Follow up Care for Breast Cancer Patients

Living Beyond Cancer

What happens now?
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Your cancer treatments are now finished. You are joining a growing number of people living with cancer who are often called cancer survivors. Follow up care is a very important part of your cancer care.

This guide describes your recommended follow up care plan. It will help you learn how to manage your life after cancer treatment, understand what you can do to reduce your risk of the cancer coming back and explain the tests that are recommended for you. Your cancer doctor has also sent your health care providers (family doctor/nurse practitioner and, if needed, surgeon) a copy of your follow up care plan.

Your family members may also be at risk for breast cancer and should talk to their health care providers about their cancer risk and the screening that is right for them.

You and your health care providers are an important part of your follow up care. Your health care provider can contact your cancer doctor anytime. If needed, you will be referred back to your cancer doctor.

We hope this guide will be helpful. If you have any questions or concerns, please talk to your family doctor/nurse practitioner/surgeon or cancer patient navigator (if there is one in your area).

Please know that you are not alone as you move forward in your recovery.
What is Follow up Care?

The goals of follow up care are to:

- Provide support. Follow up care visits allow you to discuss how you are doing and any problems you have, such as dealing with the side effects of cancer treatment and fear of recurrence.

- Check for the return of cancer or a new cancer.

Follow up care for breast cancer involves:

- Regular visits with your health care provider. These visits are very important to assess and talk about how you are doing and your current health. The visit will include a breast exam, feeling for lymph nodes in your neck and armpits and a general check-up. Blood work is not usually suggested for patients with non metastatic breast cancer (cancer that has not spread beyond the breast).

- A mammogram every year.

- You may want to perform self breast examinations. If you do, talk with your health care provider about the best way to do so.

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.

This plan is a guide and does not replace your health care provider’s advice.
## Follow up Care after Breast Cancer¹

<table>
<thead>
<tr>
<th>Follow up Care</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
<th>Years 4 and 5</th>
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</thead>
<tbody>
<tr>
<td>Health care</td>
<td>Every 4 months</td>
<td>Every 4 months</td>
<td>Every 4 months</td>
<td>Every 6 months</td>
</tr>
<tr>
<td>provider visit</td>
<td></td>
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</tr>
<tr>
<td>Mammogram</td>
<td>Annually</td>
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After year 5, you should have annual visits with your health care provider.

¹ American Society of Clinical Oncology, 2006

### Notes and Questions

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Talk to Your Health Care Provider About

- **Birth control**: Birth control methods that use hormones (such as pills, patches, injections or NuvaRing) are not suggested for women who are breast cancer survivors. Your health care provider can suggest other effective birth control methods.

- **Post-menopausal hormone replacement therapy**: Hormone replacement therapy may not be recommended. If you have menopause symptoms, ask your health care provider what you can do.

- **Menopause caused by treatment**: Symptoms can include hot flashes, mood changes (such as depression), dry vagina, painful sexual intercourse or loss of sexual interest. If you have any of these symptoms ask your health care provider what you can do.

- **Risk of osteoporosis (bones that break easily)**: All post menopausal women and women who have received aromatase inhibitor therapy are at risk for osteoporosis. Your breast cancer treatment may also increase your risk. There are ways to decrease your risk of osteoporosis, such as healthy eating and calcium supplements. It is recommended that you take Vitamin D 1000 IU daily. Regular weight bearing exercise will help to prevent osteoporosis. If you do develop osteoporosis, your doctor may suggest treatment.

- **Smoking**: Smoking may affect your recovery from treatment, increase the risk of cancer returning or getting another cancer. Helpful resources can be found at [http://www.gov.ns.ca/hpp/addictions/tobacco/makesyousick.asp](http://www.gov.ns.ca/hpp/addictions/tobacco/makesyousick.asp) and [www.smokershelpline.ca](http://www.smokershelpline.ca).

- **Alcohol use**: Excessive alcohol use may increase the risk of cancer coming back or getting a new cancer. A helpful resource can be found at [http://www.gov.ns.ca/hpp/addictions/alcohol/](http://www.gov.ns.ca/hpp/addictions/alcohol/).

- **Use of complementary therapies**: Many therapies such as massage therapy, reiki and therapeutic touch can be helpful. If you are thinking about using complementary therapies, please talk with your health care provider to make sure they will not interfere with cancer treatments.

Continued on next page
Talk to Your Health Care Provider About (continued)

- **Inherited risk of breast cancer:** The majority of breast cancer (90%) is not inherited (passed down through the family). But, it is important to identify people who could be at risk of inherited breast cancer; their screening and management options are different from a person who developed breast cancer by chance. It is important to review your personal and family history of cancer with your health care provider to see if you should be referred for a genetic assessment. Because this decision is based on family history and your own personal medical history it is important to have accurate information about the cancer in your family. Tell your health care provider the age people were diagnosed with breast (one or both sides), ovarian and male breast cancer, and the age of any family members when diagnosed with cancer. Not everyone who is referred for genetic assessment moves on to genetic testing. In families who need genetic testing, it is important that the best person is tested. Certain signs, like the age people were when they first had cancer, help to decide the best person in a family to test. The person who has the assessment may not be the person who is tested. Your health care provider can contact the Maritime Medical Genetics Service with any questions.

- **Increased risk for ovarian cancer:** The risk of ovarian cancer after breast cancer is highest in women with a family history of breast cancer. A strong family history of breast cancer may be caused by an inherited genetic change (usually in the BRCA1 or BRCA2 gene). These genetic changes can also cause ovarian cancer. If there is no genetic cause for breast cancer then the risk of ovarian cancer is not elevated.

Notes and Questions

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Returning Cancer: Signs to Watch For

One of the biggest worries for cancer patients is that the cancer may come back. If the cancer does come back, it is usually in the first three to five years. This is why the follow up care is so important. After five years, the chance of cancer coming back drops every year.

Your follow up care will focus on finding cancer that comes back in the breast or lymph nodes. It is possible to treat the cancer if it is found early.

Bone scans and CT scans are not usually part of your follow up care. These scans may be done if you have any signs that suggest cancer has come back. See the list below for some of these signs.

Please notify your health care provider if you have any of the following:

- A new pain that won’t go away.
- A cough that won’t go away.
- A lump in your breasts, neck, armpit or any other part of your body.
- Unusual changes in the site of your surgery or in the scar itself.
- A tired feeling that won’t go away.
- Loss of appetite.
- Weakness, tingling or numbness in the arm, hand or leg.
- Swelling in the arm, shoulder, breast, chest, armpit or back.
- Any new symptom that is unusual or severe and doesn’t go away, such as bone pain, shortness of breath or headaches.

Notes and Questions
Cancer Screening and Other Tests

Just like people who have not had breast 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.

**Cervical cancer screening:** Women should start having Pap tests 3 years after becoming sexually active or upon reaching the age of 21 – whichever comes later. If you have never been sexually active you do not need to have Pap tests. You should have your Pap test every three years. You can discontinue having Pap tests at age 70, only if you have a history of negative Pap test results. If you have had your cervix removed through a hysterectomy (not for cancer), you do not need to have Pap tests. Immunocompromised or HIV positive women and women who have been treated for cervical dysplasia or have a history of cancer of the cervix should have annual screening for life. Talk with a doctor or health care provider if you have any concerns about cervical cancer or are experiencing symptoms. To learn more about cervical cancer screening guidelines, call Cancer Care Nova Scotia: 1-888-480-8588 or visit www.cancercare.ns.ca.

**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 your health care provider if you have concerns about colon cancer or are having long-lasting changes in your bowel habits. To learn more about the colon cancer home screening test call Cancer Care Nova Scotia: 1-866-599-2267 or visit www.cancercare.ns.ca.

**Diabetes screening:** Starting at age 40, you should have a Fasting Plasma Glucose (FPG) test every 3 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:** You should have your blood pressure checked regularly by your health care provider.

Continued on next page
Other Ways to Protect Your Health

**Immunizations:** You should have a flu shot every fall. If you are 65 or older, or 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.

**Sun safety:** It is important to use sun protection. Use sunscreen (minimum of SPF 30); wear a wide brimmed hat, long sleeved tops, long pants and sunglasses.

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

**Physical activity:** Whether you are getting back to activities you enjoy or starting new ones, being active after treatment for cancer is important. Research has suggested a link between physical activity and decreased rates of cancer return and increased rates of survival in cancer. Physical activity can also help with fatigue, mood, body image and sleep disturbances. Always check with your health care provider before starting. For more information on how to get active visit, [www.phac-aspc.gc.ca](http://www.phac-aspc.gc.ca) and [www.heartandstroke.com](http://www.heartandstroke.com)

**Healthy eating:** There are no special foods or vitamins to take after cancer treatment. Following Canada’s Food Guide is the best approach [www.hc-sc.gc.ca/fn-an/index-eng.php](http://www.hc-sc.gc.ca/fn-an/index-eng.php). A clinical dietician can help you learn more about eating well.

For the Nova Scotia Cancer Centre 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 (1-866-599-2267) for referral to a dietician in your community.

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**Notes and Questions**
What to Expect after Cancer Treatment

Most people have some side effects after breast surgery and/or breast 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 these side effects 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 or cancer patient navigator 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 health care provider is responsible for your follow up care.

**Cancer related fatigue:** Fatigue (excessive tiredness) is very common after breast 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 exercise is one of the best ways to decrease your fatigue. There are resources available to help you learn more about cancer related fatigue. For more helpful hints visit Canadian Partnership Against Cancer: [www.cancerview.ca](http://www.cancerview.ca) idc <click on> groups <click on> public <click on> documents <click on> webcontent <click on> manage_cancer_fatigue.pdf.

**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 breast cancer. Exercising your brain by doing crossword puzzles or number games will help. For more helpful hints, visit [http://www.mayoclinic.com/health/chemo-brain/DS01109](http://www.mayoclinic.com/health/chemo-brain/DS01109) or [http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/chemotherapyeffects/chemo-brain](http://www.cancer.org/treatment/treatmentsandsideeffects/physicalsideeffects/chemotherapyeffects/chemo-brain).

**Depression:** Depression may occur 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 provider.

**Return 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 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.

*Continued on next page*
What to Expect after Cancer Treatment (continued)

**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 may be 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 cancer treatment. Your health care provider will be able to give you suggestions to manage your emotional distress.

**Early or treatment related menopause:** Women should talk to their health care provider about any changes in their periods. Cancer treatment may cause women to go into menopause or start at a younger age than usual. Women may have hot flashes, vaginal dryness, mood changes or changes in how they respond sexually. Health care providers can help with these symptoms or suggest someone to talk to.

**Sexual problems:** Cancer treatment may cause women to go into menopause which can cause sexual problems. You may have pain during sex, vaginal dryness, decreased or loss of sexual interest, decreased ability to become sexually aroused or relationship difficulties. Your health care provider may be able to give you guidance and support or suggest another health care provider who can.

**Weight gain:** Weight gain is not unusual after cancer treatment. Having healthy weight, eating well and exercise are all important for your overall health. (See page 8 for more information).

**Body Image Changes:** After treatment and surgery for breast cancer, it is not uncommon for people to experience changes in their body image. Useful advice can be found through support groups and on the websites listed on page 13. Discussions with your health care provider can also be helpful.
Programs for Cancer Survivors

Cancer Transitions

Capital Health Cancer Care Program, Cumberland County Health Centre 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
- Exercise for Wellness
- Emotional Health
- Eating Well
- Medical Care After Cancer

For more information and to register:
Capital Health Cancer Care Program call 902-473-8241
Cape Breton Cancer Centre call 902-567-8074

Living Beyond Cancer: What Happens Next?

The Capital Health 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 and at the Cape Breton Cancer Centre or via telehealth, at the Regional Hospital in your area.

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

For more information and to register, call toll free: 1-866-524-1234 or register online at: www.cancercare.ns.ca

We now have Living Beyond Cancer video segments available to watch online via our YouTube channel. These can be found by visiting www.cancercare.ns.ca and clicking on Patients and Families.

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 www.yourown2wellness.gov.ns.ca
Support & 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. Counselling can help you to find strength and meaning. It can also help you cope, adjust, and find solutions to problems. You can go to counselling on your own or with members of your family.

There is a psychosocial cancer team at the Nova Scotia Cancer Centre for people who have been diagnosed and treated for breast cancer anywhere in the province of Nova Scotia. The team provides counselling to breast 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. Although you may be medically discharged from the Cancer Program, the psychosocial cancer team is still available to help you. For more information, call: 902-473-6067 (Nova Scotia Cancer Centre).

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 1-866-599-2267.

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.

Private Medical Insurance and Employee Assistance Programs

Counselling is also covered under some private insurance plans (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 counselling sessions. Please contact your Human Resources Department for information.

Continued on next page
Support & 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:
- Canadian Cancer Society: 1-800-639-0222 or visit www.cancer.ca
- Nova Scotia Cancer Centre in Halifax: 902-473-6067
- Cape Breton Cancer Centre, Sydney: 902-567-8074
- Cancer Patient Navigators: 1-866-599-2267
- 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.

Continued on next page
Support & 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


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


Websites

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

For Breast Cancer Survivorship information, visit:
- American Society of Clinical Oncology (ASCO) Patient Site: www.cancer.net
- British Columbia Cancer Agency: bccancer.bc.ca
- Canadian Breast Cancer Foundation: www.cbcf.org or call 1-866-273-2223
- Canadian Breast Cancer Network: www.cbcn.ca or call 1-800-685-8820
- Canadian Cancer Society: www.cancer.ca <click on> Nova Scotia or call 1-888-939-3333
- Cancer.net (breast cancer male): www.cancer.net

Continued on next page
Support & Resources (continued)

Websites for Breast Cancer Survivorship information (continued)
- Healing and Cancer: [www.healingandcancer.org](http://www.healingandcancer.org)
- Living Beyond Cancer: [www.cancercare.ns.ca](http://www.cancercare.ns.ca) <click on> Patients and Families
- Rethink Breast Cancer: [www.rethinkbreastcancer.com](http://www.rethinkbreastcancer.com)
- Willow: [www.willow.org](http://www.willow.org)

For Physical Activity information, visit:
- [www.participation.com](http://www.participation.com)
- [www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3484253/k.4FE0/Healthy_living__Physical_Activity.htm](http://www.heartandstroke.com/site/c.ikIQLcMWJtE/b.3484253/k.4FE0/Healthy_living__Physical_Activity.htm)

For Fatigue information, visit:
- 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
- Canadian Partnership Against Cancer: [www.cancerview.ca](http://www.cancerview.ca) <click on> idc <click on> groups <click on> public <click on> documents <click on> webcontent <click on> manage_cancer_fatigue.pdf
- American Cancer Society: [www.cancer.org](http://www.cancer.org) <click on> treatment <click on> treatments and side effects <click on> physical side effects <click on> fatigue
- [http://www.youtube.com/watch?v=YTFPMYGe86s&feature=youtu.be](http://www.youtube.com/watch?v=YTFPMYGe86s&feature=youtu.be)

For Sexual Health information, visit:
- Canadian Cancer Society: [www.cancer.ca](http://www.cancer.ca) <click on> Cancer Information <click on> diagnosis and treatment <click on> managing side effects
- American Cancer Society: [www.cancer.org](http://www.cancer.org) <click on> treatment <click on> treatments and side effects <click on> physical side effects <click on> sexual side effects in women

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](http://bccancer.bc.ca)
- Canadian Cancer Society: [www.cancer.ca](http://www.cancer.ca) or call 1-888-939-3333
- Cancer Care Manitoba: [www.cancercare.mb.ca](http://www.cancercare.mb.ca)
- Vancouver Coastal Health: [http://vch.eduhealth.ca](http://vch.eduhealth.ca)
## Follow up Care Schedule

You can use these charts to keep track of your follow up care.

<table>
<thead>
<tr>
<th>Family Doctor/Nurse Practitioner’s visit</th>
<th>Year 1</th>
<th>Year 2</th>
<th>Year 3</th>
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<td>Mammogram every year</td>
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### Notes and Questions

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References


Developed by: Cancer Care Nova Scotia, 2014.

Special thanks to the staff at both the Capital Health Cancer Care Program and the Cape Breton Cancer Centre and the Nova Scotia Breast Cancer Site Team for their contributions to this document.

This booklet was approved by
Nova Scotia Cancer Patient Education Committee, 2014
This booklet is to be updated every three years


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Living Beyond Cancer
Follow up Care for Breast Cancer Patients

Happens now?