

what HAPPENS now

Follow up Care for
Thyroid
Cancer Patients

**Living
Beyond
Cancer**

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What HAPPENS now?

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Follow up Care for
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Your cancer treatment is now finished. You are joining a growing number of people who have been treated for thyroid cancer and who are often called thyroid cancer survivors. Lifelong, regular checkups are an extremely important part of your long-term care.

This guide describes your recommended follow up care plan. It will help you learn how to manage your life after cancer treatment and explain the tests you will need to have. Your cancer specialist has also sent your healthcare provider (family doctor/nurse practitioner) a copy of your follow-up care plan.

You, along with your health care provider are an important part of your follow up care. If needed, your health care provider can contact your cancer doctor and you may be referred back to the Interdisciplinary Thyroid Oncology Clinic (ITOC). We hope this guide will be helpful. If you have any questions or concerns, please talk to your healthcare provider or cancer patient navigator by calling **1-866-524-1234** (if there is one in your area).

This plan is a guide and does not replace your health care provider's advice.

Please know that you are not alone as you move forward in your recovery.

Notes and Questions

What is Follow up Care?

Follow up care is the care you receive after completing active treatment.

The goals of follow up care are:

- **Regular thyroid hormone level assessment.** Follow up care visits allow you to discuss your thyroid hormone replacement therapy (Synthroid or similar pills) with your healthcare provider.
- **Early detection of recurrence.** Early detection of recurrence of thyroid cancer is important. Treatment is more likely to be successful at an early stage.

Follow up care for thyroid cancer involves:

- **Regular visits** with your healthcare provider. These visits are very important to your follow up care and allow you to discuss any concerns or issues.
- **Staying involved** with your care is very important. Some people work with their healthcare provider to maintain a personal file of test results and notes.

Everyone in follow up care will not have exactly the same care because each follow-up plan is based on your treatment and how it affected your body.

Notes and Questions

Follow up Care Recommendations

Guidelines for routine thyroid cancer follow-up after discharge from the Thyroid Oncology Clinic

Recommendations	Frequency
Visit to healthcare provider for general physical examination including neck examination.	Every 6 months
Assessment of serum TSH	At least every 6 months – Labs may cancel this test if requested within 6 weeks of the previous test.
Measurement of serum thyroglobulin	Every 12 months
Neck Ultrasound	Every 2-3 years

Your specialists will send a letter at the time of your discharge to guide your healthcare provider on how to adjust your thyroid hormone levels. As noted above, you will require blood tests from time to time to maintain your thyroid hormone levels within that target range.

Notes and Questions

Returning Cancer: Signs to Watch For

One of the biggest concerns for cancer patients is that the cancer may return some day. This is why follow up care is so important. It is important to know that the chance of cancer returning drops year after year.

Although the symptoms listed may indicate cancer recurrence, these symptoms are much more commonly due to non-cancerous causes.

See your health care provider **right away** if:

- You see a swelling in your neck
- You notice an unusual lump or swelling anywhere in your body
- You cough up blood

See your health care provider if these symptoms **last more than one week**:

- Pain that will not go away or is getting worse
- Shortness of breath
- Loss of appetite
- Weight loss without trying
- Big change in your energy level or ability to be active

If you have any health concerns that you feel may be related to cancer, it is important to check with your healthcare provider.

Notes and Questions

Cancer Screening and Other Tests

Talk with your health care provider about cancer screening and other tests.

For Women

Breast Cancer Screening: Women 50 and over should have a mammogram every 2 years. If you have a strong family history or are currently using hormone replacement therapy a mammogram may be needed every year. Visit the Nova Scotia Breast Screening Program website www.breastscreening.nshealth.ca to learn more. Call **473-3960** or **1-800-565-0548** to book an appointment.

Cervical Cancer Screening: Women should start screening for cervical cancer (also called a Pap test) within three years of becoming sexually active. Once women start having Pap tests, they should have them every three years. Some women, because of their family history or their own health history, may need to be screened more often. Ask your doctor how often you need to have a Pap test.

Screening may be stopped after age 70 if the woman has had:

- Three or more negative tests since age 60.
- A total hysterectomy for benign causes.
- No history of treatment for abnormal cell growth on the cervix (also called cervical dysplasia).
- No history of cervical cancer.

To get a copy of your cervical cancer screening history, call Nova Scotia Cancer Care Program at **1-866-599-2267**.

To learn more about cervical screening visit www.nscancercare.ca.

For Men

Prostate Cancer: Talk to your doctor/nurse practitioner about your risk for prostate cancer and the benefits and harms of PSA testing. To learn more visit the Canadian Cancer Society's website www.cancer.ca or call **1-888-939-3333**.

For Both Men and Women

Colon Cancer Screening: All Nova Scotian women and men, who are between 50 and 74 years old and are registered with MSI (have a Nova Scotia Health Card), will automatically get a colon cancer home screening test in the mail every two years from the Nova Scotia Colon Cancer Prevention Program. Colon cancer screening works best when you take the test when you are feeling good – before you have any symptoms or warning signs. Talk with a doctor or health care provider if you have concerns about colon cancer or are having long-lasting changes in your bowel habit. To learn more about the colon cancer home screening test call Nova Scotia Cancer Care Program: **1-866-599-2267** or visit www.nscancercare.ca.

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Cancer Screening and Other Tests *(continued)*

For Both Men and Women *(continued)*

Diabetes screening: Starting at age 40, you should have a Fasting Plasma Glucose (FPG) test every three years. For those at high risk (family history, overweight, Aboriginal, African Nova Scotian, have a history of gestational diabetes or pre-diabetes, heart disease, increased cholesterol, increased blood pressure), more frequent and/or earlier testing should be considered. To learn more, call the Canadian Diabetes Association **1-800-226-8464** or visit **www.diabetes.ca**.

Cholesterol Screening: You should have a cholesterol test at age 40 if you are a man, or age 50 if you are a woman. Start at a younger age if you have diabetes, heart disease, if you smoke or if you are overweight. Talk with your health care provider about how often you should have this test.

Blood Pressure Checks: Get your blood pressure checked regularly by your health care provider.

Other ways to protect your health:

Immunization: You should have a flu shot every fall. If you are 65 or older, have diabetes, heart or lung problems, you should also have a pneumonia vaccine. Ask your health care provider about the benefits and risks of getting a shingles vaccination.

Protect your Skin: Having chemotherapy or radiation can make you more sensitive to harm from the sun and other sources of ultraviolet (UV) rays. Some prescription and over-the-counter medications can also make skin very sensitive to the sun. Protect yourself by being informed and using good sun protection practices at work, in your community and on vacation. Check the UV Index daily and practice sun safety as recommended. The higher the UV Index, the more protection is required. Plan activities in the shade, cover up with clothing and a wide-brimmed hat, wear sunglasses and use a broad spectrum sunscreen with a Sun Protection Factor (SPF) of 30 or higher. Avoid use of tanning beds.

Stop Using Tobacco*: Quitting smoking or other tobacco use after a cancer diagnosis does make a difference. It can result in fewer treatment and cancer-related complications. It can make your cancer treatments more effective, improve survival and reduce the chance of a recurrence or a second cancer. It is never too late to quit tobacco. Help is available. If you want to quit, talk to your health care provider or call 811 to be connected to a tobacco cessation counselor who can offer assistance over the phone and refer you to a quit program in your area. There is no cost and no referral is required. Online resources are also available at: **<https://tobaccofree.novascotia.ca/>**

*Tobacco includes smoked tobacco (cigarettes, pipes, cigars) and smokeless.

Limit or Avoid Alcohol: Discuss risks associated with alcohol use with your health care provider. Drinking alcohol increases your risk for several types of cancer.

Cancer Screening and Other Tests (continued)

Other ways to protect your health (continued)

Risk increases for some kinds of cancer with as little as one drink per day. The more you drink, the more your risk increases. The risk of cancer increases regardless of what type of alcohol you drink (beer, wine, cider, spirits or liqueur). If you do drink alcohol, comply with the Canadian low risk drinking guidelines. If you do not drink alcohol, don't start. Combining smoking with alcohol increases cancer risks even greater than the cancer risks that come from drinking alcohol or smoking on their own.

Helpful websites can be found under Supports and Resources.

Dental Health: Chemotherapy can cause dental problems. It is important that you have regular dental checkups. Your dentist will need to know that you had thyroid cancer and the type of treatments you have received. Brushing with a soft tooth brush, and using toothpaste for sensitive teeth is recommended.

Living Well After Thyroid Cancer

Eating Well:

There are no special foods or vitamins to take after thyroid cancer treatment. Following Canada's Food Guide is the best approach: www.canada.ca/en/health-canada/services/food-nutrition.

For the QEII Cancer Care Program please call the clinical dietitian at **902-473-3972**.

For the Cape Breton Cancer Centre please call the clinical dietitian at **902-567-8552**.

Call your cancer patient navigator (**1-866-524-1234**) for referral to a dietician in your community.

Physical Activity:

Whether you are getting back to activities you enjoy or starting new ones, being active after treatment for thyroid cancer is important. Physical activity can help improve appetite, energy level and sleep. Physical activity can also help reduce risk of cancer coming back, fatigue and anxiety. It is recommended you try to be physically active at least 150 minutes per week and that you should start slowly and progress gradually. It is important to always check with your health care provider about the activities and level of activity that would be best for you.

Taking thyroid pills properly:

Thyroid replacement therapy is given in the form of pills (e.g. Synthroid or similar pills). A number of foods and tablets interfere with the absorption of thyroid pills. It is crucial that you should take your thyroid replacement pill on an empty stomach (3-4 hours with no food) with water and wait for 45 minutes before taking any other pill or eating food. Most people find it easiest to take their pills first thing in the morning or before going to sleep.

Programs for Cancer Survivors

Cancer Transitions

QEII Cancer Care Program and the Cape Breton Cancer Centre offer a free six week program, *Cancer Transitions*, to help cancer survivors adjust to life after cancer.

Cancer Transitions covers these topics:

- Get Back to Wellness
- Eating Well
- Exercise for Wellness
- Medical Care After Cancer
- Emotional Health

For more information and to register:

QEII Cancer Care Program call **902-473-3449**

Cape Breton Cancer Centre call **902-567-8074**

Living Beyond Cancer: What Happens Next?

The QEII Cancer Care Program offers a two and a half hour session that focuses on some of the key issues cancer survivors face in the months following active treatment. You may attend in person at the Bethune Ballroom, VG Site or via telehealth, at the Regional Hospital in your area.

Topics include:

- What is Follow up Care
- What to Expect after Cancer Treatment
- Eating Well After Cancer
- Emotional and Practical Support
- Physical Activity

For more information and to register call toll free **1-866-599-2267** and select option 3, or to register online please go to **www.nscancercare.ca** and click on I am a Cancer Survivor.

We now have Living Beyond Cancer video segments available to watch online. These can be found by visiting **library.nshealth.ca/cancer** and clicking on Cancer Patient Education Videos.

Your Way to Wellness

Your Way to Wellness is a provincially sponsored, free program, led by volunteer Lay Leaders. The Program is designed to help people with chronic conditions learn skills to live a healthier life. *Your Way to Wellness* is offered once a week for a 2 ½ hour session over six weeks. Programs are offered all over Nova Scotia.

For more information, call toll free: **1-888-672-3444** or visit **https://yourway.novascotia.ca**

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Programs for Cancer Survivors (*continued*)

Group Learning Sessions for Cancer Patients and Families

Some cancer patients and survivors experience treatment related side effects. There are a number of group teaching sessions which focus on the most common ones.

These sessions are not support groups, but participants have the opportunity to ask questions. Each session is 2 hours. Available resources and supports are discussed. Family and friends are also welcome to attend. For the date, time and location of upcoming sessions, please call **1-866-599-2267** and select option 3.

We now have video segments available to watch online. These can be found by visiting **library.nshealth.ca/cancer** and clicking on Cancer Patient Education Videos.

Managing Your Cancer-related Fatigue: Cancer-related fatigue (tiredness) is one of the most common side effects of cancer treatment. The sessions provide practical information about cancer-related fatigue and helpful management strategies.

Taking Control of Your Cancer-related Worry and Anxiety: Most people with cancer experience worry and some level of anxiety. This session provides practical information about cancer-related anxiety and helpful coping strategies (such as deep breathing relaxation).

Taking Control of Your Cancer-related Sadness and Depression: Many people with cancer experience sadness or depression. This session provides practical information about cancer-related sadness and depression and helpful coping strategies.

Coping With Cancer-related Brain Fog: Some cancer patients and survivors notice changes in their thinking and cognitive abilities during or after treatment. This is known as cancer-related brain fog. This session focuses on understanding cancer-related brain fog and management strategies.

***Coping with Your Cancer-related Pain:** Not everyone with cancer experiences pain but many people do. This session focuses on understanding cancer-related pain and management strategies such as medication, managing energy and relaxation.

*This session is only available online at **library.nshealth.ca/cancer** and click on Cancer Patient Education Videos.

Support and Resources

Cancer affects more than your body. It has an impact on your whole life. Many people who have had cancer find that talking with a professional counselor or therapist can be very helpful. Health care providers are the experts in treating cancer, but you are the expert in the way cancer affects your life. Counseling can help you to find strength and meaning. It can also help you cope, adjust, and find solutions to problems. You can go to counseling on your own or with members of your family.

There is a psychosocial cancer team at the QEII Cancer Care Program for people who have been diagnosed and treated for thyroid cancer anywhere in the province of Nova Scotia. The team provides counseling to thyroid cancer patients & their families. Team members include psychologists, psychiatrists, social workers, nurses and spiritual care providers.

Support can be provided to you by phone or in person. If you are having difficulty coping, you can ask your health care provider, your cancer doctor or another member of your cancer team to make a referral to a member of the psychosocial cancer team (QEII Cancer Care Program).

If you live in Sydney, please call the social worker at the Cape Breton Cancer Centre at **902-567-8551**. If you live outside Halifax and Sydney, check with your cancer patient navigator, social worker or health care provider to find out about services in your district. To reach your local cancer patient navigator please call **1-866-524-1234**.

Cancer Connection – Canadian Cancer Society

The Canadian Cancer Society can connect patients or caregivers with fully screened and trained volunteers who have had cancer or cared for someone with cancer. Our volunteers listen, provide hope, offer encouragement, and share ideas for coping – all from their unique perspective as “someone who has been there.”

Call **1-888-939-3333** to get connected or logon at **www.cancerconnection.ca**.

Private Medical Insurance and Employee Assistance Programs

Counseling is also covered under some private insurance plans (i.e. Blue Cross). There may be a yearly maximum as to how much your plan will pay. Contact your insurer for the details specific to your plan.

As well, many employers offer Employee Assistance Plans which offer a limited number of free counseling sessions. Please contact your Human Resources department for information.

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Support and Resources (*continued*)

Support Groups

A support group is a group of people with similar problems or concerns. Support groups meet on a regular basis. There are many different cancer support groups. Some are for the patients. Others are for the family and/or friends of the patient. Others are open to anyone. Groups may be led by a health care professional or made up completely of peers. You can find support groups that meet face-to-face or online.

It may help to talk with the person running the group to see if the group offers what you need. You may want to check out a few different groups to find one that works best for you. It is hard to know if a support group will be right for you without going to at least two meetings.

A support group should make you feel comfortable enough to talk about what you think and feel. If it does not, speak with the facilitator privately. You may decide it is best not to continue going. Remember that it may take time to find a group that fits.

Find a support group in your area:

- Thyroid Cancer Canada: **www.thyroidcancerCanada.org**
- Canadian Cancer Society: **1-800-639-0222** or visit **www.cancer.ca**
- QEII Cancer Care Program in Halifax: **902-473-6067**.
- Social Worker at the Cape Breton Cancer Centre Sydney: **902-567-8551**.
- Cancer Patient Navigators: **1-866-524-1234**.
- Check for posters in your cancer treatment centre.
- Ask people you know who have gone through cancer, or who are currently dealing with the disease themselves.
- Call 211 to find local support groups.

Many people choose online support groups. These groups help people who may not wish to attend a face-to-face group. Be careful when looking for an online group. Anyone with internet access can create an online group, even if they do not have any real experience.

If you are interested in online groups, contact **CancerChatCanada** by visiting their website at **cancerchatCanada.ca**. Canadian cancer care professionals lead these groups. Most are available in any province or territory.

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Support and Resources (continued)

Books

After You Ring the Bell...10 Challenges for Cancer Survivor. Anne Katz. Oncology Nursing Society. 2012.

Cancer is a Word Not a Sentence by Dr. Robert Buckman

Life after Cancer. A guide for cancer survivors. Canadian Cancer Society, 2008.
Visit the CCS website: www.cancer.ca or call **1-888-939-3333**.

Life After Cancer Treatment. Facing Forward Series. U.S. Department of Health and Human Services. National Institutes of Health. 2004.
Visit the NIH website: <http://www.cancer.gov/cancertopics/coping/life-after-treatment/page1>

Living Well after Cancer. A guide for cancer survivors, their families and friends. The Cancer Council New South Wales, February, 2010.
Visit the CCNSW website: www.cancercouncil.com.au

Picking Up the Pieces. Moving Forward after surviving Cancer. Sherri Magee and Kathy Scalzo. Raincoast Books, Rutgers University Press. 2007.

The Essential Cancer Treatment Nutrition Guide and Cookbook by Jean Lamantia

The Healing Circle by Dr. Timothy Walker and Dr. Rob Rutledge, 2011.

The Places that Scare You: A Guide to Fearlessness in Difficult Times by Pema Chodron

When someone You Love Has Completed Cancer Treatment. U.S. Department of Health and Human Services. National Institutes of Health. May, 2010.
Visit the NIH website: <http://www.cancer.gov/cancertopics/coping/someone-you-love-completed-cancer-treatment.pdf>

Men Cancer Sex. Anne Katz. 2010. Oncology Nursing Society.

Women Cancer Sex. Anne Katz. 2009. Oncology Nursing Society.

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Support and Resources *(continued)*

Websites

The Web is a great source of information about moving forward after cancer, but it is also full of misinformation. These websites are ones you can rely on!

For Thyroid Cancer Survivorship information, visit:

- Thyroid Cancer Canada: www.thyroidcancer.ca
- American Thyroid Association: www.thyroid.org
- American Society of Clinical Oncology (ASCO) Patient Site: www.cancer.net
- British Columbia Cancer Agency: bccancer.bc.ca
- Canadian Cancer Society: www.cancer.ca <click on> **Nova Scotia** or call **1-888-939-3333**
- Nova Scotia Cancer Care Program: www.nscancercare.ca
- Healing and Cancer: www.healingandcancer.org
- National Cancer Institute (USA): www.cancer.gov

For Physical Activity information, visit:

- Canadian Cancer Society, Physical Activity After Treatment:
<http://www.cancer.ca/en/cancer-information/cancer-journey/life-after-cancer/your-wellness-plan/physical-activity-after-treatment/?region=on>
- The Canadian Society for Exercise Physiology (CSEP):
http://www.csep.ca/CMFiles/Guidelines/CSEP_PAGuidelines_adults_en.pdf

For Fatigue information, visit:

- Canadian Cancer Society: www.cancer.ca <click on> **Cancer Information** <click on> **diagnosis and treatment** <click on> **managing side effects** <click on> **fatigue**.
- American Cancer Society: www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue.
- <http://www.youtube.com/watch?v=YTFPMYGe86s&feature=youtu.be>

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Support and Resources (*continued*)

Websites (*continued*)

For Sexual Health information, visit:

- Canadian Cancer Society: www.cancer.ca <click on> **Cancer Information** <click on> **diagnosis and treatment** <click on> **managing side effects**
- American Cancer Society: www.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fertility-and-sexual-side-effects

For information on other ways to protect your health:

- Weather Network UV Index Nova Scotia: <http://www.theweathernetwork.com/forecasts/uv/list/cans/all>
- Government of Canada: <http://healthycanadians.gc.ca/healthy-living-vie-saine/environment-environnement/sun-soleil/index-uv-indice-eng.php>

- Canadian Dermatology Association Sun Safety: <http://www.dermatology.ca/programs-resources/resources/sun-safety/protecting-your-family/>
- <http://novascotia.ca/dhw/addictions/>
- Canada's Low Risk Drinking Guidelines: <http://novascotia.ca/dhw/addictions/alcohol-drinking-guidelines.asp>
- Fact sheet on alcohol and chronic disease: http://novascotia.ca/dhw/addictions/documents/Alcohol_Chronic_Disease.pdf

For information in languages other than English

There are a number of reputable sources of cancer information in languages other than English. We suggest the following Canadian resources:

- British Columbia Cancer Agency: bccancer.bc.ca
- Canadian Cancer Society: www.cancer.ca or call **1-888-939-3333**
- Cancer Care Manitoba: www.cancercare.mb.ca
- Cancer Council New South Wales: www.cancercouncil.com.au
- Vancouver Coastal Health: <http://vch.eduhealth.ca>

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Get Involved

Cancer patients, families, and friends have unique, valuable perspectives to share about cancer care. It is important to hear from people who have experience with the cancer system in order to see what can be changed to better meet people’s needs.

As a cancer survivor you may want to get involved with the Cancer Patient Family Network (CPFN). The CPFN is a program of Nova Scotia Cancer Care Program that connects cancer patients, survivors, family members, and friends with opportunities to improve the cancer system. As a member of the CPFN you will have opportunities to participate in focus groups and committees, complete surveys, and review patient education resources.

Contact Nova Scotia Cancer Care Program by calling toll-free **1-866-599-2267**, emailing **cancercareinfo@nshealth.ca** or visiting **www.nscancercare.ca**. For more information about the Cancer Patient Family Network, please contact the Patient Engagement Coordinator at **902-473-2637** or email **CPFN@nshealth.ca**.

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Special thanks to the Thyroid Oncology Clinic for their contributions to this document.

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