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GETTING THE SUPPORT YOU NEED

by Nicola Davies, PhD

Needing support is part of being human, especially when facing life's many challenges. If you count arthritis among the challenges you face, your everyday activities may have become painful, working or looking after your family may be difficult, and your personal relationships may be suffering. In situations like these, you could almost certainly benefit from some support, but the exact type of support that would benefit you the most will depend on the particulars of your circumstances.

Fortunately, there are many ways to access support of many kinds. This article discusses the various kinds of support people with arthritis may find helpful, as well as where and how to get that support.

Informational support

Part of what can make living with arthritis difficult is not knowing what's causing your symptoms or what you can do about them. Fortunately, the medical community has spent years developing a clearer picture of the mechanisms behind arthritis and what helps to keep symptoms under control. Getting more information about your condition starts with talking to your health-care provider.

Your health-care provider. It's important to ask your doctor to explain your diagnosis and your treatment plan so that you know what's going on. Write down specific questions before your appointments, and take notes (or have a friend or family

member take notes) so you can refer to the information later. Your doctor may also be willing to write down key points or instructions for you. Or he may have printed patient education materials for you to take home and read.

If you're not sure what to ask, the Agency for Healthcare Research and Quality provides lists of sample questions that it recommends asking, including "What are my treatment options?" and "Do I need to change my daily routine?" You can access these lists by visiting www.ahrq.gov and clicking on "Questions to Ask Your Doctor" under "For Patients & Consumers," or by calling (301) 427-1364.

Online resources. Information about arthritis and other medical conditions is also easily found on the Internet, though caution is required when accessing information online. Many things published online are not supported by clinical research, and some are just plain wrong. For reliability, try to stick to government sites such as PubMed or MedlinePlus, as well as sites associated with a university, hospital, medical journal, or other well-known, authoritative organization, such as WebMD, the Arthritis Foundation, or the Mayo Clinic.

Medication information. About 1.5 million negative reactions to medicines occur as a result of an error each year in the United States. Taking multiple medicines, as many people with arthritis do, puts you at an increased risk. One way to lower your risk is to ask either your doctor or your pharmacist to review all of the prescription medicines, over-the-counter



BenefitsCheckUp, a free service from the National Council on Aging, can help you find government programs for which you may be eligible.

(OTC) drugs, and supplements you are taking to look for possible interactions or other problems. For example, sometimes people don't realize they are supposed to stop taking one drug when their physician prescribes another for the same purpose. Sometimes people take two drugs containing the same ingredient (such as acetaminophen) without realizing it and end up taking more than is desirable. A review would find these types of problems.

If you fill all of your prescriptions at one pharmacy, the pharmacist should have access to an electronic list of everything you're taking, except for OTC drugs and supplements. You can also simply bring all of your containers of prescription and nonprescription medicines with you to a doctor appointment and ask your doctor to look them over.

Many people find it helpful to maintain their own written list of medicines with the doses they take and the time(s) of day they take them. If one of your friends or family members is handy with a computer, you could ask him to create an electronic list for you that you (or he) could easily update as your treatment regimen changes. You can then share this list with your health-care providers or a loved one who wants to help you manage your arthritis.

Self-management training. Self-management training is a kind of informational support that can help people with arthritis learn how to take care of themselves and their arthritis. The most well-known training program is the Arthritis Self-Management Program developed by Dr. Kate Lorig at the Stanford University School of Medicine. The training comprises one two-hour workshop every week

for six weeks and covers topics such as coping techniques, managing symptoms, using medication appropriately, communicating effectively, making informed treatment decisions, and developing problem-solving skills. Research has demonstrated that such training can lead to reduced pain and disability, improved quality of life, and the reduced use of health-care services.

Better Choices, Better Health (available at www.restartliving.org) is an online version of Stanford's Arthritis Self-Management Program. It focuses on the same skills as the in-person program and allows you to participate at times that fit into your schedule.

For in-person self-management training, ask your doctor where you can find a program near you. You may also be able to find more information by contacting your local Arthritis Foundation chapter online at www.arthritis.org or by calling (800) 283-7800.

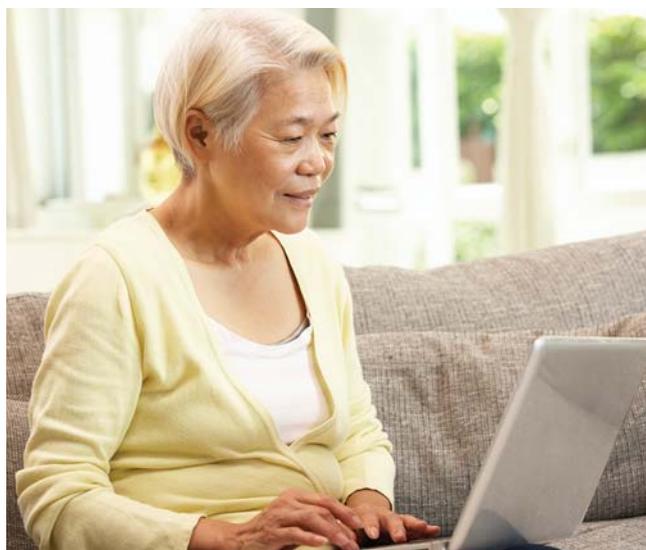
Classes, workshops, and events. Many hospitals and other health organizations offer free or low-cost lectures or classes on various health issues and chronic conditions. Check with hospitals near you and with your local Arthritis Foundation chapter to find educational opportunities in your area.

Financial support

Some charities and other groups offer financial support to people with a chronic condition who cannot afford all of their treatment costs or living expenses. Many of these organizations operate locally, so ask your health-care provider if he knows of any such resources in your area. The National Organization for Rare Disorders offers a list of groups that may be able to help you pay for certain services or pharmaceutical products. Visit www.rarediseases.org and click on "Rare Disease Information," then on "Other Resources and Tools." Your local Arthritis Foundation chapter may also be able to help.

There are also many government programs that may be able to help you pay for your medicines, or offset the costs of other essentials such as groceries and home heating. The BenefitsCheckUp, a free service from the National Council on Aging, can help you find government programs for which you may be eligible. Visit www.benefitscheckup.org or call (202) 479-1200 to learn more. You can also check for government programs that may be able to help you by going to www.benefits.gov, or by calling (800) 333-4636.

Many pharmaceutical companies have patient





assistance programs (PAPs) to help people afford the medicines they make. PAPs are particularly helpful—and in fact may only help you—if the drug you need is not covered by your insurance. Visit www.rxassist.org to check if a drug you take has a PAP associated with it and to get a summary of the PAP's eligibility requirements. You can also contact the drug company directly to see if it has a program.

Social support

Supportive personal relationships are those that let you know people care about you and value you. While social support may involve practical support—such as picking the kids up from sports practice, cooking a meal, or helping with household chores—sometimes, knowing that there is someone who is happy to see you and hear about your day can help just as much.

Oddly, it may feel easier to talk about your arthritis with a doctor you barely know than with a friend or partner. It's not uncommon to worry about seeming overly dependent, and you may feel that letting yourself “be more vulnerable” around people you know well is the last thing you want to do. But opening up to the people around you, talking about your experiences, and telling them what they can do to help can lift some of the burden of living with a chronic condition, especially the burden that comes with feeling that you're doing it all on your own. Here are some tips for maintaining good, supportive relationships with the people in your life.

Spouse or partner. If you're married or in a relationship, you might try to protect your partner from the negative effects of your arthritis or worry that your condition will make you less attractive. But acting as though nothing is wrong and denying yourself help may only make things worse. If you are open with your partner about the challenges arthritis creates,

the two of you can face those challenges together.

Your partner is probably eager to make you more comfortable. But he may not know what you need, even if it seems obvious to you. If he has to guess, he is likely to fail to offer the help you want, and he may also try to provide “help” you don't want or need. So be open and specific about the help you need (and don't need), and your significant other will be better equipped to make your life easier.

Also, be sure to encourage your partner to express openly and honestly how your arthritis is affecting him. Communicating clearly and listening patiently leads to understanding, which in turn lays the foundations for mutual support and a stronger bond.

Friends. Although your arthritis shouldn't be the only thing you talk about, letting your friends know about how your condition affects you isn't complaining: It's sharing part of your life with them, which is exactly what friends do. True friends will make an effort to accommodate your needs. If you feel too tired to go out one day, let your friends know you need to reschedule. If you're honest about why you can't make it, your friends will know you aren't just avoiding them. Also, try suggesting activities you can do easily and at times when you're likely to have the energy to do them.

Employers and colleagues. If you decide to tell people at your workplace about your arthritis, they may be able to help in a variety of ways. For example, your manager may be able to offer you more flexibility in your working hours or tasks. You might also be able to get changes made to your work environment, such as having your desk moved to a more convenient location or getting an ergonomically-designed chair. Working from home a few days a week may also be a way to save yourself the stress of commuting to and from your job.

While you should be clear about the help you need to stay productive, remember to also emphasize the things you can still do well and the ways in which you will continue to contribute.

Support groups. Arthritis can be an isolating condition, but support groups provide a circle of peers who understand what you're going through because they are going through it too. In addition to advice, encouragement, and tips on managing your condition, support groups can give you a sense of belonging in a world that might make you feel “different” because of your condition. Research has found that programs that incorporate peer support can lead to improved mood and better coping skills. Support groups also give you an opportunity to use your experiences with arthritis and the knowledge you've gained to help other people with the condition, which can feel immensely empowering.

The most useful support groups are likely to be

those whose members have had similar experiences to your own. The kind of arthritis you have, how old you are, and whether you're a man or a woman are all important factors to consider when choosing a group.

In addition to traditional, in-person support groups, there are many support groups that make their services and resources available online. For example, you can find supportive online communities at <http://community.arthritis.org>, <http://exchanges.webmd.com>, and www.facebook.com/RAChicks.

You don't need to be the most vocal member of a group to get something out of it. A study published in *The Journal of Medical Internet Research* found that so-called "lurkers"—people who read comment threads but never posted on them—drew benefits from an online support group similar to those drawn by the people who posted.

Other support organizations. Many other organizations exist to help people with arthritis. For example, the Arthritis Foundation funds arthritis research, helps promote a sense of community among people

with arthritis, and advocates to lawmakers on behalf of people with the condition. The Arthritis Foundation has also developed exercise programs specifically designed for people with arthritis—including a walking program, an aquatic fitness program, and a tai chi program—which they say have been shown to provide such benefits as decreased pain and improved flexibility. You can participate in the Arthritis Foundation's fitness programs in a class setting with a certified instructor or at home through the use of a guidebook or DVD. To learn more and to find your local Arthritis Foundation chapter, visit www.arthritis.org or call (800) 283-7800.

You can also start your own group. Starting a neighborhood walking group, for example, is easy to do and a great way to contribute to your community while giving yourself more incentive to stick to a positive lifestyle change and improve your health. **Psychotherapists.** There are a range of psychotherapies that can help you cope with the emotional impact of arthritis. Cognitive-behavioral therapy (CBT) is one form of psychotherapy that many people with arthritis have found particularly helpful. CBT often focuses on relaxation, problem-solving, and positive thinking. Addressing the emotional effects of the condition can often have a positive effect on your physical well-being.

TIPS FOR SEEKING SUPPORT

Ironic as it may sound, asking for help when you need it is a crucial part of staying self-reliant and independent. But asking for help is also a skill few of us are taught. Here are some do's and don'ts for getting the help you need.

Do:

- Observe the recurring cycles of your arthritis flares, so that you can anticipate times when you might need more help.
- Consult your health-care provider regularly.
- Be extra careful if you have other medical conditions. Approximately 80% of people with rheumatoid arthritis also have one or more other conditions. Managing the different medicines needed for a variety of conditions while avoiding side effects and drug interactions can be difficult and is one area where support is particularly fundamental.
- Familiarize yourself with your insurance coverage so you know what benefits you're entitled to.

Don't:

- Wait for pain or other symptoms to become unbearable before seeking help.
- Make treatment decisions without the advice of a qualified medical professional.

Mutual support

Take some time to think about the types of support you would welcome in your life. Perhaps you need help with particular tasks, such as cleaning the house or running errands. How about having someone to spend time with on those days when you need a little extra encouragement? Don't restrict your thinking. Make a list of all of the support you would ideally have if you could. Be as specific as possible; this will help you to know how to get what you want, and it can also help others to know what they can do to support you.

Asking for help can feel difficult, but it may make the task a bit easier to remember that everyone needs help and support at times. Your having arthritis doesn't mean that you can't also provide support to your friends, family members, and others with arthritis. In fact, it may make you better able to do so, since you know so well the value of a friendly ear, an encouraging word, or a helpful piece of information at just the right time. □

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