Managing Inflammatory Arthritis

What to Discuss with Your Health Care Team



Introduction



Inflammatory arthritis can cause permanent joint damage when it's not controlled. So even if you're feeling better always take your medication(s) and discuss any changes in your health with your health care team.

What to Discuss with Your Health Care Team

This tool has been created with input from patients to provide you with a list of potential topics you could discuss at your next appointment.

Why?

"Patients who learn about their treatment program and talk to their health care team about it tend to report fewer symptoms, including less pain and greater mobility."

The Arthritis Society

Setting goals with your health care team

You can use this tool to help you understand all types of goals related to your arthritis management. Sharing what you write in this tool with your health care team will help you work together to effectively manage and treat your inflammatory arthritis. The next few sections will help you to map out your goals.

Your Appointment



What to Discuss with Your Health Care Team

Throughout this guide, you will find a list of potential topics to be discussed with your health care team, such as:

• Lifestyle and Personal Goals

- Exercise
- Relationships
- Work, education and general interest
- Nutrition
- Travelling

Clinical Goals

- Physical health questions
- Mental health questions
- Injection goals
- Ongoing inflammatory arthritis management

Use this tool for your next appointment based on what you feel is the most important to discuss with your health care team.

- Print and complete the sections that are a priority for you to discuss
- Keep a record of your goals and your medications so you can track your progress over time
- Include your own notes and questions
- Write down any requests or questions you have about referrals and resources
- Make sure you speak up and advocate for yourself

Overview of topics you can discuss with your health care team

Lifestyle/personal goals are those you want to achieve in your life. For example, you may wish to finish a degree or travel, or maybe you want to participate in a walk or a run. It's important for you to let your health care team know what goals you have set for yourself so that they can help you meet them. Later in this guide there will be a section of personal goals for you to consider along with the following questions:

Clinical goals are those that your rheumatologist and health care team set and relate specifically to the physical symptoms of your disease. For example, a clinical goal could be to decrease inflammation in your joints by your next appointment, or a very low disease activity could be another clinical goal. The chart that your health care team keeps tracks your clinical progress at each appointment, and helps them determine how well your inflammatory arthritis is being managed. At each appointment your team will assess your physical health. If you have concerns, you can discuss your mental health with them too.

- Have you made any progress in reaching your objectives since your last appointment?
- Would you benefit from additional support/services to help you meet your personal objectives?
- Are your personal goals realistic or do you need to adapt them because of your arthritis?

Physical health

- Level and/or frequency of pain and stiffness
- Mobility
- Flares
- Management of daily tasks
- Other

Mental health

- Depression
- Anxiety
- Communication
- Lack of support, feeling overwhelmed
- Other

Review your clinical goals

Your health care team will examine your physical symptoms to decide if additional/different treatment is required. Talk to your health care team about your medications, and ask whether a change in the dose and/or medication would be beneficial to you. Also ensure that:

- You understand your current disease state, the clinical or treatment objective that's been set, and the steps necessary to meet that goal
- Your clinical goals support your personal goal(s)
- You get referrals to other health care professionals, if needed

Appointment check points

You may not have time to discuss everything on your list, but you should leave your appointment feeling that:

Print sections that are important to you and take them to your next appointment. Review the "Making the Most Out of Your Appointment" document for more information on how to get ready for your appointment.

- You understand your current disease activity level, clinical goal(s), and any changes since your last appointment
- You shared any information, concerns or questions that you had about your disease/ treatment/goals with your health care team
- You have a prescription renewal and/or enough medication(s) to last until your next appointment, and understand how to take it, if applicable
- You know where or who you can turn to for more help (nurse, website, patient support group, etc.)

Lifestyle and Personal Goals



What to Discuss with Your Health Care Team

You can personalize your goals by using the following suggestions as a guide.

Your personal and lifestyle goals may be different from others because of your inflammatory arthritis state and your age.

If you're a caregiver, it might be helpful to be part of the goal discussion.

Print this, circle the items you'd like to discuss with your health care team, and bring it to your appointment. By working together and creating your wellness plan, you can take an active role in improving the management of your inflammatory arthritis.

When establishing your exercise goals, consider:

According to the American College of Rheumatology, people with inflammatory arthritis who exercise have: less pain, more energy, improved sleep, and better day-to-day function.

Exercise goals – You are interested in finding out more about:

- Walking, biking, swimming
- Physical strength/endurance exercises I can do at home to regain strength, ability and independence
- Exercises that can help improve my flexibility and balance
- Year-round activities that can help manage my symptoms
- My current fitness level and how I can improve it
- Taking up a sport or exercise that I previously enjoyed
- Local resources for exercise and fitness tips
- Professionals in the community who can help me reach my fitness goal
- Other: ______

Inactivity can lead to a wide range of health risks or concerns:

Type II diabetes, cardiovascular disease, decreased pain tolerance, weak muscles, stiff joints and poor balance.

The **"Top ten exercises. Keeping things simple."** fact sheet from The Arthritis Society has a series of fast, simple, effective exercises. You can download it and discuss it at your appointment. It's available at: <u>http://www.arthritis.ca/document.doc?id=329</u>

Physical Activity & Arthritis Guide from The Arthritis Society. Download at: <u>http://www.arthritis.ca/document.doc?id=321</u>

Exercise and Arthritis Fact Sheet from The American College of Rheumatology. Download at: <u>http://www.rheumatology.org/Practice/Clinical/Patients/Diseases_And_</u> Conditions/Exercise_and_Arthritis/

Print this, circle the items you'd like to discuss with your health care team, and bring it to your appointment. By working together and creating your wellness plan, you can take an active role in improving the management of your inflammatory arthritis.



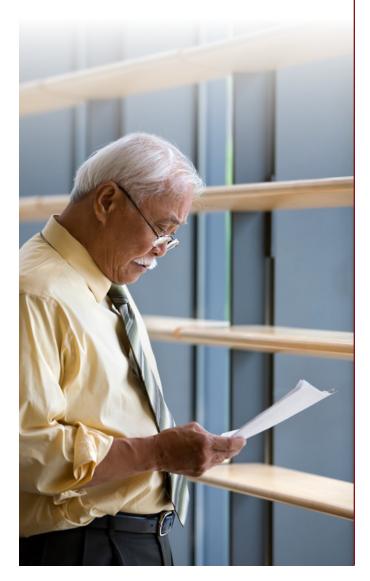
You may want to consider speaking to others with arthritis, (through support groups for people with inflammatory arthritis) particularly if you find it difficult to share with friends and family.

Relationship goals – You would like to talk about:

- Participating in family events weddings, baptism, other
- Family outings/vacations hiking, travel, sports, cooking
- Personal relationships and how to set limits with friends and family ahead of an event
- Sex and intimacy My sexual relationship with my partner does not have to suffer because of arthritis.
 If sex is a regular part of my relationship, I should try to keep it so
- How to say no to events that will exhaust or irritate me
- Managing others' expectations of me
- How to have a backup plan in place in case my arthritis flares up the day of an important event
- Ways to participate in events with family and friends even when my arthritis is acting up
- Information recommended websites/books to help family/friends better understand my arthritis
- Other: _

Intimacy and arthritis from The Arthritis Society. Download at: <u>http://www.arthritis.ca/page.aspx?pid=1039</u>

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Work, education, or general interest goals – You need to discuss:

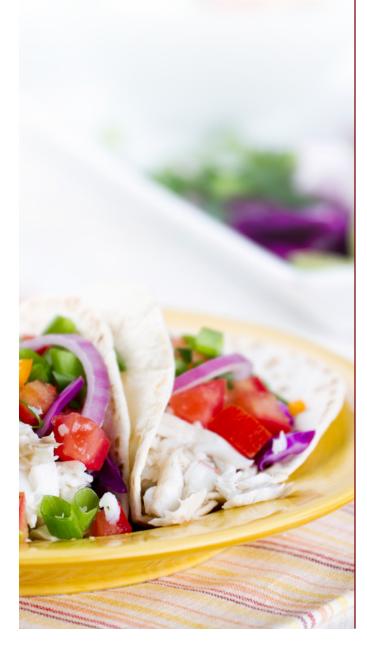
- Returning to my work, career changes, working overtime – overall considerations
- Tips to help me be more efficient or organized while I work or pursue a hobby or further my education
- Sharing my work or hobby goals with others
- Setting productivity goals, should I be more flexible in my expectations?
- Tools that could help reach my work, education or general interest goals
- Referrals to help me reach my goals

 physical therapist, occupational therapist, friend, family member, support groups, online community, other:

Notes:

Nutrition Tips

You may want to consider discussing nutrition and diet and its benefits with your team.



Nutrition plan – Your diet

One of the most important things is to eat a balanced and healthy diet. If you need to, you can work with your health care team to achieve and maintain a healthy weight to help relieve the pressure in your hips, knees, ankles and feet that can lead to pain and mobility problems. Encourage your family or caregiver to actively join you in leading a healthy lifestyle, by eating a balanced diet low in fat and high in fresh, nutrient-rich foods.

The following are examples of questions you can ask your health care team about nutrition and your diet:

- Could you recommend a professional who could help me?
- Are there any resources or support groups I can turn to for help?
- Is there a way I can record my progress to best help me?

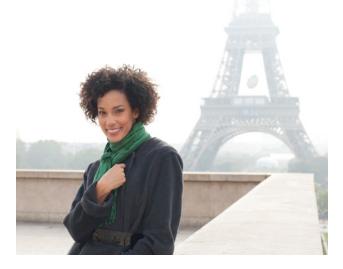
Notes:			

You may find the Arthritis Society's **"Nutrition and Arthritis"** booklet helpful. It's available at: <u>http://www.arthritis.ca/document.doc?id=322</u>

Try incorporating some of these healthy recipes from **The Arthritis Foundation** into your meal plan. Go to: <u>http://www.arthritistoday.org/what-you-can-do/eating-well/recipes/</u>

Traveling Goals

If one of your personal goals is to travel, your health care team is an excellent source for helpful tips that can help you enjoy your trip as comfortably as possible.



If you don't feel you understand something your health care team has discussed, don't be embarrassed to let them know and ask them to explain it more clearly. Remember that you are a part of the team managing your inflammatory arthritis.

Talk to them about:

- Deciding on a time when I'm most likely to feel my best
- Traveling during the holidays is that a good option for me?
- Building rest days into my trip
- Any necessary immunizations I may need
- What suitcases may be the best option for me
- Carrying my medical history and a list of my current medications
- Special insurance plans for my arthritis
- My medication requirements if refrigeration is required, what options are available while I'm traveling

Many people with inflammatory arthritis lead happy, fulfilling lives by communicating, sharing, and learning to best deal with change and setting goals. It starts with taking control over how you live with your inflammatory arthritis.

Download or print the questions

Physical Health

How I'm doing

One of the first considerations you should think of before talking to your health care team about your physical health is what your "new normal" is. If you find your "new normal" involves coping on a daily basis with pain, let your team know. Sharing that you're in pain isn't complaining, it's an important diagnostic tool that helps your team understand the current state of your disease.



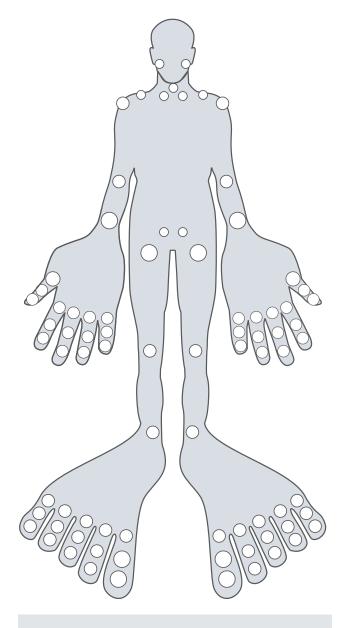
What to Discuss with Your Health Care Team

If you've been diagnosed with a new condition or have noticed any changes in your skin or nails (psoriasis), high blood pressure, migraines, digestion, bowel changes, eye pain or any other health concerns, let your team know, as this could be an extra-articular manifestation (EAM). EAMs are conditions that can be associated with inflammatory arthritis.

You may also ask your team about the "Treat to Target" approach where the goal is to reach a state of low disease activity by treating inflammatory arthritis to "target", the point where irreversible joint damage and disability is avoided.

Sect	ion 4
Your inflammatory arthritis state	 Are there signs my inflammatory arthritis has progressed since my last visit? If so, can we slow or stop this progression by treating my arthritis to target? Is there any joint damage? What can I do to preserve my joint function? Am I experiencing the usual progression of inflammatory arthritis? Other questions I may have:
Your pain concerns (circle level)	 My pain level is: Low Medium High If I'm not in pain is my inflammatory arthritis well controlled? If pain is an issue, how can we better manage my pain?
Your inflammatory arthritis activity (circle level)	 How active is my inflammatory arthritis right now: Low Medium High If this isn't where it should be, what should we do?
Your fatigue level (circle level)	 My daily fatigue level is: Low Medium High
Your sleep patterns (circle answers)	 I am able to sleep through the night Yes No Sometimes I often wake up during the night because of pain Yes No Sometimes The last night I had an interrupted night of sleep was:

Chart your inflammatory arthritis activity by circling where your joints are swollen. Inflammatory arthritis often causes the affected joints to be stiff, painful, sore, and warm to the touch. Some people experience a burning-like feeling in their joints.



For additional facts about inflammatory arthritis go to: <u>http://www.arthritis.ca/</u> document.doc?id=925

Your treatment

- Can we address the concerns I'm having with my treatment?
- Should I start taking something else?
- Why am I on so many medications?
- Can you explain what each medication does?
- What happens if I don't take my medications?

Your health changes

- I was recently diagnosed with
- I recently sustained an injury
- l've started a new treatment for my
- Will this interact with my inflammatory arthritis care?

Arthritis health facts

- 8 in 10 Canadians living with arthritis have additional chronic conditions
- Other chronic conditions include: back problems, high blood pressure, migraines, asthma, diabetes, heart disease, bowel disorders, urinary incontinence, ulcers, cancer and strokes.
- Make a note of any other conditions you may have and any medication you may be taking and share it with your health care team

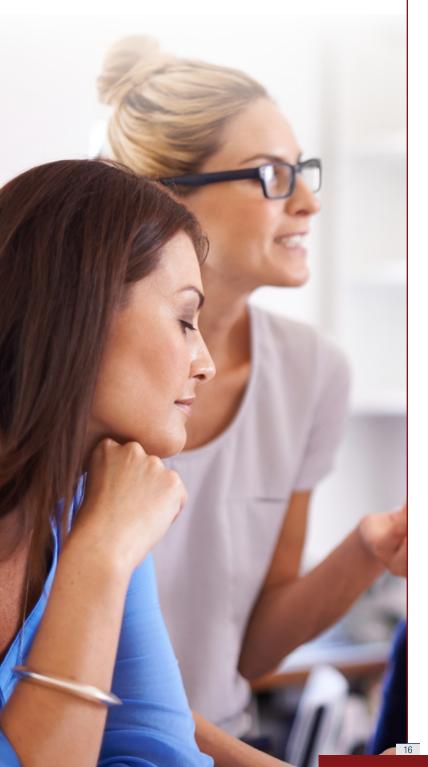
As part of your plan, your health care team needs a complete picture of your inflammatory arthritis, and any other healthrelated conditions you may have recently noticed. Share any concerns or observations you have with your team so they have an up-to-date history of your current health. The Arthritis Society also has a wide range of videos available to ensure you have the most current information about your condition.

To view go to: http://www.arthritis.ca/videos

Notes:

Download or print the questions

Mental Health



What to Discuss with Your Health Care Team

Talking about how you're feeling

Sharing the emotional toll inflammatory arthritis has on your wellbeing with your health care team and reaching out to family, friends, and your caregiver for help and resources when you're feeling overwhelmed is really important. If it's difficult for you to start this conversation with your team, the questions on the right may be helpful.

- I am overwhelmed by my diagnosis, is this normal?
- Can I talk to someone are there resources that could help me?
- On most days, I feel the following about my inflammatory arthritis (circle answer/answers):

Worried Anxious Hopeful Confident Depressed

Other observations:_____

If you're experiencing any of the - Helplessness following feelings, let your health - Loss of interest in friends, family care team know. or things I used to enjoy doing - Trouble sleeping, fatigue - Crying, unhappy - Loss of interest in sex or intimacy When you stop enjoying yourself, The following tips from your mood worsens and pain can feel The Arthritis Society may also more intense. Try treating yourself to be helpful. one of the suggestions below: Do something nice for yourself Go to dinner with friends Take in a sporting event See a play or a movie

Always speak to your health care team if you feel that something is "off" with your mood for more than a few weeks.

• I've started feeling (circle answer):

Better Worse

Since:

- Starting physical therapy
- Changing treatment, diet, or starting exercising

Other observations:

• Things at home and/or work have been (circle answer):

Different Better The Same Worse

Since:

- I asked for help at home or work
- I started exercising/physical therapy

Other observations:

- Something at work and/or home has changed
 - It has become more difficult to do (example)
 - Are there exercises I can do that would help me?
- I have been feeling less social and interested in my hobbies
 - I've been feeling this way since (date, event, or reason)
- I often feel isolated because of my inflammatory arthritis
 - Could you recommend local support groups or online communities?

Your health care team can help you with any emotional issues you are having because of your arthritis. Even if you are uncomfortable with discussing these topics, your health care team will be able to support you and your concerns.

You're not alone if you find living with inflammatory arthritis overwhelming at times. Feeling overwhelmed is normal and your health care team understands that it's one of the very difficult challenges of coping with arthritis. For more information on dealing with the emotional aspect of inflammatory arthritis go to:

The Arthritis Society

http://www.arthritis.ca/page.aspx?pid=1285

rheumatoidarthritis.net

http://rheumatoidarthritis.net/living-with-ra/managing-emotional-problems-and-stress/

Download or print the questions

Treatment Plan: Injection



What to Discuss with Your Health Care Team

There are different types of medication that are used to treat arthritis. Some of these medications are taken orally, while others are administered by injection.

Over time, you may try several different treatments and change your treatment plan. It is important to keep in mind that at one point in your treatment plan, you may need a medication that will require you to inject it.

How can you be prepared?

If injecting yourself is part of your treatment plan, your health care team will help prepare you for this. Make sure you ask them any questions you have since they're experienced and can answer concerns about selfinjection and direct you to the resources that are available to help and support you.

Knowing you're not alone and have somewhere to turn to can help make your injection experiences easier. While you may never look forward to your injection, with the proper support, there may be a time when it becomes just another part of your routine.

It can be easy to forget to take your treatment, especially if you don't take it every day. Recording your treatments can also help you get into a routine.

Talk to your health care team about how the following could ease your injection experience:

- Is it important to choose a comfortable environment to inject myself?
- Are there any relaxation techniques or tips you could recommend before self-injection?
- I keep hearing that I should hold my breath or try deep, rhythmic belly breathing when I inject myself – which one is right?
- I keep on forgetting to take my treatment, what can I do to remind myself?
- Do you have any recommendations for keeping a record or diary of my injections?
- I'm worried that injecting myself will hurt, is there something I can spray on before to numb the area?
- Am I supposed to use a new site every time I inject?
- Should I bring my treatment to room temperature before I inject myself?
- Is it okay to call my health care team if I need help with my injection?
- Is trial and error part of the selfinjection learning experience?
- Record any questions you may have in your "Making the Most Out of Your Appointment" document for future discussion.

Download or print the questions

Ongoing Inflammatory Arthritis Management



What to Discuss with Your Health Care Team

Taking small steps each day toward managing your inflammatory arthritis can help you feel better both short and long-term. While living with inflammatory arthritis is a challenge, advances in understanding arthritis have been helpful and promising in the last decade.

What you and your caregiver can do to make sure your care is on the right track

- Take your medication regularly as prescribed
- Be mindful of the positive choices you make in realizing your goals
- Reach out to family and friends for help in tracking your inflammatory arthritis
- Celebrate your successes, be proud of yourself when you realize your goal
- Reach out to other people with inflammatory arthritis through support or on-line groups

Things to think about until your next appointment

- What positive steps have I taken this week/month to manage my inflammatory arthritis?
- Should I do more to reach my goal(s) or do I need to adjust my goal(s)?
- I am working with support people (professionals, family/friends, support groups) to achieve my goals
- I am sharing what it's like to live with inflammatory arthritis with family and friends so they can better understand my arthritis and have realistic expectations of me
- I am feeling better about my inflammatory arthritis overall because I have a management plan and a health care team in place

Future

Use this tool and your "Making the Most Out of Your Appointment" document to reach your goals in the future. They can be your customized tools to help you measure any progress you've made towards reaching your major goals, and be realistic resources for new goal setting.

Download or print the questions

Download or print the complete discussion tool to prepare for your doctor's appointment.