doctors, physical therapists, occupational therapists, nutritionists, and nurses, including the entire sta of the Stanford Arthritis Center. They represent a sound program essentially the same as th recommended by most health authorities today. If you have particular questions please talk them ov with your doctor.

We would like you to feel that you are part of our cast of thousands. If you have comments o 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 yo who are just joining, a hearty welcome.

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

Part I

Understanding Those Aches and Pains

Chapter 1

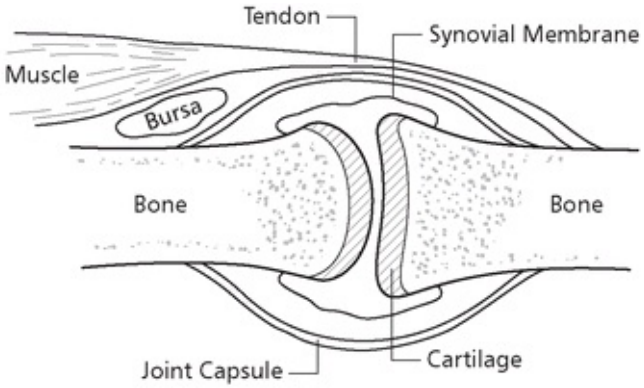
Arthritis: What Is It?

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

In order to understand how to work with your condition, it is necessary to know a little about it. fact, arthritis is not just a single disease. There are over 120 kinds of arthritis, all of which hav something to do with one or more joints in the body. Even the word *arthritis* is misleading. The *art* 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 arthritis, the joint is not inflamed. A better definition might be "problems with the joint, or th ligaments, tendons, and muscles near the joint." "Rheumatism" is a broader term that encompasses a 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 lik and what the various parts do.

A joint is a meeting of two bones for the purpose of allowing movement. It has the following s 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 yo 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 time 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 flui 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 ther 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 on or more of these parts. For example, when the synovial membrane becomes inflamed, this is tru 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*, th problem is chiefly *synovitis*, an inflammation of the synovial membrane. This inflammation must b reduced with medication in addition to your self-management program. In *ankylosing spondylitis*, th problem is an *enthesopathy*, an inflammation where the ligaments attach to the bone. Th inflammation also needs to be suppressed by medication, and the affected joints need to be regular and vigorously stretched. In *osteoarthritis*, the problem is a breakdown of the joint cartilage, but it ca be helped by exercise and proper use of your joints. In *gout*, the problem is crystals in the joint spac that cause inflammation and pain. In *fibromyalgia*, the problem is not the joint, but the muscles an ligaments. Each kind of arthritis is different and requires different medical treatment. However, th 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 arthriti rheumatoid arthritis, osteoarthritis, and fibromyalgia.

If you are interested in knowing more about these and other types of arthritis, read *Arthritis: A Tak Care of Yourself Health Guide*, by Dr. James F. Fries (Cambridge, Mass.: Da Capo Press, 1999), o 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.

Pathology	Rheumatoid arthritis	Osteoarthritis	Fibromyalgia
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.
Heredity	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.

Chapter 2

Rheumatoid Arthritis: Inflamed Joints

Rheumatoid arthritis (RA) is more than just arthritis. Indeed, many doctors call it “rheumato disease” to emphasize its widespread nature. The name is trying awkwardly to say the same thin *rheum-* refers to the stiffness, body aching, and fatigue that often accompany rheumatoid arthriti People with RA often describe feeling much as though they have a virus, with fatigue and aching 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 peop around the world. Most of these people (about three-quarters) are women. The condition usual appears in middle life, in the forties or fifties, although it can begin at any age. Rheumatoid arthritis children is quite different. Rheumatoid arthritis has been medically identified for about two hundr years, although bone changes in the skeletons of some Mexican Indian groups suggest that the disea 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 heal 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 ca result in deformities of the joints. Fortunately, most people with RA do better than this, and most ca lead normal or nearly normal lives. Fear of rheumatoid arthritis, sometimes greatly exaggerated, ca be as harmful as the disease itself.

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

This, then, is rheumatoid arthritis, a process in which inflammation of the joint membrane, ov 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 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 si being slightly worse in right-handed people and vice versa. Occasionally the condition skips about an erratic fashion. The wrists and knuckles are almost always involved. The knees and the joints of t ball of the foot are often involved as well, and any joint can be affected. Of the knuckles, those at t base of the fingers are most frequently painful, while the joints at the ends of the fingers are oft 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 vess Nodules come and go during the course of the illness and usually are not a big problem. They tend occur in people with the most severe kinds of RA. In rare cases, they become sore or infecte particularly if they are located around the ankle. Even more rarely, they form in the lungs or elsewhe inside the body.

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

The *sed rate* is another frequently used blood test. This test’s full name is *erythrocyte sedimentatio rate;* the name sometimes is abbreviated ESR. The test doesn’t help in diagnosis, but it does help te the severity of the disease. A high sed rate (over 30 or so) suggests that the disease is quite active. Th C-Reactive Protein (CRP) test also measures the amount of inflammation. The joint fluid sometimes examined in rheumatoid arthritis in order to look at the inflammatory cells or to make su 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 chang to be seen in the bones or cartilage in the first few months of the disease, even when it is most sever X-rays can help the doctor determine if damage to the bones or cartilage has occurred as the disea 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 themselve Usually there are general problems such as muscle aches, fatigue, muscle stiffness (particularly in t morning), and even a low fever. Morning stiffness is often considered a hall-mark of RA and sometimes termed the *gel phenomenon.* After a rest period or even after just sitting motionless for few minutes, the whole body feels stiff and is difficult to move. After a period of loosening up, motio becomes easier and less painful. People often have problems with fluid accumulation, particular around the ankles. Rarely, the rheumatoid disease may attack other body tissues, including the white of the eyes, the nerves, the small arteries, and the lungs. Anemia (low red-blood-cell count) is qui common, although it is seldom severe enough to need any treatment. Some patients will develo *Sjögren’s,* or sicca syndrome, in which the tear fluids and the saliva dry up, causing dry eyes and d mouth. This happens because the lacrimal (tear) glands and the salivary glands become involved in t 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 becom infected and require immediate treatment. Suspect infection if a single joint, usually a knee, becom suddenly and severely worse.

Rheumatoid arthritis is one of the most complicated and mysterious diseases known. It is challenge to patient and physician alike. Fortunately, the course of RA can be dramatically changed most individuals. New treatment strategies are much more effective than the old ones. More so tha with any other form of arthritis, RA requires you to develop an effective partnership with your docto 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 image that comes to mind is of a person in a wheelchair, with swollen knees and twisted hands. Tru many such people have rheumatoid arthritis. On balance, rheumatoid arthritis is the most destructiv kind of arthritis known. Erosion of the bone itself, rupture of tendons, and slippage of the joints ca result in crippling. But most people with rheumatoid arthritis do very much better than this. Many 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 th worst forms of rheumatoid arthritis tends to lessen with time. The arthritis usually becomes le aggressive. The inflammation (synovitis) is less active and the fatigue and stiffness decrease. Ne joints are less likely to become involved after several years of disease. But even though the disea becomes less violent, any destruction of bones and ligaments that occurred in earlier years wi persist. Thus, deformities usually will not improve, even though no new damage is occurring. Henc it is important to treat the disease correctly in the early years so that the joints will work well after th disease inflammation subsides.

Treatment

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

treatments are those that will help you maintain a life that is as nearly normal as possible. Often th worst treatments are those that offer immediate relief. They may allow joint damage to progress may cause delayed side effects that ultimately make you feel worse. So you must develop som patience with the disease and with its management. You have to adjust your thinking to operate in th same slow time scale that the disease uses. You and your doctor will want to anticipate problem before they occur so that they may be avoided. The adjustment to a long-term illness, with th necessity to plan treatment programs that may take months to get results, is a difficult psychologic 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 th very slowly damage the joint structures. Good treatment reduces this inflammation and stops th 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 b treating the inflammation that causes the pain. By and large, pain relievers such as codeine, Percoda 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 inflammatio and this is good. But rest also lets joints get stiff and muscles get weak. With too much rest, tendon become weaker and bones get softer. Obviously, this is bad. So moderation is the basic principle. may help you to know that your body usually gives you the right signals about what to do and what n to do. If it hurts too much, don't do it. If you don't seem to have much problem with an activity, g ahead. As a rule, if you continue to have pain caused by exercise for more than two hours aft exercising, you have done too much.

A particularly painful joint may require a splint to help it rest. Still, you will want to exercise th joint by stretching it gently in different directions to keep it from getting stiff. You will not want t use a splint for too long, or you may want to use it just at night. As the joint gets better, you will wa to begin using the joint, gently at first, but slowly progressing to more and more activity. In genera favor activities that build good muscle tone, not those that build great muscle strength. Walking an swimming are better than moving furniture and lifting heavy weights, since tasks requiring a lot strength put a lot of stress across the joint. And regular exercises done daily are better than occasion sprees 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 na after lunch? Yes, if you're tired. Should you undertake some particular outing? Go on a trip? Yo know your regular daily activity level. Common sense will help you answer most such questions. Fu normal activity should be approached gradually, with a long-term conditioning program that includ rest when needed and gradual increases in activity during nonresting periods.

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

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

continued for years. Great progress has been made recently with disease-modifying antirheumat drugs (DMARDs), causing a virtual revolution in the treatment of rheumatoid arthritis (see Chapt 19). These crucial drugs should be prescribed early in the course of the disease. The most importa rule now is “Don’t do too little, too late.” At present, the DMARD drugs are Plaquenil, Azulfidin gold shots, oral gold (Ridaura), penicillamine, methotrexate, Imuran, leflunomide, minocyclin cyclosporin, and the cytokine treatments. More are under development. The great majority of patien 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 use as detailed in Chapter 18. Every patient with RA should become familiar with the uses of aspiri which, used correctly, can be a good analgesic drug with an acceptable level of side effects. Aspir variants, such as Disalcid and Trilisate, may better protect the stomach lining. Drugs roughly simil to aspirin are called *nonsteroidal anti-inflammatory drugs* (NSAIDs) and are also frequently use Examples of such drugs are Lodine, Relafen, Motrin, Voltaren, Naprosyn, Indocin, and Feldene. Th new COX-2 selective inhibitors are among the least toxic drugs on the stomach but may pose risks the heart. There is increasing use of acetaminophen (Tylenol), which is not an anti-inflammatory dru 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 (Plaqueni (page 298) are often used as the first DMARDs. Gold injections (page 295) are often very helpful ar sometimes result in complete disappearance of the arthritis if used early enough. Methotrexate h become the most frequently used, and probably the best, DMARD. Penicillamine can also result dramatic improvement. Azathioprine (Imuran), leflunomide (Arava), minocycline, and the cytokin treatments are also in this category.

Corticosteroids, most frequently prednisone, are strong hormones with formidable long-term sid effects. Their use is controversial in rheumatoid arthritis; some physicians feel that they shou almost never be used, while others use them only in very small doses, except in unusu 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 replacemen shoulder replacement, synovectomy of the knee, metatarsal head resection, and synovectomy of th knuckles are among the most frequent operations. These are discussed in Chapter 21.

Chapter 3

Osteoarthritis: Worn Cartilage

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

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

The tissue involved in osteoarthritis is the cartilage. This gristle material faces the ends of th bones and forms the surface of the joint on both sides. Our ears and nose are also made of cartilag Gristle is tough, somewhat elastic, and very durable. The cartilage, or gristle, does not have a bloo supply, so it gets its oxygen and nutrition from the surrounding joint fluid. In this it is aided by bein elastic and able to absorb fluid. When we use a joint, the pressure squeezes fluid and waste produc out of the cartilage, and when the pressure is relieved, the fluid seeps back, together with oxygen an nutrients. Hence, the health of the cartilage depends on use of the joint. Over many years, the cartilag may become frayed and may even wear away entirely. When this happens, the bone surface on on side of the joint grates against the bone on the other side of the joint, providing a much less elast joint surface. With time, the opposing bony surfaces may become polished, a process calle *eburnation.* As this happens, the joint may again move more smoothly and cause less discomfort. Th 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 inflammation. The suffix *-itis* denotes inflammation, and with osteoarthritis very little inflammatio is to be found. Hence, some experts prefer the term osteoarthrosis, which does not imp inflammation. Otherwise, both words mean the same.

There are three common types of osteoarthritis. The first and mildest causes knobby enlargement the finger joints. The end joints of the fingers become bony and the hands begin to assume th appearance we associate with old age. The other joints of the fingers may also be involved. This kin of arthritis (or arthrosis) usually causes little difficulty beyond the cosmetic. There may be som 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 joi*

disease. Bony growths (spurs) appear on the spine in the neck region or in the lower back. Usually th bony growths are associated with some narrowing of the space between the vertebrae. This time th disk, rather than cartilage, is the material that becomes frayed. Changes in the spine begin early in li 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 th 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 wi have only one.

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

Careful studies of people who regularly put a lot of stress on joints (such as individuals who opera pneumatic drills or run long distances on hard paved surfaces) have been unable to show a relationsh between these activities and the development of arthritis. Hence, intensive activity does n predispose you to arthritis any more than intensive activity predisposes you to heart disease. In fac the very opposite may be true. On the other hand, injury to the joint, as in knee injuries in footba players, may lead to osteoarthritis in the injured joint. Excess body weight can lead to OA of the hip knee.

Features

The bony knobs that form around the end joints of the fingers are called *Heberden’s nodes,* after th British doctor who first described them. Similar knobs can be found in the middle joints of the finger Usually, the bony enlargement occurs slowly over a period of years and is not even noticed. In mo 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 thr or four weeks in a single finger joint. The sudden swelling causes redness and soreness until th process is complete; then it stops hurting altogether. This syndrome is seen in women in their fortie earlier than the more usual form of osteoarthritis. These patients frequently have other fami members with the same problem. This “familial” form of osteoarthrosis doesn’t really seem ve much worse over the long run, but one joint after another may suddenly develop a bony knob over short period.

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