

Rheumatoid arthritis: A guide for caregivers

We've developed this guide to help you understand rheumatoid arthritis and support you on your care journey by sharing practical ways you can live life to the fullest while caring for a loved one with rheumatoid arthritis.





Caring for someone with rheumatoid arthritis (RA)

Whether your loved one has been recently diagnosed with rheumatoid arthritis (RA) or has been living with RA for some time, this unpredictable disease will impact not only their daily life and wellbeing, but also yours as a caregiver.

Rheumatoid arthritis is an autoimmune disease that commonly affects joints in the hands, wrists, and feet. In people with RA, the immune system mistakenly sends inflammation to their own healthy joints; when the lining of the affected joint becomes inflamed, the person experiences pain and swelling, reduced mobility, and physical weakness.

RA can also affect other tissues throughout the body and cause problems in organs such as the lungs, heart, and eyes. It is a chronic condition that may require around-the-clock care.

As a caregiver, it's important to know that there are resources and strategies to support you as you manage the demands of this role.



Symptoms of rheumatoid arthritis (RA)

Living with RA isn't easy. Your loved one will experience flares—times when symptoms get worse—as well as remission periods when the symptoms get better. They may experience some or all of these RA signs and symptoms:

- Pain or stiffness of multiple joints
- “Gelling”, or stiffness of joints, especially in the morning, that lasts an hour or more
- Warmth or redness over joints
- Reduced ability to move the joints such as difficulty making a fist, twisting objects, opening objects, or climbing stairs
- Fever, fatigue, weight loss, or decreased appetite
- Lumpy growths that form under the skin, most commonly on the elbows, hands, or feet



— Understand the symptoms of rheumatoid arthritis to know what to expect



Recognizing the signs of caregiver burnout

RA is a chronic and disabling disease that can lead to your loved one becoming physically and psychologically dependent on you.

As a caregiver, you may be so focused on their needs that you don't realize that your own health and wellbeing are suffering.

Throughout your journey, it's important to recognize the following signs of caregiver burnout and talk to a doctor and seek out support before you get to the point where you feel overwhelmed.

Be mindful of these signs of caregiver burnout:

- 1 Feeling **overwhelmed** or constantly worried
- 2 Feeling **tired** often
- 3 Getting too much **sleep** or not enough sleep
- 4 Gaining or **losing weight**
- 5 Becoming easily **irritated** or **angry**
- 6 **Losing interest** in activities you used to enjoy
- 7 Feeling **sad**
- 8 Having **frequent headaches**, bodily **pain**, or other **physical problems**
- 9 **Abusing alcohol or drugs**, including prescription medication



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Ask for support
before you feel
overwhelmed.



The best way to avoid burnout is to have the support of others.



Avoiding burnout and seeking support

The person with RA needs you to be a healthy care partner, so it's important to make time to look after your own mental health and strengthen your relationship with your loved one.

Take care of yourself

Make time to exercise, eat healthy foods, stay hydrated, and get enough sleep. The stress of caregiving can lead some people to develop or increase unhealthy habits, or to abuse alcohol or drugs, including prescription medication. If you need help making healthy lifestyle choices, reach out to a professional for support.

Nurture your relationship

Talk openly with your loved one about guilt, anger, or fears about RA. It's important to feel that you are equals, and not just a caregiver and patient.

Focus on having positive interactions and nurturing the relationship you had before you became their caregiver. Sharing a meal, watching a favourite TV show, or chatting about something unrelated to RA are great ways to stay connected.

Acknowledge your limits

Pay attention to your emotional and mental health needs, which can be impacted by your role as a caregiver. It's important to know you don't have to tackle everything alone; if you are having trouble coping, talk with your doctor or counselor, or seek out a caregiver support group or online caregiver support resources.

Ask for help

Don't hesitate to reach out to your network of family members, close friends, or neighbours to help with caregiving tasks. **Tip:** Make a list of easy tasks someone else can take on once in a while, such as cooking a meal, picking up a prescription, or driving your children somewhere when necessary. When someone asks you how they can help, be ready to accept their offer and give them a specific chore that they can do for you.

Check employer benefits

Find out if your loved one's insurance covers a home health aide—and use it to arrange support for tasks such as meal preparation, transportation to appointments, and household chores.

Your employer may also offer a plan that helps families who are caring for loved ones.



Living with rheumatoid arthritis (RA)

People with RA may experience pain, unsteadiness, and deformity that can make it difficult for them to execute daily tasks, which means your role as a caregiver may be a demanding, around-the-clock job.

It's common for people with RA to have stiff and painful joints in the morning, making it difficult for them to get up and start the day. As the disease progresses, everyday chores like cooking, laundry, cleaning, and garden work, as well as recreational activities, can become a challenge. They may also have to give up driving if the RA impacts their ability to operate a vehicle safely.

In addition to everyday life and work, RA also affects relationships and sexuality. The disease may have an impact on your individual roles, the division of chores in the household, mutual plans, and leisure activities you can enjoy together.

In response to the limitations that RA imposes on your loved one, you as a caregiver may need to take on some or all of the following roles:

- Day-to-day **practical assistance**
- Social **support**
- Understanding and adhering to **treatment plans**
- Keeping track of **appointments**
- **Managing** other aspects of life, such as transportation and budgeting



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Talk to your healthcare provider about strategies to help you manage.

In addition to assisting with physical tasks, there are many ways you as a caregiver can support to your loved one living with RA.



Strategies for caregivers

Here are some tips to help you navigate your care journey:



Advocate for your loved one

Get involved and work together with their healthcare team to develop a treatment plan. The goals of RA treatment are to: stop or reduce inflammation to the lowest possible level, relieve symptoms, prevent joint and organ damage, improve function and overall well-being, and reduce long-term complications.



Manage their medication

Keep a list of all over-the-counter and prescription drugs that your loved one takes, including what each does, when to use it, and when to refill it. People living with RA often take multiple medications; it is important to keep a current list and take it to every appointment. There are digital apps for your smart phone or tablet that can help you keep track of medications and provide reminders when they need to be refilled.



Encourage physical activity

Help your loved one lower pressure on their joints and boost their overall health by encouraging them to do low-impact aerobic activities such as walking and exercises to improve muscle strength.*



Arrange physical or occupational therapy

Seek out a physical or occupational therapist who can help your loved one find activities that are the best fit for them, and at the level or pace that provides the most benefit.



Encourage rest

Recognize when your loved one needs to scale back on physical activity. Rest will help when the disease flares and a joint becomes inflamed, or when they feel tired. At these times, suggest they do gentle range-of-motion exercises, such as stretching, which helps keep the joint flexible.



Support emotional needs

Sometimes, all you need to do is listen when your loved one needs to express their emotions to experience relief. You don't always have to solve their problems; it can help just to be attentive and sympathetic.



Be prepared

Make an emergency plan so you know what to do if your loved one is experiencing a flare, an unusual symptom, or a reaction to one of their medications. If they are taking a biologic medication that needs to be refrigerated, consider getting a back-up generator in case the power goes out.



Take time for yourself

As a caregiver, you need time for your interests outside of caregiving. Take the time and keep up with things that are important to you—before you become exhausted. This will give you strength to continue and help prevent feelings of loneliness and isolation.

**For more information about physical activity, visit these resources: [14 Ways to Work Out with Arthritis](#), [Exercise and Arthritis](#)*



Ask for help

You may be a spouse, partner, child, family member or friend providing care on a regular basis to someone with rheumatoid arthritis. Your role as a caregiver is an important one.

Accept that you may need help with everyday household and caregiving tasks. Family and friends can be vital members of your circle of care. Tell your friends and family that you need their help. Most people want to help, but they don't know what you need. Friends often worry that offering help might seem intrusive, so let them know their help is welcome. Don't hesitate to be specific with your support needs.

Keep a list of projects, errands and services that others can do. Then, the next time someone offers to help in some way, you can guide them on how to best support you.

People with rheumatoid arthritis often need significant help with daily care. In many cases, family and friends may not be able to do it alone, and additional help may be needed. Talk with your medical team or your local Arthritis Society to determine what additional professional care is available. This additional help may be covered by the government or private insurance.



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Additional resources

Huddol

Visit the largest online caregiver support network in Canada, where you can learn, share and connect with experts and other caregivers.

huddol.com

Arthritis Society

The Arthritis Society is a national health charity, fueled by donors and volunteers, with a vision to live in a world where people are free from the devastating effects that arthritis has on lives.

Arthritis.ca

Arthritis Consumer Experts

A national organization that provides free, science-based information and education programs in both official languages to people with arthritis. ACE serves people living with all forms of arthritis by helping them take control of their disease and improve their quality of life through education and empowerment.

JointHealth.org

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