



Working with your Care Team and Making Treatment Decisions

This resource is for people who are newly diagnosed or actively managing a psoriatic condition. It provides a guide to examining treatment goals, weighing treatment options, making treatment decisions, working with your care team, and identifying other supports that you or your loved ones may need throughout your condition.

For more information on psoriasis, psoriatic arthritis, treatments and supports and access to treatments in Canada, visit cpn-rpc.com

1. WHY LEARN TO WORK WITH YOUR CARE TEAM AND MAKE TREATMENT DECISIONS?

You've received your diagnosis, informed yourself about the condition, and met with members of your care team — hopefully your family physician or nurse practitioner and a specialist, like a dermatologist. Maybe you're also receiving care from a naturopathic doctor, a yoga teacher, or another therapist. From this list of providers, you may have received one or more treatment options.

Now you're asking yourself: What's right for me? What are they going to do to my body, mind, emotions? How much will they cost? Do I qualify for coverage for any of them? If not, how much will I need to pay? Treatment decisions can

sometimes feel overwhelming! Making this more complex, your treatment decisions, your care team, and the benefits, costs and known risks of them may change over time. For psoriatic conditions in particular, you may find that some treatments become less effective over time. This means the skills and tools that you need to work with your care team and make treatment decisions are really important, so that you and your loved ones can manage changes whenever they happen.

This resource aims to provide you with some tips and tools to help you think through treatment decisions and work well with your care team.

2. MAKING TREATMENT DECISIONS AND WORKING WITH YOUR CARE TEAM

This resource is about helping you make treatment decisions and will guide you through working with your care team as a part of this process. In particular, we will talk about:

- **setting your goals,**
- **discovering more about how you think,**

- **assessing your treatment options, and**
- **weighing your treatment options in order to make treatment decisions.**

How to work with your care team and loved ones as part of the treatment decision-making process will also be touched on throughout this section.

When establishing goals for your condition, making decisions about treatments, and monitoring the impacts of what you do over time, some people find it helpful to write everything in one place, such as a binder or journal. Keeping a journal or binder helps you keep all of your information organized and helps you track changes over time.

SETTING YOUR GOALS:

- The first important question to ask yourself is “what do I hope to achieve?”
- Define your personal goal or goals for your psoriatic condition. Use your own terms to describe your goals.
- Make them specific, measurable, and achievable. Examples include:
 - “I want to be able to wear a bathing suit.”
 - “I need to ease or get rid of the itching, burning, and/or pain.”
 - “I want to wear black clothing again.”
 - “I need to reduce my feelings of embarrassment.”
 - “I need to be able to go back to work.”
 - “I need help to take care of myself better — eat better, rest, laugh, and exercise.”
- Then ask yourself: “Which goal is most important to me? How would I rank my goals in order of importance?”
- Your goals may change over time, so check-in on your goals at least once a year. Sometimes, you may need to do this more frequently.

Be sure to recognize the difference between your “needs” versus your “wants” and prioritize your needs.

- Share your goals with your care team. Have a conversation about how the treatment options and other supports they’re recommending might help you achieve your goals.
- If any treatments support your goals, ask all the questions you have about those treatments. The following section on treatment options has a tool to help you with these questions. Keep notes of all of this information in your binder. Either you or a support person attending the appointment with you can take notes of the information your care team shares with you.

Also be sure to think about goals that you might be able to achieve in the short-term, the mid-term, and the long-term.

TRACK YOUR PROGRESS OVER TIME:

- Track the impacts of your treatment choices on achieving your goals over time. Write about your experiences in your journal or binder and date the entries. It’s also important to include in your dated entries information about how you’re feeling, any changes in your diet or appetite, and whether or not you’ve had any other illnesses (e.g., the flu). Sometimes different factors can contribute to a flare-up. Use this valuable information with your care team during your appointments to talk about what’s working and what’s not working, and whether or not you are achieving your goal(s).
- Physician appointments often need to be focused and direct. It’s important to know your top question or concern prior to the appointment and address it. If time allows, you can then touch on any other important questions or concerns that you’ve identified. If you have other care team members, such as nurses or pharmacists, you could also ask them some of your other questions that relate to their expertise (e.g., drug dosing and interactions for a pharmacist) to see what they recommend.

CONTINUE TO EDUCATE YOURSELF

- It's also important that you use your goals to do your own research and learning about your psoriatic condition. Be sure to check your sources for credibility. Some credible sources of information include: your primary care practitioner (family physician, nurse practitioner); your specialist(s) (dermatologist, rheumatologist); your other care team providers like nurses, social workers, or dietitians; your support group; your pharmacist; credible internet sources such as this one, Health Canada, the U.S. Food and Drug Administration, European Medicines Agency, the ministry of health in your province or territory; health non-profits like the Canadian Psoriasis Network; and the public library.
- If and when feasible, you can also attend learning events associated with psoriatic conditions. Also, talk to family and friends, especially people who've lived with the same condition. What have they learned? What do they suggest? Information is power.
- Write down what you learn. Adjust your goals and questions for your care team over time based on your new insights.



DISCOVERING MORE ABOUT HOW YOU THINK:

- Many factors influence how you think and make decisions.
 - Your personality (e.g., intuitive/logical, stories/numbers, risk taker/risk averse)
 - your age and stage in life (e.g., child/youth/adult/senior, parent, pregnant/trying to become pregnant, retired)
 - your sex and gender (e.g., cis-male, cis-female, intersex, trans)
 - your physical and mental health
 - your emotions
- your cultural norms
- your social circumstances including where you live, what you do for work, whether you have support from friends or family

These are all examples of factors that influence how you think and make decisions.

- Other factors, like your symptom severity, your health history, your past treatment experience, your physiological makeup may also determine what treatments are most suitable for you.

HERE ARE SOME QUESTIONS TO REFLECT UPON TO HELP YOU DISCOVER MORE ABOUT HOW YOU THINK:

When I think about the factors listed above, which ones have the most meaning and are most important to me? Why?

Whose advice do I trust when I must decide something? Why? Do they understand me and have my best interests at heart?

Based on the factors that are influencing my ability and willingness to think and make treatment decisions now, what kind of supports do I need to help me see the whole picture so I can weigh both the pros and cons of treatment options and consider the implications on my short-, mid-, and long-term goals?

Has my thinking or have my personal circumstances changed so that I need to rethink a treatment decision I made before?

ASSESSING YOUR TREATMENT OPTIONS:

- You'll find that there is often more than one treatment option available to you and different types available too (e.g., clinical options like prescription medication; over-the-counter options like creams; nutritional options like diet changes; emotional or psychological options like support groups or therapy; and traditional or complementary options like indigenous traditional healing, traditional chinese medicine, or naturopathy.)
- What options are suitable for you may depend on things like the severity of your symptoms and how they are affecting your day-to-day life.
- Often it's safe to combine different treatment options to try to get a better result and achieve your goals. However, it's very important to be careful about potential known or unknown contraindications. A contraindication is when one treatment interacts negatively with another one and creates harmful effects.
- Keep a log in your journal of your current treatment plan. Include everything - whether it's vitamins you buy or prescription medication. Share your treatment plan with every health provider you see about your psoriatic condition, including your pharmacist. Make sure they're considering what you're already taking and doing before they make any new recommendations or change your treatment. Keep notes of any changes in how you feel once a new treatment is introduced alone or in combination with another. Talk to your care team immediately if you notice any harmful effects or have any concerns.



BENEFITS VERSUS RISKS:

- All treatments, for any health condition, have potential positive effects and potential risks. Many also have uncertainties; things we just don't know yet. Uncertainties in medicine refer to anything that suggests some level of doubt, or lack of confidence, about a treatment's positive and negative effects. It can also refer to doubt about when it's best to use the treatment; who will benefit; or results of studies done to assess the treatment. Every time we make a treatment decision with our care team, we are weighing the benefits, risks, and uncertainties for ourselves.
- To start, let's distinguish between the positive effects, troublesome effects, and negative toxic effects of treatments. It's important to gather information about potential positive and negative effects of treatments from credible sources, such as your physician(s) and your pharmacist.

Positive effects: A positive effect of treatment is also called a benefit. Three kinds of positive effects exist:

1. A positive effect of treatment can modify disease by slowing it down or even reversing it. This kind of treatment effect may also provide relief from symptoms of the disease.

2. A positive effect of treatment can manage disease. The treatment does not change the fact that the disease exists. It may prevent the progression or worsening of the disease.

3. A positive effect of treatment can manage symptoms. The treatment does not change the fact that the disease exists. Instead, its goal is to reduce or control symptoms of the disease, such as itchiness or pain.

Troublesome effects:

A toxic effect of treatment is also called a harm. A troublesome effect is less serious than a negative toxic effect because it is not life-threatening. Even so, a troublesome effect can be severe, such as a bad headache. A troublesome effect may last only a short time, or it may be present for as long as the treatment continues. It can affect whether you decide to continue a treatment. The same treatment may cause certain troublesome effects in one person, but not in another.

Negative toxic effects:

A negative toxic effect is both negative and serious. In rare cases, a toxic effect can cause a severe reaction, like birth defects, drug dependence, or death. Patients must report any noticeable toxic effects to their physician right away, so that the effects do not progress. The same treatment may cause toxic effects in one person, but not in another.

- Research the following questions for each treatment option:
 - What is known about the positive and negative effects of this treatment?
 - If the treatment is licensed by Health Canada, how recent was the licensing? For information on licensing visit Health Canada.
 - Was the treatment turned down for licensing or removed from markets anywhere in the world? If so, why?
 - If a treatment is on the market in Canada, is it licensed with full authorization (Notice of Compliance, or NOC) or with conditional authorization (Notice of Compliance with Conditions, or NOC/C)?
 - Is funding for this treatment covered by any source, such as a provincial, territorial or federal government, the company that manufactures it, or a private insurance company? If not, why? What are my options for coverage?
- Is there someone within my care team whose job it is to help me figure out how to get my treatment paid for? If not, can anyone in my care team or within a patient group like the Canadian Psoriasis Network connect me to such a person, if they exist in my health system?
- Are there treatments being researched for my psoriatic condition? What are they? Check out: <https://www.canadianpsoriasisnetwork.com/clinical-trials/>
- Here is a tool with questions to help you work with your physician to understand the risks, benefits, and uncertainties of the treatment(s) they're recommending to you.

ASSESS THE POSSIBLE POSITIVE EFFECTS/BENEFITS

What are the known possible benefits of this treatment for my psoriatic condition? Does it change the way the disease progresses, or does it provide relief from symptoms?

How long does it take before I should feel the benefits of the treatment?

How long does treatment benefit last if I take it as recommended?

Does my doctor believe the studies for this treatment were designed well? Are there new studies on the treatment that deal with the treatment's benefits once it was used in the general population for some time? If so, what are the results?

Did the research show whether or not this treatment is likely to work for "people like me"? ("People like me" are patients who were part of the study that had the same characteristics as yours, such as your sex, your condition type, the severity of your condition.) If so, how likely is the treatment to work for me?

Did the research show the lowest dose that is effective for a patient like me?

What kind of treatment is it and how is it administered (e.g., pill, cream, injection)?

Is this treatment likely to work on aspects of my psoriatic condition that are most important to me in achieving my goal(s)?

ASSESS THE POSSIBLE NEGATIVE EFFECTS/RISKS

How safe is this treatment option for me? What is the likelihood of someone like me experiencing any harmful or toxic effects?

If I might experience a harmful or toxic effect, can it be managed in my case? How long would it take for me to experience the harmful or toxic effect? If I stop treatment, will the harmful or toxic effect stop? How long after I stop the treatment?

How safe is this treatment option, generally, for most people?

What do I do if I experience a harmful or toxic effect? Who do I contact between appointments if I notice any harmful or toxic effects from the treatment?

ASSESS THE UNCERTAINTIES

Are there any uncertainties about the treatment that I should consider?

Ask any other questions about what you or your loved one still do not know or feel unclear about when considering the effects of a treatment.

- You want to have a sense of the time period for how long a treatment will take to start working. It's also important to know who to talk to and what to do next if things aren't working out as hoped by the end of that time period or if you experience any negative effects from the treatment.
- Create a calendar for yourself that tracks your timelines so you remember to follow-up. If you

like digital, put it in your phone's calendar. If you like paper, get a calendar dedicated to tracking the achievement of your goals. Put the timelines in it and put it in your binder. Keep all of the names and contact info for your care team members with your calendar in your binder (or in your phone's contact list).



CONSIDERING OTHER IMPACTS OF TREATMENT DECISIONS:

- It's important to realize that some treatment choices may have other impacts on you or your loved one's lives. Here are some examples to consider:
 - Visits to an office, clinic or hospital and the impact this has on you and/or a loved one's daily routines
 - Need to travel away from home
 - Need for home care
 - Need to inject yourself on a regular basis
 - Impacts on other treatments being used (e.g., having to stop another treatment or reduce it)
- Need for other treatments to manage the negative effects of this treatment (new medicines or starting other therapies such as physiotherapy)
- The commitments required in joining a clinical trial
- Effects on finances
- Effects on daily activities or life choices (e.g., making changes to meal times, what foods you eat, or birth control due to the treatment)

WEIGHING YOUR TREATMENT DECISIONS:

- Now that you've assessed your treatment options, how do you decide what is right for you?
- Go back to your goals. Thinking about your goals, decide on two or three possible **positive treatment effects** that are most important to you for each treatment you are considering.

Then, for each treatment, decide how they rank for your two or three most important positive effects.

- Now, consider these questions:
 - What treatment options can I exclude? Why?
 - What treatment option(s) are most likely to meet my main goals?
 - What treatment option(s) do I feel most confident about?

TREATMENT OPTION #1
Best positive effect
Next best positive effect
Least important positive effect

TREATMENT OPTION #2
Best positive effect
Next best positive effect
Least important positive effect

TREATMENT OPTION #3
Best positive effect
Next best positive effect
Least important positive effect

TREATMENT OPTION #4
Best positive effect
Next best positive effect
Least important positive effect

NOW, CONSIDER THESE QUESTIONS:

What treatment options can I exclude? Why?

What treatment option(s) are most likely to meet my main goals?

What treatment option(s) are most likely to meet my main goals?

- Thinking about your goals, decide on two or three possible **negative treatment effects** that are most important to you for each treatment you're considering.
- For each treatment, decide how they rank for your two or three most important negative effects.

Now, consider these questions:

- What treatment options can I exclude? Why?
- What treatment option(s) are most likely to meet my main goals?
- What treatment option(s) do I feel most confident about?

TREATMENT OPTION #1
Worst negative effect
Next worse negative effect
Least important negative effect

TREATMENT OPTION #2
Worst negative effect
Next worse negative effect
Least important negative effect

TREATMENT OPTION #3
Worst negative effect
Next worse negative effect
Least important negative effect

TREATMENT OPTION #4
Worst negative effect
Next worse negative effect
Least important negative effect

NOW, CONSIDER THESE QUESTIONS:

What treatment options can I exclude? Why?

What treatment option(s) are most likely to meet my main goals?

What treatment option(s) do I feel most confident about?

FINALLY, CONSIDER THE UNCERTAINTIES AND THE IMPACTS OF YOUR CHOICES:

How do I feel about any uncertainties in what experts say about the treatment(s) I'm considering?
How does this affect my comfort level with each treatment?

How do I feel about the other kinds of impacts on me or my loved ones if I take this treatment (e.g., need to travel, impact on finances)? What are the important impacts to me? Can I list them in order, from most to least important? How do they apply to my preferred treatment options?

Can I identify which treatment options I feel most confident about and why?

Take some time to think about your life circumstances, goals, as well as the people most important to you. Use these questions as a guide:

- Does my age make a difference to my treatment options?
- Does being male, female, intersex, or trans make a difference to my treatment options?
- Do I have any other physical or mental health problems that could affect the type of treatment that may be best for me?
- Do I have medical coverage to pay for the treatment or can I afford it?
- Could my daily routines — related to family, work, where I live — affect whether I am able to take the treatment as recommended?
- Are there important people in my life that could or should influence my decision? If so, who are they and what is their role?
- Which treatment(s) may help me achieve my goals?
- Which treatment(s) do I have most confidence in? Why?

- Which treatment(s) best suit my own circumstances? Why?
- Which treatment(s) do I have least confidence in? Why?
- Which treatment(s) least suit my goals and my circumstances?

Lastly, recheck your thinking. What else — rightly or wrongly — might have affected your thinking and decisions? For example:

- My emotions: fear, hope, feeling frustrated or desperate.
- The way people I care about are feeling.
- My assumptions — or other people's assumptions — about the treatments or about other things related to my psoriatic condition. Are those assumptions reasonable? Are they still valid based on what I know now?

By this point in your process, you have thoroughly assessed and weighed your options. You have narrowed them down. You're ready to choose treatment options that you think have a good chance of helping you achieve your goal(s).

LAST THOUGHTS:

- Remember to go through this process at least once a year, or whenever something changes in your life that makes you realize you need to reconsider your goals or treatment options.
- Finally, please remember that it is very important that you tell your health care team about your experiences with your treatment(s). In particular, let them know if:
 - you respond well to the treatment they recommended and it helps you achieve your goal(s);
 - you do not respond to the treatment;
 - the treatment stops working for you or becomes less effective over time;
 - you experience any negative effects from the treatment;
 - you experience any negative effects when a new treatment is introduced and combined with other treatments; or
 - anything else is affecting your ability to stick to your treatment.

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²Some of the content in this section was adapted, with permission, from YOUR TREATMENT DECISION GUIDE A step-by-step process to help patients think about the positive and negative effects, and the uncertainties, of treatments by Linda Wilhelm, Louise Binder, and Robyn Lim (2017).