



# Self-Advocacy Guide



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## INTRODUCTION

Effectively managing the symptoms of arthritis can be a challenge. This resource will provide you with information and strategies to help you take an active role in your treatment to ensure you are getting the care you need. It's about being your own advocate. Find out what actions you can take towards creating a treatment plan that works for you and that helps you lead a healthier, fuller life.

## PART 1: TAKING AN ACTIVE ROLE IN YOUR TREATMENT PLANNING

### Learn about your condition

Patient empowerment begins as we educate ourselves about our own health. Ensuring that your treatment needs are met means taking action to learn about your condition. This will help you to communicate more effectively with your healthcare team and to approach decision-making from an informed perspective.

The Arthritis Society is committed to helping you take an active role in your treatment planning by providing you with:

- Reliable and up-to-date disease information online and in your community.
- [Online interactive modules](#).
- A connection to other individuals living with arthritis through our community events and group programs.

To learn more about your particular form of arthritis, visit the Arthritis Society's resource at [https://arthritis.ca/about-arthritis/arthritis-types-\(a-z\)](https://arthritis.ca/about-arthritis/arthritis-types-(a-z)).

### Set goals for your treatment

For now, there is no cure for arthritis, so treatment focuses on the best way to manage the disease and its symptoms. Your unique treatment goals will change as your disease and life changes.

It is a good idea to write down your treatment goals and update them as needed. Some may be related to day-to-day activities, like being able to walk a certain distance, or having more energy on the weekends to do social activities. Other goals may be specifically related to your symptoms, such as experiencing fewer flare-ups.

Take a moment to think about your treatment goals, big and small. Make a list or use our printable **Goal Tracker** (Appendix A). Keep the Goal Tracker handy, such as on your fridge door or a bulletin board so you can be reminded of your goals and can track your progress more easily.

## Prepare for an appointment

Before an appointment, complete the **Healthcare Appointment Checklist** (Appendix B). This checklist will help you prepare for an appointment and ensure that you and your healthcare professional have all the information needed to understand your condition, make the best use of the available time, and make the best decisions together for your treatment plan. While not everything on the checklist will be necessary for each appointment, it's good practice to review your checklist prior to meeting with a member of your healthcare team and to follow through on any relevant items. This list may be particularly helpful if you are meeting with someone for the first time. Over time, you may decide to alter the list as your circumstances change and you learn more about your condition.

## Track your symptoms

In most cases, your symptoms will need to be described to members of your treatment team. Tell them how the symptoms affect your day-to-day activities and overall life. As you might have experienced, this isn't always easy, as each day's activities can change your symptoms. Keep track of them so you can effectively communicate their impact and understand what contributes to making them worse or better. Start the process of tracking your symptoms well in advance of your appointment – it will be hard to remember if you try to write everything down the day before.

Our printable **Daily Symptom Tracker** (Appendix C) is a simple tool to help you with this. Once you're familiar with the tracker it will only take a minute or two to fill it out each day. It may be useful to print and share the information with your treatment team member during your appointment. Keep in mind that not all members of your treatment team will need all the information you prepare.

NOTE: The daily symptom tracker is not meant to provide you with a diagnosis; it is a tool to help you to keep track of information about your arthritis, related symptoms and treatments to share with members of your treatment team.

## Prepare your questions

Keep in mind that healthcare professionals have limited time to listen to your story. Review materials such as your **Goal Tracker** (Appendix A), **Appointment Checklist** (Appendix B) and **Daily Symptom Tracker** (Appendix C) to help determine the most important issues. Try to sum them up in 30 seconds or less. An example of this is, "I've been experiencing more frequent flare ups since our last appointment. I want to explore what we can do to help with this."

If you have many questions or concerns and you feel like you'll need more time during an appointment, let the receptionist know when booking it. Most healthcare professionals have their own ways to accommodate longer appointments from time to time, but will need to know in advance.

For a printable list of important questions to ask, visit our **Key Questions for Your Healthcare Professional** (Appendix D) resource.



## Important questions to ask:

Whether it's your first appointment or one of many, here are some questions to consider asking. Not every question will apply to every appointment or type of healthcare professional. Review these questions and use them when necessary.

**What did the test result show?** Your specialists and sometimes your family doctor will order tests to rule out various conditions and to help make a diagnosis. Many forms of arthritis can be challenging to diagnose. Ask your doctor what your test results mean for you and your treatment plan. You can ask for a printed copy of any blood test results or imaging study reports, but you may be required to pay the costs of making these copies. Some labs will provide you with online reports from your tests.

**When should I notice improvement from my current treatment?** After diagnosis, your doctor will prescribe medication or recommend a treatment regimen. While every patient responds differently to treatment, your doctor will be able to give you an idea of what to expect. Some medications, such as those used to manage pain symptoms, act relatively quickly. Others are known to take longer to make a difference you can feel.

Your doctor should be able to explain:

- the goal of your treatment;
- when to expect some positive results; and
- how long it might take to determine whether the treatment is a good fit for you.

To learn more about medications used for the treatment of arthritis, visit the [Arthritis Society's Medication page](#).

**If my current treatment doesn't work, what are my options?** If you are someone who likes to think ahead, you may find comfort in knowing what comes next. It allows you to mentally prepare. Visit the [Your Patient Journey webpage](#) for more information.

**In addition to my prescribed medications, what should I be doing to help manage my arthritis?** Complementary or alternative treatments can help you manage your symptoms. Discuss these with your doctor to determine what approach might be best for you.

Lifestyle changes, (such as [weight management](#), [nutrition](#), [exercise](#), [physical or occupational therapy](#)) and self-management tools (such as [mindfulness](#), [meditation](#), [heat/cold](#), or [assistive devices](#)) can be useful components of your treatment plan.

Tap into your treatment team member's experience and ask for suggestions above and beyond medications. Be specific when you discuss what aspects of arthritis bother you the most and how it affects your ability to perform important daily activities.

**What does my future hold?** Arthritis is a lifelong condition and you will notice changes periodically. Your doctor can help you to understand what to expect in the near future and longer-term with regard to potential "flare ups", control of the disease and its progression, as well as possible future treatments.

Source: adapted from <http://arthritis.about.com/od/buildyourhealthcareteam/fl/6-Questions-Arthritis-Patients-Must-Ask-Their-Doctor.htm>

## Communicate with your treatment team

Effective communication is key to getting the care you need. Think of your last appointment: did you feel satisfied when you left the appointment? Don't be afraid to tell your healthcare professional what's on your mind. Your treatment team is there to meet YOUR needs. Open communication can ensure that they understand your concerns as well as how to best address them.

When meeting with your treatment team members, you should feel comfortable discussing health issues, sharing treatment goals and asking questions. It's important to be honest if you are uncomfortable with any decisions or if you don't understand information provided. If a treatment isn't working, rather than stopping the treatment, discuss alternatives with your treatment team member. To learn more about the various types of healthcare professionals that may be part of your arthritis treatment team, please visit [Your Treatment Team webpage](#).

## During and after your appointment

**Make sure to give the full story.** Provide as much information as you can about your current condition, focusing on key points to keep your explanation brief. Describe whether there was a trigger that led to your symptoms or if there have been any changes recently.

### **Be honest**

If there is some aspect of your treatment plan that you think will be hard to follow or that you're uncomfortable with, explain this to your treatment team member. Never stop a treatment before discussing it with your healthcare professional.

### **Don't be afraid to speak up**

Tell your treatment team member what's on your mind, even when it is difficult or embarrassing. This can be challenging, but the more your team members know, the more they can help you.

### **Know your options**

Ask for all possible treatment options from your healthcare professional. It is rare for there to be just one.

### **Check to make sure you understand**

Make sure you understand everything your treatment team member has said. If you're not sure, repeat back what they told you and ask if you've understood correctly. You can also ask your treatment team member to repeat the information, write it down or draw a diagram.

### **Partner with your treatment team**

Let your treatment team know that it's important to you to be part of your treatment decision-making. Emphasize that you respect their expertise, but you want to understand their thinking when making recommendations. Let them know your expectations about treatment planning so they can clearly communicate to you what is possible.

## **After your appointment**

Once you and your healthcare professional agree on a treatment plan, it is important for you to understand what you need to do between appointments. Take notes during your appointment for reference later. Afterwards, make a record of what happened. We've created a downloadable **Post-Appointment Record** (Appendix E) tool that you can use to help record treatment team member's advice during your appointment.

## Addressing issues

You may not always be satisfied with everything you are told by your healthcare professional. In these instances, consider the following:

- Make sure you have provided all the information that you can to help with diagnosis and treatment planning, including information about your needs and treatment goals.
- Be clear with your treatment team. If something is not working or will not work for you, have an open, honest and respectful discussion about any misgivings you may have.
- Double-check that you are following the treatment plan as recommended by your team.
- Consider connecting with a patient group in person or online to find support and solutions that meets your needs

If you have followed the steps above and remain unsatisfied, talk to your doctor about being referred to another specialist. This is never easy, but if you are uncomfortable with the diagnosis or treatment plan recommended to you, get a second opinion. Keep in mind that if you live in a smaller, or under-served community, you may need to travel to another region for a second opinion.

## **If you have a serious concern with a treatment team member**

It is possible that you may have a serious concern about a member of your treatment team. Sometimes difficulties may arise when communication between you and the member of your treatment team is not clear. It is always best to explain your concerns directly to your treatment team member. Call the office and ask for time to meet and discuss your concerns. If it is too uncomfortable or inappropriate for you to present your concerns in person, you can write a letter or ask to speak to the clinic manager or the team member's supervisor. It is important to present your concerns factually and respectfully. You may come to a resolution and there will be no need to take it any further. If you are not satisfied with the resolution, there are other approaches you can take.

Most members of your treatment team are members of either a regulatory or certifying body. These organizations have a formal complaints process for you to follow if you wish to file a complaint. Contact the appropriate organization for details. For example, your family doctor will have a diploma that certifies that he or she is a member of the College of Family Physicians in that province. One responsibility of the College is to respond to concerns and to investigate complaints from members of the public about doctors licensed to practice medicine in that province.

## PART 2: UNDERSTANDING YOUR COVERAGE OPTIONS

### Your government health insurance plan

Canada's governmental health care is commonly known as Medicare. Medicare is legislated federally through the *Canada Health Act*, which identifies what health care services must be funded by the provinces and territories. Your doctor, hospital services and most diagnostic testing fall into this category.

Some provinces or territories fund other health care-related expenses such as medication, physiotherapy, glasses, dental and home care, but usually only for particular groups of people. These groups may include seniors, children and youth, people with low income, or those who are receiving social assistance. Some programs are also available to people with certain disabilities or illnesses. Some regions also pay for in-home or home care services.

If you're not a member of a covered group, you will have to pay for these services another way, either "from your own pocket" or through a private insurance plan. Even in cases where your insurance covers your medications or treatments, you will often have to pay a portion of the bill yourself.

### Hospital care coverage

If you are admitted to hospital, the government will pay for the doctor services, medications and diagnostic tests ordered by physicians. They also cover the services of "allied healthcare professionals" — health professionals who are not doctors — when they are requested by the physicians.

When you are discharged from the hospital, your coverage may change. Drugs and services that you received free of charge in hospital may become your responsibility. There are considerable differences from province to province in what is covered. The eligibility for public plans is set by whichever government is administering it. Usually only Canadian citizens and permanent residents are eligible.

Check with your provincial or territorial ministry or department of health for details about your public health insurance plan, what services are covered, and if you are eligible to receive coverage for additional healthcare services.

### Private group insurance

Private insurance plans are group plans usually sponsored by an employer, union or association. These plans pay some of the healthcare services not covered by your public plan.

If you are part of a group benefit plan, you will likely receive an information booklet or access to a website about the healthcare services that are covered. These may include:

- prescription medication;
- additional hospital coverage (for example, a private hospital room);
- out-of-country coverage;
- services like physiotherapy, counselling, chiropractic;
- equipment such as eye glasses or orthotics; and
- dental services.



Each plan is different and coverage will vary. In some cases, you may receive a card to present to your pharmacist or healthcare professional up front to cover all or part of your medication or treatment. In other cases, you will have to pay the bill then make a claim to the insurance company. Remember to always get a receipt!

To learn about what your plan has to offer, review the information provided by your employer and the insurance company. Information about your insurance policy may also be found on the insurance company website in a section dedicated to members. In the case of prescription medications, some insurance companies will offer an online tool so you can check if they are covered.

If you are still unsure if your medication is covered by your private insurance plan, call your insurance company before you go to the pharmacy. Or you can ask your pharmacist — many plans have a web-based service that tells the pharmacist how much is covered and how much you will need to pay.

*Source: adapted from <http://www.drugcoverage.ca/en-ca/private-insurance>*

## Individual & family health plans

If you do not have access to a group benefit plan, it is possible to buy an individual or family health plan. Consult an insurance broker for more details and keep in mind that you can sometimes access an insurance plan through an association or group like the Canadian Association for Retired Persons or the Canadian Automobile Association. This gives you the advantage of a better rate, as the costs are shared over a larger number of plan members.

## **Coordinating your benefits coverage**

If you are covered by more than one benefit plan, you may be able to further minimize the amount you pay. This most often occurs when you and your spouse each have a plan, or when a child is covered by a parental plan, but also has a work plan.

Though coordinating benefits can sometimes be tricky to figure out, reviewing your plans can help you decide which benefit plan to submit to first. Whatever portion is left unpaid may be claimed through the second insurer.

You may find that one insurer won't cover a medication or treatment, but another will. Or you may reach the maximum amount you can claim with one company, but be able to claim further expenses from the second.

## Key Insurance Definitions

Whether you're researching your region's health plan or trying to understand your workplace health insurance forms, it can seem like they're written in a different language. Here are some key terms and concepts to help you make sense of it.

### **Formulary**

A formulary is the list of prescription medications or products that are covered under an insurance plan. The federal, provincial and territorial governments participate together in a process called the Common Drug Review. An expert committee evaluates new drugs and gives

evidence-based recommendations about which should be covered by public drug benefit plans. Often private insurance plans base their formularies on the public plan formulary in their jurisdiction.

## **Generic Substitution**

When a drug is first introduced, it is usually patented by the drug company that developed it. This means that for a period of time, only they can manufacture and sell it.

When the patent expires, other companies can produce generic versions of the drug. Generic versions of a drug contain the same active ingredients as the brand name drug, but typically cost less. Many benefit plans (public and private) require the pharmacist to provide you with the least expensive version of the drug, regardless of what was written on your prescription.

There can sometimes be differences between the name brand and generic versions of drugs. If the generic product has not worked for you, your physician can indicate “no substitution” on your prescription. The difference in cost may be covered by your plan, or you may be required to pay for it yourself. Sometimes an insurance company will require your doctor to present medical evidence as to why you require the non-generic version of a drug.

## **Benefit**

The payment made by an insurance company after approving a claim.

## **Claim**

A formal request to the insurance company for payment of a benefit.

## **Co-insurance**

An arrangement in a health insurance plan where you and the insurance company share the cost of the items covered. You usually pay a set percentage (for example, 20 per cent) and the remainder (80 per cent) is paid by the insurance plan.

## **Co-payment or Co-pay**

A predetermined fee a plan member pays for healthcare services. This amount is usually a flat fee.

## **Deductible**

The amount that plan members have to pay themselves before the insurance kicks in. For example, you might have an annual \$500 deductible, meaning you cover the first \$500 for health services before your insurance company begins to pay. There may also be a set deductible for each prescription drug.

## **Premium**

A fee paid to the insurance company or health plan to provide insurance coverage. Depending on your type of plan, this may be paid, all or in part, by a third party such as your employer.

## **Plan Member Payments**

Additional costs that you, the plan member, may have to pay. If you are part of a health insurance plan, whether public, private or individual, there are likely additional costs you'll have to pay when you make a claim or seek reimbursement for a benefit.

## Other sources of coverage

Beyond private insurance, you may be able to access additional funding to offset your healthcare costs. Some of these additional sources of funding include the following:

- Workers' Compensation Board
- Provincial Compassionate Programs
- Provincial Exceptional Access Programs
- Pharmaceutical Company Compassionate Programs
- Patient Support Programs
- Medication Reimbursement Specialists
- Tax Credits

### **WORKERS' COMPENSATION BOARD**

Each province and territory has an organization responsible for paying medical costs for workers injured on the job. This may include prescriptions and services such as physiotherapy, occupational therapy and chiropractic treatments. Each provincial or territorial board has its own process for approving claims and covering various medical costs.

### **PROVINCIAL COMPASSIONATE PROGRAMS**

Compassionate programs exist to help Canadians who have high prescription costs compared to their household income. The eligibility criteria vary across these plans. Usually these programs will provide support for the drugs that are listed on that province or territory's formulary. Check your region's Ministry or Department of Health website to see what's available to you.

### **PROVINCIAL EXCEPTIONAL ACCESS PROGRAMS**

An Exceptional Access Program (EAP) or Special Access Program (SAP) helps patients access drugs that aren't currently listed for coverage on a formulary, or for which there are no alternatives. To apply for the EAP/SAP, your physician must submit a request that documents your medical information and a clinical rationale for requesting the unlisted drug, with reasons why a covered drug is not suitable.

### **PHARMACEUTICAL COMPANY COMPASSIONATE PROGRAMS**

It is worth checking with your doctor about possible programs run by the company that makes the medication that you need. Some companies provide assistance to help offset or reduce your out-of-pocket costs not covered by your public or private drug plan. This is typically made available for expensive drugs, where paying for them yourself could be prohibitive.

### **PATIENT SUPPORT PROGRAMS**

If you take expensive medications, like a biologic, a patient support program may be available to help fund the drug. Check with your prescribing physician as they should know if such a program exists for your drug and how to get information.

### **MEDICATION REIMBURSEMENT SPECIALISTS**

If you are struggling with insurance coverage, your prescribing physician, pharmacist or local hospital may be able to direct you to a medication reimbursement specialist. These specialists are situated in hospitals and pharmacies across the country. Their role is to help you find ways to pay for your medications.

## **TAX CREDITS**

Federal health-related tax measures, include:

- tax credits for medical expenses, disability, caregivers and infirm dependents;
- tax rebates to public institutions for health services; and
- deductions for private health insurance premiums for the self-employed.

*Source: Health Canada, Canada's Health Care System, 2005*

## Advocating with Insurance Companies

If your private health insurance plan doesn't cover your needed treatment, you may decide to advocate for further coverage under your plan. The following steps may be helpful when advocating for the coverage you need.

### **Gather Necessary Information**

Make sure you know your benefits policy number, employer's name/policy number, and your physician's phone number. If you are requesting specific medication, find the drug identification number (DIN) —your doctor can give this to you or you can find it on Health Canada's website at <https://health-products.canada.ca/dpd-bdpp/index-eng.jsp>.

### **Keep Your Plan Sponsor Informed**

If your insurance plan is through your workplace, let your Human Resources Manager know what the insurance company told you and explain that your physician considers this treatment vital to your health and well-being. If your plan's sponsor is a union or association, call your representative and let them know what's happening. They may have had others in the same situation and might be able to help.

### **Make the Call**

Call your insurance company's benefits department to confirm that they do not cover the treatment. Ask them why. You could also ask your doctor to call them for you. Determine if the insurance company excludes this particular treatment from all of its plans, or if the exclusion is specific to the level of plan you have. If it's the latter, a plan sponsor has the option of making an exception. You can advocate with your plan sponsor to have your treatment covered.

If the insurance company will not cover the specific treatment you need, have your physician write a letter of appeal, giving the reasons why you need this treatment. If the appeal is rejected, you can contact the insurance company's ombudsperson to file a complaint and request reversal of their decision.

### **Consult With Others**

If you are part of a patient support group, discussion board or chat room, ask if others have experienced something similar. Did they have any success? What approaches would they recommend? If you aren't yet part of a group, you may want to look into local or online communities of other people with arthritis.

The Arthritis Society's mission includes the important goal of ensuring people have access to timely and effective care. Connect with the Arthritis Society to see if you can play a role in their ongoing advocacy initiatives with other critical volunteers.

## PART 3: ADVOCATING FOR CHANGE

### The role of federal government in health care

Getting a sense of how our health care system works will make it easier for you to advocate for change when needed. This section provides information about the role of the federal government in the Canadian health care system. Canada's federal government plays many health-related roles. They include:

- setting national principles for health care under the *Canada Health Act*;
- providing financial support to provinces/territories;
- health protection and safety programs (food safety and nutrition, regulation of pharmaceuticals, medical devices, consumer products and pest management products);
- funding for health research and health promotion;
- disease prevention and surveillance;
- public health programs; and
- funding for health care for certain groups, including serving members of the Canadian Forces, Royal Canadian Mounted Police, eligible veterans, refugee protection claimants, inmates in federal penitentiaries, First Nations people living on reserves, and Inuit.

The federal government ensures that all health care in Canada follows the *Canada Health Act*. This set of principles guarantees that no matter where you live in Canada, you will receive medically necessary hospital and physician services. All provincial and territorial health care must follow the *Canada Health Act*.

Visit [Health Canada](#) for more information about Canada's health care system.

### The role of provincial and territorial governments in health care

The federal government provides financial support to provinces and territories to help them deliver health care services. Canadian Provinces and territories must follow the *Canada Health Act* to receive federal funding in support of health care. The *Canada Health Act* lists five basic principles. Universal services must be:

- available to all eligible residents of Canada;
- comprehensive in coverage;
- accessible without financial and other barriers;
- portable within the country; and
- publicly administered.

The provinces and territories fund and administer most of Canada's health care services. Each provincial/territorial health insurance plan covers medically necessary hospital and doctors' services, without deductible amounts, co-payments or dollar limits. These services are paid for from their tax revenues with some funding assistance from the federal government.

Each province/territory decides how to spend its tax revenue and what health care services will be covered under its public insurance plan and for which groups. For that reason, services such as home care, therapy and prescription drugs (outside of hospitals) vary across Canada.

*Source: Health Canada, Canada's Health Care System, 2005*



Visit [Health Canada](#) for more information about Canada's health care system.

## Identify your issue

Sometimes there are barriers to accessing the treatment you and your healthcare team decide is best for you. In the “Advocating for Change” section, you'll find information that will help you communicate with government to make your voice heard on issues of concern for people with arthritis. Your efforts can bring about real, lasting change that can benefit a lot of people. For more information, visit the Arthritis Society's [Self-Advocacy Toolkit](#).

Using the **Advocacy Worksheet** (Appendix F), write down the issue you are facing, and record the journey that has brought you here — the history of the steps you have taken so far and the healthcare professionals you've spoken to.

## Clarify the issue

The people who make decisions about treatment coverage are very busy. The key to reaching them is making sure that they can quickly identify why you're contacting them and what you require. Distilling your story into issues that can be addressed is the foundation of your advocacy plan. Determine the most important parts of your story and concentrate on facts.

Our **Framing Your Issues and Developing Your Messages Worksheet** (Appendix G) can help you with this process.

## Do your research

Do background research and know the core facts about your issue. Research helps you decide what you want to change, how you will go about it, and who to approach. It can also help you establish that you are not the only one in this situation, which can bring urgency to the issue.

Using a variety of sources and perspectives helps your credibility and increases the likelihood of success.

For more information on researching an issue and advocating for your cause, see the Background Research section of the Self-Advocacy Toolkit. It lists:

- possible sources of information;
- types of information you might seek out; and
- tips for researching your issue.

## Establish a goal

You've likely thought about potential solutions to your issue. It's now time to develop your advocacy goal. What are you hoping to achieve? What is your “ask”? No matter what your goal is, it should be:

- **Specific:** Ensure that you have a clear sense of what particular outcome you are seeking and how it can be accomplished.
- **Achievable:** Make sure your goal is possible to attain and that your audience is able to perform the action you need.

- **Measurable:** You should be able to measure the impact of your goal – what will indicate if you have been successful?
- **Time-limited.** Set a deadline for your goal to guide your planning.

## Engage your audience

Who has the ability or influence to make the change you are seeking? Determining your audience is a key step in formulating your advocacy plan. Once you have clarified and researched your issue, you need to find the right person or people to approach.

If your issue is about what is covered by your provincial/territorial health insurance plan, the decision makers are your members of provincial/territorial parliament, beginning with your local elected official, and the Minister responsible for health. If you can get them to see why this change would be a good thing for both you and them, you will greatly increase your odds of success. Understanding the challenges your audience may face can also help you. Identify any reasons why they might be tempted to say no, and have your responses ready. Change takes time. There are different ways to engage with your audience such as sending a **written letter/email** (Appendix H), **making a phone call** (Appendix I), or **meeting face-to-face** (Appendix J). Be prepared to be patient, but take steps to make sure that your issue isn't forgotten. Always follow up with a **thank-you letter** (Appendix K) and remind them that you are waiting for a response.

To help determine who might be involved in decision-making about your issue, visit the **Who's Who and Who Does What Chart** (Appendix L).

## **APPENDICES**

[Appendix A - Goal Tracker](#)

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# Arthritis Goal Tracker

Use the Goal Tracker to write down your treatment goals. Keep the Goal Tracker handy, such as on your fridge door or a bulletin board so you can be reminded of your goals and can track your progress more easily.

Date	Treatment Goal	Reason	Shared with Healthcare professional?	Updates
<i>(Example) January 29</i>	<i>Improve joint pain to be more physically active</i>	<i>New plan to lose weight</i>	<i>Discussed with physiotherapist</i>	<i>Do knee strengthening exercises twice a day</i>
<i>(Example) April 8</i>	<i>Review current medications with rheumatologist to determine if any changes required</i>	<i>More frequent flares</i>	<i>Make appointment with Rheumatologist, review Chronic Pain Management program</i>	<i>Made appointment, completed Arthritis Society module on Chronic Pain Management</i>

Date	Treatment Goal	Reason	Shared with Healthcare professional?	Updates



# HEALTH-CARE APPOINTMENT CHECKLIST

DATE:

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## A FEW WEEKS BEFORE

- Ask a family member or friend to join you as a companion.  
**HINT** Share this checklist with him/her.
- At least two weeks before the appointment start using the Symptom Tracker to track symptoms and identify factors that may be contributing to them.
- Start a list of the issues and questions you want to ask.

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## A FEW DAYS BEFORE

- If your joint pain is undiagnosed, complete the Joint Pain Symptom Checker and bring to your appointment.
- List all of your medications (prescription and off the shelf), vitamins and supplements, include the strength, how often you take and when the prescription started/ends.
- List all of your treatments, e.g., massage, chiropractic, acupuncture, naturopath, etc.
- Make a list of allergies or sensitivities, especially to medications.
- Write down any other concerns you have with your treatments and medications.
- Collect test results, medical histories, the referral/requisition for this appointment, and any other information that you've been asked to bring to this appointment.
- For medical tests, call ahead and confirm if there is anything that you must do — like fasting, avoiding caffeine, etc.

APPOINTMENT WITH:

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## THE DAY BEFORE

- Review your list of issues/questions to make sure the most important are asked first.
- If you are bringing a companion with you, share your concerns and support needs, e.g., take notes at the appointment.  
**HINT** Share your list of issues/questions with your companion so he/she can help keep track of the answers and remind you to ask anything you forget.
- Review this Checklist and make sure you have everything you need to take to your appointment.
- Make sure you have a pen and paper for you or your appointment companion to take notes or with permission, a device to record the conversation.

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## IMMEDIATELY AFTER THE APPOINTMENT

- Review the notes to make sure everything important was captured accurately including new/changed treatments, follow up actions, next appointment, etc.

# DAILY SYMPTOM TRACKER

DATE:

NAME:

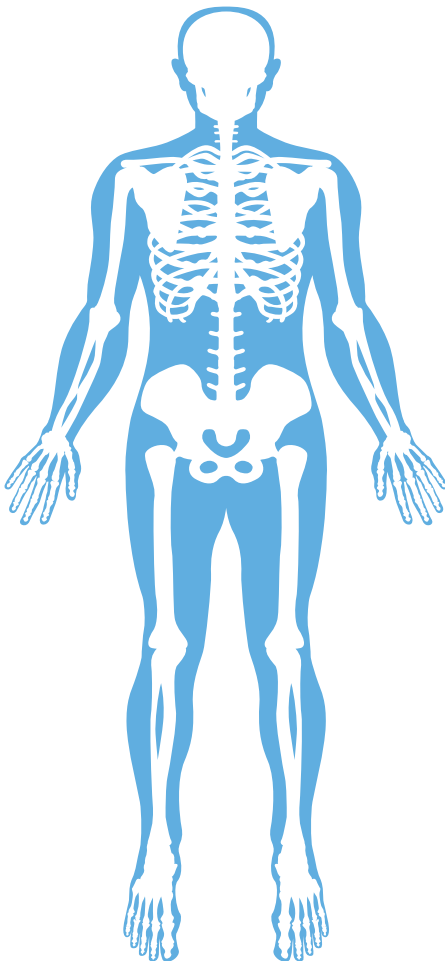
\_\_\_\_\_

\_\_\_\_\_

This is a great tool for you and your health-care provider to spot patterns and help manage your care. It is recommended you fill it out daily for at least two weeks prior to seeing your health-care provider.

## MEASURE YOUR PAIN

Circle where it hurts:



Rank your pain:

1 ↔ 5

1 = minimal pain

5 = worst pain

Morning:

Midday:

Evening:

# HOW WAS YOUR DAY?

Please rate yourself on the following scales:

Fatigue		1	2	3	4	5	
		No fatigue			Very tired		
Mood		1	2	3	4	5	
		Happy/ relaxed			Depressed/ anxious		
Stress		1	2	3	4	5	
		Low			High		
Physical activity/exercise		1	2	3	4	5	
		Physical activity			No physical activity		
Healthy eating		1	2	3	4	5	
		Healthy eating			Unhealthy eating		
Social life		1	2	3	4	5	
		Lots of interaction with family and friends			No interaction with family and friends		

## Did anything out of the ordinary happen today?

Please make a note of anything that happened outside of your usual routine, e.g., activities, medications, treatments, overall health.

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# Prepare for your Appointment: Key Questions for Your Healthcare Professional

Whether it's your first appointment or one of many, here are some questions to consider asking. Not every question will apply to every appointment or type of healthcare professional. Review these questions and use them when necessary.

## What did the test result show?

Your specialist and sometimes your family doctor will order tests to rule out various conditions and to help make a diagnosis. Many forms of arthritis can be challenging to diagnose. Ask your doctor what your test results mean for you and your treatment plan. You can ask for a printed copy of any blood test results or imaging study reports, but you may be required to pay the costs of making these copies. Some labs will provide you with online reports from your tests.

## When should I notice improvement from my current treatment?

After diagnosis, your doctor might prescribe medication or recommend a treatment regimen. While every patient responds differently to treatment, your doctor will be able to give you an idea of what to expect. Some medications, such as those used to manage pain symptoms, act relatively quickly. Others are known to take longer to make a difference you can feel.

Your doctor should be able to explain:

- the goal of your treatment;
- when to expect some positive results; and
- how long it might take to determine whether the treatment is a good fit for you

To learn more about medications used for the treatment of arthritis, visit the Arthritis Society's [Medication](#) page.

## If my current treatment doesn't work, what are my options?

If you are someone who likes to think ahead, you may find comfort in knowing what comes next. It allows you to mentally prepare. Visit the Arthritis Society's [Your Patient Journey](#) webpage for more information.

## In addition to my prescribed medications, what should I be doing to help manage my arthritis?

Complementary or alternative treatments can help you manage your symptoms. Discuss these with your doctor to determine if any of these approaches might be right for you.

Additionally, lifestyle changes, (such as weight management, nutrition, exercise, physical or occupational therapy) and self-management tools (such as mindfulness, meditation, heat/cold, or assistive devices) can be useful components of your treatment plan.

Tap into your treatment team member's experience and ask for suggestions above and beyond medications. Be specific when you discuss what aspects of arthritis bother you the most and how it affects your ability to perform important daily activities.

## What does my future hold?

Arthritis is a lifelong condition and you will notice changes periodically. Your doctor can help you to understand what to expect in the near future and longer-term with regard to potential flare ups, control of the disease and its progression, as well as possible future treatments.

Source: adapted from <http://arthritis.about.com/od/buildyourhealthcareteam/f/6-Questions-Arthritis-Patients-Must-Ask-Their-Doctor.htm>



# Post-Appointment Record

## Who did I see?

- Name: \_\_\_\_\_
- Profession: \_\_\_\_\_
- Contact information: \_\_\_\_\_
- Name of receptionist/office manager: \_\_\_\_\_
- Date of next appointment?: \_\_\_\_\_

## What did I learn?

- Diagnosis: what is my medical condition? \_\_\_\_\_
- Prognosis: what is the likely course or outcome of my condition over time?  
\_\_\_\_\_
- Test results and next steps: \_\_\_\_\_

## Changes to Medications

- New dosage? \_\_\_\_\_
- Take it at a different time? \_\_\_\_\_
- If stopping a medication, do I stop immediately? Finish what I have? Taper off?  
\_\_\_\_\_  
\_\_\_\_\_

*Hints: Take a list of all your medications to your appointment and mark any changes. Remember to ask for a prescription if needed and to inform your pharmacist of any changes.*

## New Medications

- When to start? \_\_\_\_\_
- How is it administered? (oral, injection, etc.) \_\_\_\_\_
- How long will it take for the medication to have an effect? \_\_\_\_\_
- How long will I take it for? \_\_\_\_\_
- Are there any side effects or interactions to look out for?  
\_\_\_\_\_  
\_\_\_\_\_

## Referral to another healthcare professional

Ask for a copy of the referral form. If it's not available ask:

- Name of healthcare professional: \_\_\_\_\_
- Contact information: \_\_\_\_\_
- Specialty: \_\_\_\_\_
- Reason for referral: \_\_\_\_\_
- Is it covered by my government insurance? \_\_\_\_\_



## Referral for tests

Ask for a copy of the referral form. If it's not available ask:

- Name of test(s): \_\_\_\_\_
- Will doctor's office make appointment, or will I? \_\_\_\_\_
- Office/lab number: \_\_\_\_\_
- Reason for test: \_\_\_\_\_
- How do I find out how to prepare?: \_\_\_\_\_
- How/when will I be notified of results? \_\_\_\_\_
- Is it covered by my government insurance? \_\_\_\_\_

## Recommendations for things I can do myself

- What new actions can I take or changes I can make to help manage my arthritis?  
\_\_\_\_\_  
\_\_\_\_\_
- Why is the change being recommended (for example, is a change in diet to help with weight loss or to avoid complications with medications?)  
\_\_\_\_\_  
\_\_\_\_\_
- Where can I look for help to make this change?  
\_\_\_\_\_  
\_\_\_\_\_
- Is there anything I need to look out for? (for example, an exercise class that is 'arthritis friendly')  
\_\_\_\_\_  
\_\_\_\_\_

## Call them back

Don't hesitate to call your treatment team member's office if you:

- feel worse
- have more questions
- have problems with your medication
- have problems with other treatments
- have not received your test results

# ADVOCACY WORKSHEET

*This worksheet is designed to help you create your advocacy plan.*

## **SECTION A: THE ISSUE**

Write down what the issue is that you are facing. Remember to include only facts. Think about the history of the issue, any interactions with professionals, etc.

## **SECTION B: CLARIFY THE ISSUE**

Think about the 2 or 3 most important parts of your issue. For example, "I could not get access to medication when I needed it", or "There weren't enough specialists for me to see one in a reasonable time".

## **SECTION C: DETERMINE YOUR GOALS**

What do you want to achieve with your advocacy efforts? For example, "More rheumatologists in my region" or "Coverage of my medication by my provincial drug plan".

**SECTION D: TELL YOUR STORY**

Telling your story effectively means organizing your issue. Write down your experience in 100 words or less.

**SECTION E: AUDIENCE**

To whom do you want to tell your story? Make sure that your audience is someone able to assist you with your desired outcome. Include name, address, phone numbers and e-mail.

**SECTION F: KEY MESSAGES**

Write down your 2-3 key messages that will engage your audience. Key messages should be less than 25 words each!

**SECTION G: REQUEST**

State your "ask" – what is the one thing you are asking your audience to do for you?

**SECTION H: NEXT STEPS**

Summarize what you have promised to do, and what your audience has promised to do. Include timeline/deadlines if applicable.

## FRAMING YOUR ISSUES and DEVELOPING YOUR MESSAGES WORKSHEET

**ISSUES:** *(Write down your issue from your Advocacy Worksheet)*

- 1.
- 2.
- 3.

**GOALS:** *(Write down what you are looking to achieve with your advocacy efforts)*

**AUDIENCE'S AGENDA:** *(Write down key points about what, if any, action has been taken by your audience on your issue and goal, or interest they have shown. Take note of any policies your audience has about your issue and goal, e.g. your provincial government has a policy to reduce wait times for hip and knee surgeries by 2014)*

**KEY MESSAGES:** *(Write down your key messages. Remember, your key messages should be 25 words or less)*

- 1.
- 2.
- 3.

**PUT IT TOGETHER:** *(Write down how your goal fits in to your audience's agenda, i.e. how taking action on your goal will provide a "win" OR how your goal supports a change that your audience wants OR how your goal is part of your audience's mandate)*

## SAMPLE PHONE CALL GUIDE

Use the following as a guide to help you organize your thoughts before placing a call to your advocacy audience. You should be sure to customize your plan to reflect your own issues and experiences.

### Introduce Yourself:

Hello, my name is \_\_\_\_\_ and I am calling regarding \_\_\_\_\_.  
(your name) (general issue)

### *Political Advocacy*

I am a constituent of \_\_\_\_\_.  
(name of audience)

### Why Are You Calling?

I'm calling to discuss scheduling a meeting with \_\_\_\_\_. I am personally  
(name)  
impacted by \_\_\_\_\_ and I would like to discuss this issue with him/her.  
(issue)

### Ask For a Response

Is there a time that \_\_\_\_\_ is available to meet in the next  
(name)  
\_\_\_\_\_?  
(timeframe)

### *OR, if leaving a message:*

Please let me know when \_\_\_\_\_ is available in the next  
(name)  
\_\_\_\_\_. You can contact me by (phone or email).  
(timeframe)

### Say Thank You

Thank you for your time and consideration of this important issue. I look forward to the meeting on

\_\_\_\_\_ / speaking to \_\_\_\_\_ on \_\_\_\_\_.  
(date/time) (Name) (date/time)

### *If leaving a message:*

I look forward to hearing back from you.



## MEETING YOUR AUDIENCE

Before you meet with your audience, know what you need and know your key messages.

What to do	What to say
Step 1 Introductions	Introduce yourself and the other attendees, if any
Step 2 Small talk - building the relationship	Talk about something you might have in common with your audience, but watch your time -Did you read something about him/her in the newspaper? -Have you worked in the same industry?
Step 3 Talk about your audience's work on your issue and goal in general terms	Acknowledge what your audience has done and say thank you
Step 4 What does your audience know about your issue?	Ask your audience what they know about your issue  Deliver your key messages
Step 5 Paint the Picture	Tell your personal story
Step 6 What do you need?	Your audience needs to know how he/she can help you -What can be done to achieve your goal? Remember, this should be a concrete action your audience is in a position to take.
Step 7 Ask for a commitment	Does your audience have any questions about your issue and goal? -What is your audience prepared to do to help? -What will your audience do next and when? -What can you do to help your audience help you?
Step 8 Sum up the meeting	Remind your audience about what he/she said she would do to help and when -Acknowledge what you have committed to do -Thank him/her for his/her time -Book another meeting if it's appropriate
Follow-up after the meeting	Write a brief note thanking your audience for his/her time and including what action both you and your audience have promised to take and when -Send your thank you by e-mail or post -Follow-up if agreed-to actions are not taken in agreed times.

## WRITTEN LETTER FORMAT

Use this template to prepare to write a letter to your audience.

Your address	
Date	
<b>Address</b> <i>When writing to your MP or provincial representative, use their constituency office address whenever possible.</i>	
<b>Salutation</b> <i>Make sure you use the correct form of address and salutation – [Click here] for help.</i>	
<b>State your main issue</b>	
<b>Your personal story</b> <i>Include a brief summary of your personal experience with the main issue.</i>	
<b>Facts supporting your concern</b> <i>Be sure to only include the facts that directly support your concern. Don't overwhelm your reader with too many facts and figures!</i>	
<b>Specify how your audience can make a difference</b>	
<b>Final remarks / contact info</b>	

## SAMPLE THANK YOU LETTER

*After meeting with your audience, be sure to thank them for their time – and particularly if they are to follow up on any actions discussed during your meeting. Make sure you customize the letter below to reflect your issue, meeting, and follow up required.*

Date

Mr. John Doe, *Title*  
321 Queen Street  
Any town, Any province  
M7M 7M7

Dear Mr. Doe,  
Thank you for your time on \_\_\_\_\_. It was a pleasure meeting you in person and having the  
(date)  
opportunity to bring my concerns to your attention. As you will recall, I was most interested in  
speaking to you about \_\_\_\_\_.  
(specific issue)

*If you committed to providing more information:*  
You asked if I could send you some more information about \_\_\_\_\_. The  
(requested info)  
information you requested is enclosed.

*If your audience made a commitment:*  
Your commitment was to \_\_\_\_\_,  
(specify commitment made)  
and I very much appreciate your willingness to do this by \_\_\_\_\_.  
(timeframe)

*If you made a commitment:*  
I made a commitment to \_\_\_\_\_, and will keep you up-to-date.

I look forward to speaking with you again.

Sincerely,  
[NAME]

# WHO'S WHO AND WHO DOES WHAT

## Who's Who – Finding your elected representatives

Level of Government	Elected Representative	Website to visit
<p><b>Federal</b> Canada's federal government is located in Ottawa, Ontario. The head of the federal government is the <b>Prime Minister</b>. Generally, the federal government collects taxes from across the country and re-distributes money to the provinces to run a large variety of programs and services. The federal government has direct decision-making power about foreign affairs, and participates in national discussions about domestic issues.</p>	<p>Elected representatives in the federal government are called <b>Members of Parliament (MP)</b>, and gather in the <b>House of Commons</b> in Ottawa.</p>	<p>Find your MP in <a href="#">English</a> Find your MP in <a href="#">French</a></p>
<p><b>Provincial</b> Each province has an elected government, headed by the <b>Premier</b>. Each provincial government is located in the provincial capital city. Provincial governments collect some taxes and receive funding from the federal government to provide a large variety of programs and services, and have direct decision-making power about programs and services.</p>	<p>Elected representatives in provincial governments have different names, depending on the province.</p> <p>In Newfoundland and Labrador, elected representatives are called <b>Members of the House of Assembly (MHA)</b>.</p> <p>In Ontario, elected representatives are called <b>Members of Provincial Parliament (MPP)</b>.</p> <p>In Quebec, elected representatives are called <b>Members of the National Assembly (MNA)</b>.</p> <p>In all other provinces and territories, elected representatives are called <b>Members of the Legislative Assembly (MLA)</b>.</p>	<p>Find your provincial representative:</p> <p>Newfoundland and Labrador New Brunswick (E) New Brunswick (F) Nova Scotia Prince Edward Island Quebec (E) Quebec (F) Ontario (E) Ontario (F) Manitoba (E) Manitoba (F) Saskatchewan Alberta British Columbia Yukon (E) Yukon (F) Northwest Territories (E) Northwest Territories (F) Nunavut (E) Nunavut (F) Nunavut (I)</p>

**Who Does What – Which level of government is responsible?**

Issue	Institution Responsible	Person to Approach
Income Supports (EI, CPP, CPP -D, Disability Tax Credit)	Federal Government	Member of Parliament (MP)
Income Supports (Disability Support Program, Social Assistance)	Provincial/Territorial Government	Member of Provincial Parliament (MPP) Member of the Legislative Assembly (MLA) Member of the National Assembly (MNA) Member of the House of Assembly (MHA)
Access to Medications	Provincial/Territorial Government*	MPP/MLA/MNA/MHA
Access to Physicians/Specialists	Provincial/Territorial Government	MPP/MLA/MNA/MHA
Access to Care, e.g. surgery and diagnostic imaging*	Provincial/Territorial Government	MPP/MLA/MNA/MHA
Assistive Devices Support Programs	Provincial/Territorial Government*	MPP/MLA/MNA/MHA
Hospitals	Provincial/Territorial Government*	MPP/MLA/MNA/MHA
Long-Term Care facilities	Provincial/Territorial Government*	MPP/MLA/MNA/MHA
Post-Secondary Education (affecting all schools)	Provincial/Territorial Government	MPP/MLA/MNA/MHA
Public Transit	Municipal (City/Town) Government	Councilor/Alderman
Parks and Recreation	Municipal (City/Town) Government	Councilor/Alderman
Social Housing	Municipal (City/Town) Government	Councilor/Alderman
Social Services, e.g. daycare, social assistance	Municipal (City/Town) Government	Councilor/Alderman
Long-Term Care/Seniors Housing (municipally -run)	Municipal (City/Town) Government	Councilor/Alderman
Elementary School Education	Local School Board	School Trustee
Secondary School Education	Local School Board	School Trustee

\* In most provinces/territories, responsibility is delegated to a Regional Health Authority. Regional Health Authorities (in Ontario, these are called Local Health Integration Networks, or LHINs) are organizations mandated by the province to prioritize and customize health programs and services based on the needs of local communities.

**Arthritis. Give before it takes.™**



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SOCIETY

1.800.321.1433 | [arthritis.ca](http://arthritis.ca)