

Melanoma, Skin Cancer, and Ocular Melanoma Patient

Decision-Making Guide

With a tear-away checklist for both patients and physicians



Save Your Skin Foundation (SYSF) is a Canadian patient-led not-for-profit group dedicated to the fight against skin cancers, and melanomas through nationwide education, advocacy, and awareness initiatives. Save Your Skin Foundation is committed to playing an active role in reducing the incidence of skin cancer in Canada, and to providing compassionate support for all Canadians living with skin cancers.

The following tear-away pages of this brochure are designed to be used as companion checklists for patients and physicians to use during appointments. The lists are designed to ensure coverage of common early-appointment discussion topics from both the patient and physician perspective, while offering space for both parties to take notes about the conversation.

This checklist is also available in digital form on the Downloadable Resources page:



This is not a medical document nor is it intended to provide medical advice of any kind. That is a matter between you, your support system if you choose and your healthcare team.

FOR PHYSICIANS



What We Offer



Save Your Skin Foundation can assist patients newly diagnosed with skin cancers and melanomas with their informational and wellness needs.

We also offer:

- Offer informational webinars for patients and physicians led by members of our medical advisory board
- Publish reports with treatment news and updates from global oncology conferences
- Publish patient-reported experience measures on topics from mental wellness, side effects, logistical experiences, genetic testing, and specific treatment types
- Operate in the health policy space, providing feedback on Federal and Provincial policy and preparing drug submissions for the Canadian Agency of Drugs and Technologies in Health (CADTH) and the Institut national d'excellence en santé et services sociaux (INESSS)
- Are fully bilingual.



Save Your Skin Foundation

Email: info@saveyourskin.ca

Phone: 1.800.460.5832



Appointment Decision-Making

Checklist

APPOINTMENT DATE:
PROGNOSIS
Size and Staging Information
CARE PLAN
Should I Receive Genetic Testing?
Treatment Options
Benefits, Risks, and Uncertainties
Is there a risk that this will limit my treatment plan?
Logistical Considerations: Caregiver? Travel?
Would my treatment choice here impact any subsequent treatments?
TREATMENT TIMELINE
Treatment Start Date and Timeline
FINANCIAL CONSIDERATIONS
Coverage Options
Will I Have to Take Time Off Work?
QUALITY OF LIFE
How Will These Options Impact My Quality of Life?



Questions to Ask Your Doctor



Tips and Recommendations:

Other Considerations

Explore holistic support, covering fertility, and more. Understanding treatment impacts on fertility and exploring preservation options is vital for melanoma or skin cancer patients.

Fertility Preservation Options:	 Explore fertility preservation methods before starting cancer treatments. Discuss fertility concerns with your healthcare team. Consider consultation with a fertility specialist.
Healthy Lifestyle Practices:	 Maintain a balanced diet to support overall health. Stay physically active within the recommended guidelines for your condition. Prioritize sleep for optimal well-being.
Stress Management:	 Explore stress-reducing activities such as meditation or yoga. Consider counseling or support groups for emotional well-being.
Connect with Fertility Resources:	 Access educational materials on fertility preservation. Attend workshops or seminars on managing fertility concerns. Seek support from organizations specializing in fertility issues.
Communication with Healthcare Team:	 Keep an open dialogue with your healthcare team regarding fertility concerns. Discuss any lifestyle changes or concerns that may impact your overall well-being.



Save Your Skin Foundation offers information about the different types and stages of skin cancers, melanoma treatment options, and strategies for advocating for yourself in the Canadian healthcare system.

We also offer:

- Support groups and fireside chats
- Informational webinars
- Materials to help you prepare for appointments
- Treatment decision-making guides
- One-on-one emotional and financial support
- An extensive community of cancer patients, survivors, and caregivers
- Advocacy resources
- Fully bilingual content.





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What's ultimately decided, and why?

In this section, you can document the decisions made by your healthcare team regarding your course of treatment. Whether it's surgery, immunotherapy, or a combination of treatments, having a clear record of what has been decided is crucial for understanding your treatment plan. Use this space to jot down the specifics discussed during your appointments, including the recommended treatment options, their potential side effects, and any additional
instructions provided by your healthcare provider.
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List of Professionals

Family Doctor Dr.
Tel
Medical Oncologist Dr.
Tel
Dermatologist Name
Tel
Plastic Surgeon Name
Tel
Other Surgeon Name
Tel
Nutritionist Name
Tel
Social Worker Name
Tel
Receptionist Name
Tel
Psychologist Name
Tel

List of Professionals

Oncology Pharmacist Name
Tel
Support Group Name
Tel
Physiotherapist Name
Tel
Patient Pharmacist
Tel
Other
Tel
Other
Tel
Other
Tel
Other
Tel
Other
Tel

Symptoms

If you experience any side effects from your medications, you can write them down and talk to your doctor on your next visit. However, if it is urgent, please go to the hospital emergency room.

DATE & TIME	MEDICATION NAME	SYMPTOMS



Symptoms

MEDICATION NAME	SYMPTOMS
	MEDICATION



Treatment Plan

WEEK	DAY									
	М	Т	W	Т	F	S	S			

Weight

Week						
kg						
lb						

Treatment Plan

WEEK	DAY									
	М	Т	W	Т	F	S	S			

Weight

Week						
kg						
lb						

Treatmen	t
Medication Name	
Date	
Time	
Location	
Appoint m	ents
Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Week from _____ to ____

Week from to				
Treatmen	t			
Medication Name				
Date				
Time				
Location				
Appointm	ents			
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

Week from to				
Treatmen	t			
Medication Name				
Date				
Time				
Location				
Appoint m	ents			
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

Week from to				
Treatmen	t			
Medication Name				
Date				
Time				
Location				
Appoint m	ents			
Monday				
Tuesday				
Wednesday				
Thursday				
Friday				
Saturday				
Sunday				

List of Medications

Follow-up after melanoma treatment depends on the stage of the melanoma. The following follow-up schedule is based on the information from the National Comprehensive Cancer Network. However, your doctor may have a plan for you depending on your individual situation

Stage	Follow-up
Stage 0 in situ	At least an annual skin examination for lifeMonthly self-skin examination by patient
Stage IA	 History and physical examination (with emphasis on nodes and skin) every 3-12 months for 5 years, then annually as clinically indicated At least annual skin examination for life Monthly self skin and lymph node examination by patient
Stage IB-IV	 History and physical examination (with emphasis on nodes and skin) every 3-6 moths for 2 years, then every 3-12 months for 2 years, then annually as clinically indicated Chest x-ray, LDH, Complete Blood Count every 6-12 months (optional) Routine imaging is not recommended for stage IB or IIA disease CT scans to follow up for specifi c signs and symptoms Consider CT scans to screen stage IIB and higher for recurrent or metastatic disease At least annual skin examination for life Monthly self skin and lymph node examination by patient

List of Medications

When?	Medication Name	Appearance (colour, shape, etc.)	Dosage	Why?

List of Medications

When?	Medication Name	Appearance (colour, shape, etc.)	Dosage	Why?



FOR PATIENTS



Follow-up and Monitoring

After a melanoma diagnosis, the risk of recurrence or another melanoma is increased. Therefore, your doctor will perform a full-body skin examination again, at least every year, for the rest of your life. It is also your responsibility to make sure to call your doctor and set up the appointments.

Self-monitoring

Performed regularly, self-examination can alert you to changes in your skin and aid in early detection. So pay attention to your body and observe for any changes. You should do it at least once a month and make it a habit. Some changes may be external that you can see from the mirror, while there also may be changes inside of your body that you will only be able to feel.

Be aware of any signs and symptoms. Your doctor will teach you how to examine your skin and lymph nodes. When you do self-examination, look for changes in moles (colour, size, thickness, texture), any new growths, sores that do not heal, and abnormal areas of skin. Make sure you check the back of your body. Use a mirror or have someone check for you. Contact your doctor right away if you notice any abnormalities.

A schedule like the one below is followed if you have no signs or symptoms of melanoma. If you do develop new signs or symptoms, your doctor will investigate them and determine appropriate treatment and follow-up based on your test results.



Appointment Tracking Sheet

Date	Follow-Up Appointment

Appointment Tracking Sheet

Date	Follow-Up Appointment

Additional Resources

Explore additional resources and support through our innovative QR code system. Scan the QR codes below to access a wealth of information, ranging from educational materials about melanoma and skin cancer to helpful tips for self-care and coping strategies.

MONTHLY SUPPORT CALLS LOVED ONES SUPPORT

ABOUT MELANOMA



ABOUT SKIN CANCERS



VIDEO RESOURCES



MENTAL HEALTH SUPPORT







Glossary of Treatment Terms

Biomarker: "A biological molecule found in blood, other body fluids, or tissues that is a sign of a normal or abnormal process, or of a condition or disease. A biomarker may be used to see how well the body responds to a treatment for a disease or condition. Also called molecular marker and signature molecule." (National Cancer Institute Dictionary)

BRAF Kinase Inhibitor: "A substance that blocks a protein called BRAF. [...]It may be found in a mutated (changed) form in some types of cancer, from [the start of a clinical trial] to disease including melanoma and colorectal cancer. Blocking mutated BRAF kinase proteins may help keep cancer cells from growing. Some BRAF kinase inhibitors are used to treat cancer." (National Cancer Institute Dictionary)

BRAF V600 Mutation: "A type of mutation (change) in the BRAF gene that causes a mutant form of the BRAF protein to be made. This results in uncontrolled cell division and growth, which can lead to cancer. Drugs that target this mutant BRAF protein may kill cancer cells or stop them from growing. [...] Checking for the BRAF V600 mutation in tumor tissue may help plan cancer treatment." (National Cancer Institute Dictionary)

Clinical Benefit (CB): "The achievement of complete response, partial response, or stable disease in a patient." ("Clinical Endpoints in Oncology- A Primer," Delgado and Guddati 2021)

Complete Response (CP): "The disappearance of all signs of cancer in response to treatment. This does not always mean the cancer has been cured." (National Cancer Institute Dictionary)

Disease Control Rate (DCR): "Percentage of patients with complete response, partial response, or stable disease as a result of their therapy." ("Clinical Endpoints in Oncology- A Primer," Delgado and Guddati 2021)

Disease Free Survival (DFS): "In cancer, the length of time after primary treatment for a cancer ends that the patient survives without any signs or symptoms of that cancer. In a clinical trial, measuring the DFS is one way to see how well a new treatment works. Also called diseasefree survival, relapse-free survival, and RFS." (National Cancer Institute Dictionary)

Disease Progression (DP): "Cancer that continues to grow or spread." (National Cancer Institute Dictionary)

Distant Metastasis: "Refers to cancer that has spread from the original (primary) tumor to distant organs or distant lymph nodes. Also called distant cancer." (National Cancer Institute Dictionary)

Duration of Clinical Benefit (DoCB): "The time progression or death in patients who achieve complete response, partial response, or stable disease for 24 weeks or longer. It is a primary endpoint that is used in clinical trials in which disease stabilization in order to prolong survival is the primary goal." (Clinical Endpoints in Oncology- A Primer," Delgado and Guddati 2021)

<u>Duration of Response (DoR):</u> "The time from [the start of a clinical trial] to disease progression or death in patients who achieve complete or partial response. It is closely related to [diseasefree survival] and measures how long a patient will respond to treatment without tumor growth or metastasis." (Clinical Endpoints in Oncology-A Primer," Delgado and Guddati 2021)

Immune Checkpoint Inhibitor (ICI): "A type of drug that blocks proteins called checkpoints that are made by some types of immune system cells, such as T cells, and some cancer cells. These checkpoints help keep immune responses from being too strong and sometimes can keep T cells from killing cancer cells. When these checkpoints are blocked, T cells can kill cancer cells better. [...] Some immune checkpoint inhibitors are used to treat cancer." (National Cancer Institute Dictionary)

Immunotherapy: "Immunotherapy is a type of cancer treatment that helps your immune system fight cancer. [...] Immunotherapy is a type of biological therapy. Biological therapy is a type of treatment that uses substances made from living organisms to treat cancer." (National Cancer Institute)

Objective Response (OR): a measurable response (National Cancer Institute Dictionary)

Glossary of Treatment Terms

Objective Response Rate (ORR): "The percentage of people in a study or treatment group who have a partial response or complete response to the treatment within a certain period of time. A partial response is a decrease in the size of a tumor or in the amount of cancer in the body, and a complete response is the disappearance of all signs of cancer in the body. In a clinical trial, measuring the objective response rate is one way to see how well a new treatment works." (National Cancer Institute Dictionary)

<u>Partial Response (PR):</u> "A decrease in the size of a tumor, or in the extent of cancer in the body, in response to treatment". (National Cancer Institute Dictionary)

<u>Progression-Free Survival (PFS):</u> "The length of time during and after the treatment of a disease, such as cancer, that a patient lives with the disease but it does not get worse. In a clinical trial, measuring the progression-free survival is one way to see how well a new treatment works." (National Cancer Institute Dictionary)

Relapse-Free Survival (RFS): "In cancer, the length of time after primary treatment for a cancer ends that the patient survives without any signs or symptoms of that cancer. In a clinical trial, measuring the relapse-free survival is one way to see how well a new treatment works. Also called disease free survival" (National Cancer Institute Dictionary)

Targeted Therapy: "Targeted therapy is a type of cancer treatment that targets proteins that control how cancer cells grow, divide, and spread. [...] As researchers learn more about the DNA changes and proteins that drive cancer, they are better able to design treatments that target these proteins" (National Cancer Institute)

TIL Therapy: "A type of treatment in which tumour-infiltrating lymphocytes (a type of immune cell that can recognize and kill cancer cells) are removed from a patient's tumour and grown in large numbers in a laboratory. These lymphocytes are then given back to the patient by infusion to help the immune system kill the cancer cells" (National Cancer Institute). Please note that TIL therapy is still considered an experimental approach; research in this area is ongoing to further optimize the effectiveness and safety of TIL therapy and to explore its potential for treating other types of cancer.

Treatment-Related Adverse Events (TRAEs):

"An adverse event (also referred to as an adverse experience) can be any unfavorable a nd unintended sign, symptom, or disease temporarily associated with the use of a drug, without any judgement about causality or relationship to the drug." (Clinical and Translational Science Institute)

Tumor Mutational Burden (TMB): "The total number of mutations (changes) found in the DNA of cancer cells. Knowing the tumor mutational burden may help plan the best treatment. For example, tumors that have a high number of mutations appear to be more likely to respond to certain types of immunotherapy." (National Cancer Institute Dictionary)

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