

What can you do to manage your psoriasis?

A decision aid for psoriasis patients

This decision aid is for you if you have psoriasis and are thinking of starting treatment for the first time or changing your treatment. This aid is to help you learn about treatment so that you can make a choice with your doctor. *Your doctor can provide more details on options based on your own needs and health issues.*

What is psoriasis? It is a disease of red, scaly skin spots that can be itchy and painful. Sometimes it also causes tender, swollen, stiff joints. The risk of heart attacks, strokes, high blood pressure, cholesterol problems and diabetes may be higher in those with more severe psoriasis. People who have psoriasis may feel embarrassed and stressed about their disease. Although the causes are still not fully known, psoriasis may be due to genes and abnormal immune system activity. It may be made worse by factors such as stress, weather changes, skin injury, infections, or some drugs. If not treated, psoriasis may remain stable or worsen. But control of psoriasis without treatment is not likely.

How do doctors determine severity?

Doctors measure severity by counting the amount of body covered with psoriasis (body surface area or BSA) and whether certain key regions are involved (such as face, hands/feet, genitals). The effect of psoriasis on your life quality is also important. Psoriasis may be mild if it involves less than 5% BSA, does not involve key regions or has little impact on life quality. Moderate to severe psoriasis involves 5% BSA or more, may affect key body areas or may have high impact on life quality.

Step 1: Assess the impact of your psoriasis

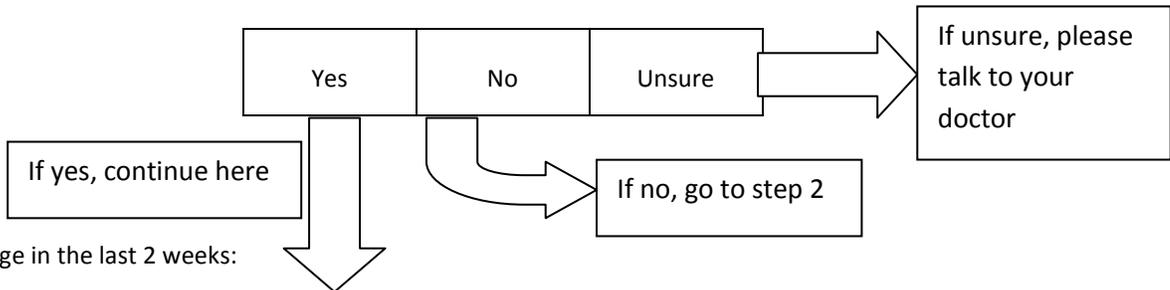
How long have you had psoriasis? _____

Please circle your responses for the following questions:

- a. On average in the last 2 weeks:

Questions	Not at All	Very mild	Mild	Moderate	Severe	Very Severe
<i>How severe has your psoriasis been?</i>	0	1	2	3	4	5
<i>How itchy has your psoriasis been?</i>	0	1	2	3	4	5
<i>How painful has your psoriasis been?</i>	0	1	2	3	4	5

- b. In the past 2 weeks, have you had stiffness, pain and/or swelling of your joints (arthritis)?



- c. On average in the last 2 weeks:

Questions	Not at all	Very little	A little	Somewhat	Quite a bit	Extremely
<i>How painful has your arthritis been?</i>	0	1	2	3	4	5
<i>Has arthritis reduced your ability to do daily activities?</i>	0	1	2	3	4	5

Step 2: What treatments have you used for psoriasis? List most recent first, starting with what you are currently using.

Name of Therapy	How long did you use it?	Did you use it as prescribed?	Why did you stop?
<i>Current Treatment:</i>			
<i>Previous Treatment:</i>			
<i>Previous Treatment:</i>			

Step 3: Treatment options: benefits and risks

What are your options?

There are many treatment options available to you. They include **topicals** (such as creams and lotions), **phototherapy** (light therapy), **pills** (taken by mouth) and **injections** (into your skin, muscles or veins). It is likely you will discover one or more that will fit with the level of your psoriasis, lifestyle, and what you prefer. Each person responds differently to treatment and you may need to try several before you find one that is best for you.

Right now, you can make one of four treatment choices:

1. *Stay with your current treatment, using it as prescribed*
2. *Stay with your current treatment, but think about other options (such as changing or adding another treatment)*
3. *Change from current treatment to one that is more intensive*
4. *Stop current treatment for a period of time*

Please go over these 2 questions before you look at the next pages:

1. *Are you pleased with your current treatment?*

Yes	No	Uncertain
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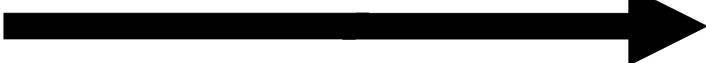
- a. If no or uncertain, please explain **why?**

2. *Do you know the treatment options available to people with psoriasis?*

Yes	No	Uncertain
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TREATMENT OPTIONS: Common types of psoriasis treatments

Start by thinking about the treatment you now use and whether you feel this is the right one for you.

	For milder psoriasis		For more severe psoriasis	
	Topicals	Phototherapy	Pills	Injections
What is this?	<ul style="list-style-type: none"> - applied directly onto skin such as creams, gels, lotions, sprays, ointments and solutions - Can take some time to apply and may be messy - Can be combined with other treatments 	<ul style="list-style-type: none"> - Treatments using sun light or light lamps (natural sunlight, UVB or UVA) - Can be done in some clinics or at home Requires extra time and space (if done at home) - Can be used with other treatments 	<ul style="list-style-type: none"> - Taken by mouth (orally) - May require you to stop and start or change treatment from time to time to reduce risk of serious side effects with continued use 	<ul style="list-style-type: none"> - Treatments which are injected into skin, muscle or veins - Can be done in doctor's office, special clinic, or at home
Examples	Topical corticosteroids Calcipotriol/Calcitriol (Vitamin D analogues) Combo corticosteroids and vitamin D analogues Retinoids (Vitamin A analogues)	UVB Narrowband UVB Broadband PUVA	Acitretin Cyclosporine Methotrexate	Adalimumab (Humira) Etanercept (Enbrel) Infliximab (Remicade) Alefacept (Amevive) Ustekinumab (Stelara)
Who should use this treatment?	<ul style="list-style-type: none"> - For all levels of severity: alone in mild; combined with others if moderate-severe - If this is your first time using treatment 	<ul style="list-style-type: none"> - For any severity level if topicals alone not working well enough 	<ul style="list-style-type: none"> - For moderate to severe psoriasis - If topicals and phototherapy not working well enough or not practical - If looking for long term or continued therapy 	<ul style="list-style-type: none"> - If you have moderate to severe psoriasis and other treatments not working well enough
Who should not use this treatment?	<ul style="list-style-type: none"> - If you are not going to use it as prescribed, they may not work as well 	<ul style="list-style-type: none"> - If you have bad reactions to sunlight, other disease worsened by light, history of skin cancer or are taking drugs that make you sunburn faster 	<ul style="list-style-type: none"> - Some types of pills may be unsafe if you have high blood pressure, liver disease, high cholesterol, kidney disease, chronic infections, or cancer 	<ul style="list-style-type: none"> - Some types of injections may be unsafe if you have heart failure, blood disease, nerve disease, chronic infections, or cancer
Special Situations	<ul style="list-style-type: none"> - If you are pregnant, planning to become pregnant in near future, or breastfeeding - tell your doctor as there may be risks with some of these treatments. 	<ul style="list-style-type: none"> - If you are pregnant, planning to become pregnant in near future or breastfeeding, phototherapy is considered a safe option. 	<ul style="list-style-type: none"> - If you are pregnant, planning to become pregnant in near future or breastfeeding - tell your doctor as many of these pills should be avoided. - If you have psoriatic arthritis, methotrexate may be helpful. 	<ul style="list-style-type: none"> - If you are pregnant, planning to become pregnant in near future or breastfeeding - inform your doctor as there may be risks with some of these medicines. - If you have psoriatic arthritis, Enbrel, Humira and Remicade may be helpful.

Treatment Options for Mild, Moderate, and Severe Psoriasis

On the following pages, you'll be given more facts about:

1. Topicals
2. Phototherapy
3. Pills
4. Injections

Based on the quality of research, the proof shown will be rated as follows:¹⁻⁴

Gold 
Highest quality proof, lowest risk for bias

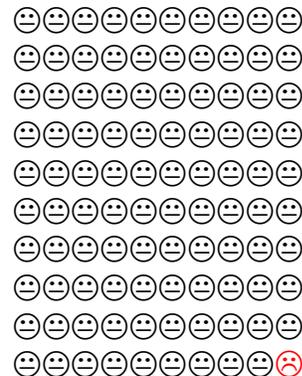
Silver 
Strong quality proof, some risk for bias

White 
Some proof available but greater risk for bias

How well a treatment works is shown with green smiling faces against a background of 100 faces. That is, if 100 people were to use this treatment, the number of green, smiling faces shows those who achieve good (or better) control of psoriasis. In some cases, research may show a range of responses. In the chart, darker green shows the lower range while lighter shows the upper range. In the diagram below, this means that 50-60/100 people would achieve good control.



Risk of serious side effects is also shown against the same background of 100 faces using red, sad faces. That is, if 100 people were to use this treatment, the number of red, sad faces shows those who would have serious side effects. In the diagram below, this means that 1/100 people would have a serious side effect.



Treatment Options if you have Mild or Moderate Psoriasis: Topicals

	Topical Corticosteroids	Vitamin D Analogues	Combination Corticosteroids + Vitamin D analogues	Topical Retinoids (Vitamin A Analogues)
Number of people who achieve good control (within 12-16 weeks)	37-68/100  	22-60/100  	56/100  	5/100  
Serious Side Effects	Rate not reported; rates similar to people taking no treatment (placebo)			
When you can expect some progress	In 1-2 weeks	In 2-4 weeks	In 1-2 weeks	In 1-2 weeks
Other features	Can be used as long-term therapy; can combine with other treatments; Blood testing not needed			
How to use	Applied to affected areas , <i>once or more</i> daily			
Total cost (\$C)* to treat 1% BSA** per yr	29-65	176-194	270	216
Other Concerns	Long-term use can lead to skin thinning, stretch marks, blood vessel marks, easy bruising. Strong agents used for a long time may lead to decrease in some of your own hormone levels.	May make skin briefly red, tender or itchy; Caution if you have problems with high calcium levels, kidney or liver disease.	As for topical corticosteroids and vitamin D analogues	May make skin briefly red, tender or itchy; and increase skin reaction to sunlight

* Total cost includes medication, blood and other tests (if any), and physician visits

**BSA refers to body surface area and 1% BSA almost equals the size of your palm

Treatment options if you have Mild, Moderate or Severe Psoriasis: Phototherapy

	PUVA 	UVB Narrowband 	UVB Broadband 
Number of people who achieve good control Number with serious side effects (12-16 weeks)	90/100  	63-75/100  	
Serious Side Effects	Rate not reported; Increased risk of skin cancer (if >200 treatments)	Rate not reported, but considered rare	
	Eg. : Skin cancer, eye or skin damage, viral infections		
When you can expect some progress	In 1-2 wks; with 2-3 treatments per week		
Where it can be given	Special treatment centers only	Some clinics or in your home if special light treatment boxes purchased	
Ease of Use	Must take pills before light treatment (UVA) 2-4 times/week	Treatment 2-3 times/week	Treatment 2-3 times/week
Total cost* C\$/yr	~ \$390	~ \$315	
Other Considerations	- Skin cancer and eye exams, blood testing required - Eye protection needed after taking pills - Shouldn't take this if you have skin cancer or diseases made worse by artificial or sunlight	- Skin cancer exams - Caution if you have skin cancer or diseases made worse by artificial or sunlight	- Skin cancer exams - Caution if you have skin cancer or diseases made worse by artificial or sunlight

* Total cost includes medication, blood and other tests (if any), and physician visits

Treatment Options if you have Moderate or Severe Psoriasis: Pills

	Acitretin 	Cyclosporine 	Methotrexate 
<p>Number of people who achieve good control</p> <p>Number with serious side effects (12-16 weeks)</p>	<p>25-50/100</p> 	<p>50-70/100</p> 	<p>36-60/100</p> 
<p>Serious Side Effects</p>	<p>Rate not reported though rare</p> <p>Eg: bone and/or joint problems, kidney damage, high blood pressure, cancer, lung damage, liver damage)</p>	<p>2.3/100 per month</p>	<p>0/100 per month</p>
When you can expect some progress	In 4 to 8 weeks	In 4 weeks	In 4 to 12 weeks
Other features	Long term, continuous use	Not long term use	Long term, continuous use
Ease of Use	Daily by mouth	Twice daily by mouth	Once weekly by mouth
Total cost* C\$/yr	~ \$1640	~ \$3400	~ \$712
Other Concerns	<ul style="list-style-type: none"> - Blood tests required - Avoid if pregnant or planning to become pregnant in near future as drug may harm the fetus - Caution if have high lipids or arthritis 	<ul style="list-style-type: none"> - Blood, TB (tuberculosis) and urine tests, blood pressure checks - Avoid if you have kidney disease, high blood pressure, cancer, chronic infections - Caution if pregnant or planning to become pregnant in near future 	<ul style="list-style-type: none"> - Blood tests and TB (tuberculosis) tests - Can be toxic with liver or kidney disease, caution if you have liver/blood disease - may need liver biopsy if used long term - Can affect sperm so men should avoid fathering children while on treatment (and up to 3 months after) - Can damage fetus: so avoid pregnancy while on treatment (and up to 1 month after)

* Total cost includes medication, blood and other tests (if any), and physician visits

Treatment Options if you have Moderate or Severe Psoriasis: Injections

	Humira/ Adalimumab 	Enbrel/ Etanercept 	Remicade/ Infliximab 	Stelara/ Ustekinumab 
Number of people who achieve good control; Number with serious side effects (12-16 weeks)	69/100 	48/100 	79/100 	70/100 
Serious Side Effects	0.5/100 per month	0.6/100 per month; but no greater than no treatment	1.1/100 per month; but no greater than no treatment	Rate not reported
	Eg: Cancer, serious infections, autoimmune conditions, liver damage, medicine reactions, heart damage, serious allergic reactions			Eg. Serious allergic reactions; potential for cancer and serious infections
When you can expect some progress	In 4 weeks	In 6 - 8 weeks	In 1 - 2 weeks	In 2 weeks
Other Features	Long term, ongoing use	Long term, ongoing use	Long term, ongoing use	Long term, ongoing use
Ease of Use	Every other week	Twice a week for 12 weeks, can then reduce to once a week	By vein : 3 times over 6 weeks, then every 8 weeks	First 2 treatments 4 weeks apart, then every 12 weeks
Total costs* C\$/yr	Range from \$18000 - \$30000			
Other Concerns	- Blood and TB testing, chest x-ray - Avoid if you have nerve disease, heart failure, cancer, chronic infection - Caution if, or at risk of, pregnancy	- Blood and TB testing, chest x-ray - Avoid if you have nerve disease, heart failure, cancer, chronic infection - Caution if, or at risk of, pregnancy	- Blood and TB testing, chest x-ray - Avoid if you have nerve disease, heart failure, cancer, chronic infection - Caution if, or at risk of, pregnancy	- Blood and TB testing, chest x-ray - Avoid if you have cancer or chronic infection. - Caution if, or at risk of, pregnancy

* Total cost includes medication, blood and other tests (if any), and physician visits

My values: *What is important to me?*

Please circle the number that shows the importance of these statements to you (with 1 meaning *not important*; 5 meaning *extremely important*). Feel free to write any extra comments after each section.

not important

extremely important

How important is it for you to use a treatment that works well for psoriasis?

Examples: I can achieve excellent control.
I can maintain the improvement.
Other (please specify):

1 2 3 4 5

How important is it for you to consider the side effects of your treatment?

Examples: Side effects are known and documented.
Side effect rates are low.
Other (please specify):

1 2 3 4 5

How important is the speed of effect of your treatment?

Example: I will see results quickly.
Other (please specify):

1 2 3 4 5

How important is the cost of treatment to you?

Examples: I have a drug plan.
My annual cap allows me to afford \$20000/year or more.
Other (please specify):

1 2 3 4 5

How important is it for treatment to be easy to use?

Examples: I can administer treatment on my own.
I can receive treatment in my doctor's office.
Other (please specify):

1 2 3 4 5

How important is it for you to avoid using certain types of treatments?

Example: I prefer topicals, phototherapy, pills, injections, other
Other (please specify):

1 2 3 4 5

How important is it to see other features or benefits from your treatment?

Examples: I can use the treatment for the long term.
I can use the treatment for maintenance.
Other (please specify):

1 2 3 4 5

How important are other concerns with the treatment?

Example: Other testing is required.
I have a medical condition that may affect treatment.
Other (please specify):

1 2 3 4 5

Recall your 4 treatment options. Please choose the one that best describes how you feel now about treatment for your psoriasis (circle the number of your response).

1. Stay with your current treatment, using it as prescribed
2. Stay with your current treatment, but think about other options (such as changing or adding another treatment)
3. Change from current treatment to one that is more intensive
4. Stop current treatment for a period of time

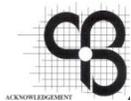
If you chose 2 or 3 (consider other options or change to a more intensive one) - what treatment do you prefer and why? Please rate your options from 1 to 4, with 1 being your highest choice and 4 being your lowest choice.

In order of what I prefer:	Treatment Type	Why?
1		
2		
3		
4		

Did you have enough help to decide on treatment ?

If not, what other help do you need?

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FOR MORE INFORMATION, PLEASE VISIT THE FOLLOWING SITES:

www.psoriasis.org (National Psoriasis Foundation)

www.skinpatientalliance.ca/

www.dermatology.ca/patients_public/

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