

# what HAPPENS now?

Follow up Care for  
**Cancer  
Patients**

**Living  
Beyond  
Cancer**

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**Cancer  
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## What is Follow up Care?

### The goals of follow up care are to:

- **Provide support.** Follow up care visits allow you to discuss your progress and any problems you have, such as dealing with the short term and long term side effects of your cancer treatment and fear of recurrence.
- **Check for return of your cancer or a new cancer.**

### Follow up care involves:

- **Regular visits with your health care provider.** These visits are very important to assess and talk about your progress and your current health.

- **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.

- **Other tests** may be recommended depending on how you are doing.

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

## Follow up Care After Cancer<sup>1</sup>

Follow up Care	Year 1	Year 2	Year 3	Years 4 and 5
Doctor/Nurse practitioner visit	Every 3-6 months	Every 3-6 months	Every 3-6 months	Every 6-12 months

After year 5, you should have annual visits with your health care provider.

<sup>1</sup> American Society of Clinical Oncology, 2006



## Cancer Screening and Other Tests

Just like people who have not had cancer, it is important for you to continue with routine screening for cancer and other diseases. Some examples are given below but others may be needed depending on your family history.

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

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### For Women

**Cervical Cancer Screening:** Women should start screening for cervical cancer (also called a Pap test) within three years of becoming sexually active or upon reaching the age of 21, whichever comes later. Women who have never been sexually active do not need Pap screening. Pap testing should be done every three years. Women with a history of cancer of the cervix or who have been treated (by LEEP, laser, cryotherapy,

cone, hysterectomy) should be screened annually for life. Immunocompromised or HIV positive women should be screened annually for life. Women can discontinue having Pap tests at age 70 if they have had three or more negative Pap tests in the previous 10 years. Women who have had a total hysterectomy for benign causes with no treatment for abnormal cell growth on the cervix can discontinue Pap screening.

The screening guidelines only apply to women with no symptoms of cervical cancer who are, or have been, sexually active. If a woman is experiencing symptoms such as irregular bleeding or pain, she should speak with her health care provider.

To learn more about cervical cancer screening guidelines, call Nova Scotia Cancer Care Program: **1-888-480-8588** or visit **www.nscancercare.ca**.

**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 **902-473-3960** or **1-800-565-0548** to book an appointment.

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### For Men

**Prostate Cancer:** Talk to your health care provider 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**.

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## Cancer Screening and Other Tests *(continued)*

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### For Both Men and Women

**The Nova Scotia Colon Cancer Prevention Program:** 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. 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](http://www.nscancercare.ca)**.

**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](http://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:** You should have your blood pressure checked regularly by your health care provider.

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### Notes and Questions

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## Other Ways to Protect Your Health

**Immunizations:** 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.

**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. 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, follow 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.

**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.

**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 cancer and the type of treatments you have received. Brushing with a soft tooth brush and using toothpaste for sensitive teeth is recommended.

**Helpful websites can be found under Supports and Resources, page 13.**



## What to Expect After Cancer Treatment

Most people have some side effects after cancer treatment. Side effects can start right away or they can take weeks to months to begin. Some side effects improve with time, while others may go on for many years or may be permanent. These side effects may be physical or emotional.

If any of the side effects noted below are a problem for you, talk to your health care provider. If there is a cancer patient navigator in your area, they can also help. Call **1-866-524-1234**. Your health care provider should be able to provide you with support, connect you with other services and give you information about local resources.

If you visit a clinic with a group practice, it is best if one family doctor or nurse practitioner is responsible for your follow-up care.

### Some common side effects from cancer treatment are:

**Cancer-related Fatigue:** Fatigue (excessive tiredness) is very common after cancer treatment and can last a long time. Your health care provider will assess your fatigue and suggest ways to prevent or manage it. Regular physical activity is one of the best ways to decrease your fatigue. There are resources available to help you learn more about your cancer-related fatigue. For more helpful hints visit the websites listed at the end of this booklet.

**Brain Fog or Chemo Brain:** Some people notice they are forgetful, have trouble focusing, have memory problems or are confused after being diagnosed and treated for cancer. Exercising your brain by doing crossword puzzles or number games will help. For more helpful hints visit the websites listed at the end of this booklet.

**Depression:** Depression is common after cancer treatment. Continuing to be active with your family, and in your community, can help you deal with depression. Physical activity and hobbies are also helpful. Your health care provider may suggest other approaches, such as medication or talking to a counselor. The Depression Hurts website has information you may find helpful, [www.depressionhurts.ca](http://www.depressionhurts.ca). Your family members may also have issues with depression, anxiety and mood swings. They, too, will benefit from contacting their health care provide.

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## What to Expect After Cancer Treatment (*continued*)

### Some common side effects from cancer treatment are (*continued*)

**Difficulty Returning to Work:** Many people experience distress at the idea of returning to work after treatment. When you do go back, you may find your work more challenging than before your cancer treatment. Talk with your employer, your workplace's employee health staff and your health care provider about how to deal with your work related concerns.

**Lymphedema:** Arm or neck swelling (lymphedema) can occur after surgery or after radiation treatment. Signs of lymphedema include swelling or tightness of your arm, neck, shoulder or chest; a feeling of heaviness or aching in your arm. A compression garment is used to decrease the swelling.

Moderate physical exercise of your arm and moderate weight lifting or resistance training do not increase your risk of developing lymphedema. In fact, all these activities can be helpful. If you develop lymphedema, you can be referred to the Lymphedema Clinic in Halifax by your health care provider or you can self-refer by calling the Clinic at **902-473-2151**.

If you prefer to be seen in Sydney, a referral needs to be made to the Physiotherapy Department at the Cape Breton Cancer Centre. Referrals can be from physicians or any other health care provider. For more information call **902-567-7748** and the fax number is **902-567-7869**.

**Shoulder Stiffness:** This is usually related to surgery to remove your lymph nodes in your armpit or radiation in that area. Gentle exercise may help. Your health care provider or local pharmacist can suggest other options if the stiffness continues.

**Aches and Pains:** You may have general body aches as a side effect of your treatments. This may last for a time after your therapy is completed. Usually acetaminophen, heat or warm baths and gentle exercise will help. If your aches and pains continue to interfere with your ability to enjoy yourself, your health care provider can suggest other options.

**Trouble Sleeping, Anxiety, Mood Swings:** It is not uncommon to have emotional distress after your cancer treatment. Your health care provider will be able to give you suggestions to manage your emotional distress.

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## Programs for Cancer Survivors

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### Cancer Transitions

The 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
- Emotional Health
- Exercise for Wellness
- Medical Care After Cancer

For more information and to register: QEII Cancer Care Program call **902-473-3449**; Cape Breton Cancer Centre call **902-567-8074**

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### Living Beyond Cancer: What Happens Next?

The Nova Scotia Health Authority 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 and at the Cape Breton Cancer Centre or via telehealth, at the Regional Hospital in your area. The sessions are held the last Wednesday of the month.

#### Topics include:

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

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.

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### 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, please phone, toll free: **1-888-672-3444** or visit **<https://yourway.novascotia.ca>**

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### Programs for Cancer Survivors (*continued*)

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#### 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](http://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](http://library.nshealth.ca/cancer) and click on Cancer Patient Education Videos.

## Support and Resources

Cancer affects more than your body. It can have 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.

The QEII Cancer Care Program has a psychosocial cancer team for people who have been diagnosed and treated for cancer anywhere in the province of Nova Scotia. The team provides counseling to 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).

To reach the social worker at the Cape Breton Cancer Centre please call **902-567-8551**.

If you are unable to travel to Halifax or Sydney, check with your health care provider to find out about public and private services in your district. To reach your local cancer patient navigator please call **1-866-524-1234**.

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### **Cancer Connection – Canadian Cancer Society**

The Canadian Cancer Society can connect patients or caregivers with fully screened and trained volunteers who've had cancer or cared for someone with cancer. 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](http://www.cancerconnection.ca)**.

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### **Private Medical Insurance and Employee Assistance Programs**

Counseling is also covered under some private insurance plans (e.g., 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.

## Support and Resources *(continued)*

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### 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:

- 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, or who are currently dealing with cancer themselves.

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 qualifications.

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

You can also call **211** to find local support groups.

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## Support and Resources *(continued)*

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### Books

Most of these helpful books are available in your local library or bookstore:

**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](http://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.

**Living Well after Cancer. A guide for cancer survivors, their families and friends.** The Cancer Council New South Wales, February, 2010.

**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 Journey: Overcoming the Crisis of Cancer.** Alastair J Cunningham. 2010.

**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.

**When a Parent is Sick: Helping Parents Explain Serious Illness to Children.** Joan Hamilton, Clinical Nurse Specialist, Cancer Care, QEII, Halifax.

**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)**

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#### **Websites**

The Internet is a great source of information about moving forward after cancer, but it is also full of misinformation. You can rely on these websites:

- American Society of Clinical Oncology (ASCO) Patient Site: **[www.cancer.net](http://www.cancer.net)**
- British Columbia Cancer Agency: **[bccancer.bc.ca](http://bccancer.bc.ca)**
- Canadian Cancer Society: **[www.cancer.ca](http://www.cancer.ca)** <click on> **Nova Scotia** or call **1-888-939-3333**
- Nova Scotia Cancer Care Program: **[www.nscancercare.ca](http://www.nscancercare.ca)**
- Healing and Cancer: **[www.healingandcancer.org](http://www.healingandcancer.org)**
- Living Beyond Cancer: **[www.nscancercare.ca](http://www.nscancercare.ca)** <click on> **Patients and Families** <click on> **I am a Cancer Survivor**

- National Cancer Institute (USA): **[www.cancer.gov](http://www.cancer.gov)**
- National LGBT Cancer Network: **[www.cancer-network.org](http://www.cancer-network.org)**
- Rainbow Health Ontario: **[www.rainbowhealthontario.ca](http://www.rainbowhealthontario.ca)**
- National Comprehensive Cancer Network: **[www.nccn.org/patients/resources/life\\_after\\_cancer](http://www.nccn.org/patients/resources/life_after_cancer)**

#### **For Physical Activity information:**

- Canadian Cancer Society, Physical Activity After Treatment: **[www.cancer.ca/en/cancer-information/cancer-journey/life-after-cancer/your-wellness-plan/physical-activity-after-treatment/?region=on](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): **[www.csep.ca/CMFiles/Guidelines/CSEP\\_PAGuidelines\\_adults\\_en.pdf](http://www.csep.ca/CMFiles/Guidelines/CSEP_PAGuidelines_adults_en.pdf)**
- Heart and Stroke Foundation: **[www.heartandstroke.com](http://www.heartandstroke.com)**
- Public Health Agency of Canada: **[www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca)**

#### **For Fatigue information:**

- Canadian Cancer Society: **[www.cancer.ca](http://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.cancer.org/treatment/treatments-and-side-effects/physical-side-effects/fatigue)**
- **[www.youtube.com/watch?v=YTFPMYGe86s&feature=youtu.be](http://www.youtube.com/watch?v=YTFPMYGe86s&feature=youtu.be)**

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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**.

## Follow up Cancer Care Schedule

**You can use this chart to keep track of your follow up care.**

	Year 1	Year 2	Year 3	Year 4	Year 5
<b>Family Doctor/Nurse Practitioner Visit</b>	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD
Every 3-4 months during Years 1-3	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD		
Every 6 months during Years 4-5	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD
	YYYY/MM/DD	YYYY/MM/DD	YYYY/MM/DD		

## Glossary

**Benign** A mass of cells, or tumor, that aren't cancer.

**Cancer Screening** The use of tests to find cancer before signs of cancer appear.

**Chemotherapy** **1** Drugs that kill cancer cells by damaging or disrupting the making of the genetic code. **2** Drugs that stop the growth process of cells in an active growth phase. **3** Drugs that kill fast-growing cells throughout the body, including normal cells and cancer cells.

**Fatigue** Severe tiredness despite getting enough sleep that limits one's ability to function.

**Follow up testing** **1** A close watch by your care team for cancer using tests. **2** Tests done after treatment to check for signs that the cancer has come back.

**Hormone replacement therapy** Drugs used to increase hormone levels.

**Hysterectomy** Surgery that removes the womb (uterus).

**Mammogram** A picture of the insides of a breast that is made by a test that uses x-rays.

**Menopause** The point in time when a woman will experience no more menstrual periods.

**Pap test** A procedure in which cells are removed from the neck of the womb (cervix) to be tested for disease.

**Prostate-specific antigen (PSA)** A protein made by the prostate.

**Radiation** A cancer treatment that uses high-energy radiation to kill cancer cells. It can be referred to as radiation, radiotherapy, or x-ray therapy.

**Screening** Testing done on a regular basis to detect a disease in someone without symptoms (also called screening tests).

**Side Effect** An unhealthy physical or emotional response to treatment.

**Symptom** A physical sign or patient report of a health condition.

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Developed by: Nova Scotia Cancer Care Program, 2016.

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