

My Partner Has
Breast Cancer:
How can I help?



A
Parallel Journey

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A Parallel Journey

“What is going to happen to us?
I don’t know if I can get through this.
How do I help?”

A breast cancer diagnosis can be devastating to the patient, to her partner or spouse, to family and friends. Suddenly normal life is no longer normal. There are medical appointments and treatments and there will be emotional turmoil for everyone.

As a partner, whether you are male or female, you will have to deal with this new reality. You will want to know how best to support your partner, practically and emotionally. You will also have concerns and needs of your own to deal with.

This booklet was written for you, the partner of a woman facing breast cancer. It is based on interviews with breast cancer survivors and partners with support from staff at the BC Cancer Agency and Canadian Cancer Society. The Vancouver Island Regional Advisory Group of the Alliance for Breast Cancer Information and Support, BC & Yukon has put this booklet together to acknowledge your role in this journey and to encourage you to take care of yourself during the months ahead. At the end of each section you will find practical resources to use during your “Parallel Journey.”

LEARNING ABOUT BREAST CANCER

“You are entering unfamiliar territory. You may at times feel as though you are learning a new language and culture.”

Knowledge can enable you and your partner to make informed choices about medical care and to manage the effects of cancer on your lives. The more you know, the better you will be able to:

- ☞ access current and accurate information,
- ☞ ask questions as new information becomes available,
- ☞ feel confident in the decisions that are made.

You may learn differently than your partner and have different views on how much information is helpful. You may, for example, prefer to get information mainly from the oncologist. Your partner may prefer to seek information through other sources. Which ever way you decide to gather information, it must work for you. One practical way to support your partner is by asking what information she needs and then to help find it.

To learn more about breast cancer the following are available to you.

Resources For LEARNING ABOUT BREAST CANCER

1. Information Kit for the Newly Diagnosed

Your partner would have received this kit from her surgeon's office. Enclosed in the kit are a variety of books and booklets which help to explain the journey. As well, the Breast Cancer Companion Guide is a wealth of information on breast cancer and resources available. It also provides you with questions that can be asked at medical appointments.

If your partner did not receive a free information kit, call the Cancer Information Service at 1.888.939.3333 and request one.

2. BC Cancer Agency Library Services

Each BC Cancer Agency centre has a Library with access to a comprehensive collection of books, journals, pamphlets, video and audio materials for loan. If you are not able to access these libraries in person, resources can be mailed to you.

- ☞ A toll-free number is available to speak directly with a librarian and the library catalogue is on-line.

1-888-675-8001 ext 8001

www.bccancer.bc.ca/Library

Your local public library may also carry the books and resources listed in this guide. Various resources can be purchased through your local book store or on-line web sites.

3. Canadian Cancer Society Cancer Information Service

Trained information specialists answer questions (by phone and email) from patients and family members about cancer including:

- ☞ Understanding cancer and its treatments
- ☞ Seeking financial help and resources
- ☞ Community resources and services

Monday to Friday from 9 am – 6 pm. Translation services are also available.

1-888-939-3333

www.cancer.ca

4. Websites

The BC Cancer Agency library recommends websites with credible breast cancer information.

- ☞ BC Cancer Agency www.bccancer.bc.ca
- ☞ Canadian Cancer Society www.cancer.ca
- ☞ National Cancer Institute (US) www.cancer.gov
- ☞ American Cancer Society (US) www.cancer.org
- ☞ Abreast & the Rest www.abreastandtherest.ca
- ☞ Oncolink (US) www.oncolink.org

TAKING CARE OF YOURSELF

“If we don’t take care of ourselves we won’t be able to take care of anyone else.”

One of the most important things you can do to help your partner and family is to look after yourself. Often caregivers are tempted to put their needs low on the priority list, leading to fatigue, stress and burnout. Take care of yourself and you will be better able to take care of your loved ones.

As one partner said, “You will find yourself taking on many roles. At times you will feel like coach, general manager, psychologist and public relations coordinator.” In order to balance many roles and prevent burn-out, take the time for stress-reducing activities.

The following are some ideas that have worked for other partners.

- ☞ Continue living your life and keep up your routines as much as possible.
- ☞ Do not feel guilty about having fun. It is important to continue to have fun with your family and friends. Think about how good it feels after you have laughed out loud. Laughter is a good coping tool.
- ☞ Make the effort to eat well and get plenty of rest. This will increase your stamina and ability to cope.
- ☞ Try to get regular exercise, even if it is just something as simple as walking the dog. Continue to be active and enjoy the activities that help you to release stress.
- ☞ Take the time to recharge your batteries. Continue to participate in hobbies or relaxation activities. Whether it is fishing or golfing, gardening or painting, set aside time to enjoy it.
- ☞ If you have a trusted friend, talk to him or her. If you are part of a team, group or club that meets regularly, these people may be a great source of support. Voicing your concerns may help alleviate them.
- ☞ Find people to speak to who have been through the same thing. They can give you an idea of what to expect as well as resources and coping strategies that have helped them.

- ☞ You may find it helpful to attend a support group. Some people find it helpful to speak with a counsellor.
- ☞ Be aware of signs of fatigue, stress or depression. These signs include lack of interest or enjoyment in hobbies, activities or eating; changes in sleep patterns; or feeling overwhelmed for prolonged periods of time. You may not even realise this is happening. If you, your partner or anyone else notices any of these signs in you, see your doctor.

Resources For TAKING CARE OF YOURSELF

Available through the BC Cancer Agency library, local book stores, public libraries and websites.

Books

Helping your mate face breast cancer: Tips for becoming an effective support partner. 5th Ed by Judy Kneece (2003)

The Relaxation and Stress Reduction Workbook by Davis, Robbins & McKay (2008)

Breast Cancer Husband: How to help your wife (and yourself) through diagnosis, treatment and beyond by Marc Silver (2004)

A Woman's Comfort book: A self-nurturing guide for restoring the balance by Jennifer Loudon (2005)

Websites

National Cancer Institute (US)

This site offers a selection of booklets providing information and support to assist caregivers in coping. Enter "when someone you love" into the SEARCH

www.cancer.gov

Cancer Chat Canada

Professionally led on-line support groups for Canadians affected by cancer. For patients and caregivers.

www.cancerchatcanada.ca

Support For TAKING CARE OF YOURSELF

Patient & Family Counselling Department, BC Cancer Agency

Centres offer a variety of counselling, relaxation sessions, web-based support groups and other groups for partners.

Abbotsford Centre
604.851.4710 or Toll-free 1.877.547.3777

Centre of the North (opens late 2012)
250.645.7300

Centre of the Southern Interior
250.712.3900 or Toll-free 1.888.563.7773

Fraser Valley Centre
604.930.4000 or Toll-free 1.800.523.2885

Vancouver Centre
604.877.6000 or Toll-free 1.800.663.3333

Vancouver Island Centre
250.519.5500 or Toll-free 1.800.670.3322

Cancer Information Service Canadian Cancer Society

Offers a toll-free service by trained staff linking you with local resources in your community

1.888.939.3333 www.cancer.ca

DAY TO DAY LIFE

“It’s hard to know what to do. I want to support her, but I’m just not sure how.”

You can help your partner in some very practical ways. This may mean taking on different or more responsibilities than your usual ones. It may mean taking the initiative or asking your partner, “What can I do to help?” It may even mean stepping back a bit from time to time so that your partner can resume her usual responsibilities to keep things as normal as possible. Together you are the best judges of what will work for the two of you.

As one partner stated, “Realize your spouse may not be telling you how hard it really is in order to protect you.”

The following are ideas which have been reported as helpful to consider.

Around the house

The daily household chores will build up quickly if not addressed: house cleaning, grocery shopping, doing laundry, walking the dog, as well as general maintenance of home, yard and car.

Cooking

Preparing family meals can be extremely helpful. Keep in mind your partner may be very sensitive to cooking smells. See resources for cookbook suggestions.

Children

You may need to arrange for transportation for your children to and from school and their other activities; help with bath and bedtime; and help organize special outings and shopping trips.

Friends

You may wish to delegate household chores or help with the children when friends offer to help. You may also act as a buffer when needed. You may want to handle phone calls and answer the door. You should both decide beforehand what to communicate.

Work

Many partners recommend telling your employer and colleagues of your situation so that they can support you at work in many ways. You may wish to negotiate time away from work and/or reduce your workload and travel during heavy treatment times.

Financial Issues

You may find you need support with a variety of issues related to financial support such as lodging, travel and home care costs. Assistance plans are available for those who qualify.

This is a big list and many of these tasks you will assume naturally. Not all of these actions will work for you. But having your help in areas that are normally hers will reduce your partner's responsibilities at a time when she is stressed and low in energy. As a spouse stated, "It's time to pitch in. Just be there."

As many partners emphasized, "Don't be too proud to accept help." There is a lot to do, and allowing friends and family to help will assist them to feel useful and you to manage day to day life.

Resources For DAY TO DAY ISSUES

Available through the BC Cancer Agency library, local book stores, public libraries and websites.

Books

Stand by Her: A breast cancer guide for men by John Anderson (2010)

Help me live: 20 things people with cancer want you to know by Lori Hope (2005)

The Cancer Survivors Guide: Foods that help you fight back by Neal Barnard & Jennifer Reilly (2008)

Goes down easy: Recipes to help you cope with the challenge of eating during cancer treatment by Elise Mecklinger (2006)

Booklet

Financial Information for Cancer Patients. BC Cancer Agency (2010)

This booklet is available at your local BC Cancer Agency Centre and on-line at www.bccancer.bc.ca >> Patient/Public Info >> Coping with Cancer >> Practical Support

Support For DAY-TO-DAY

HealthLink BC

Trusted Pharmacy, Nutrition and Nurse Information at your fingertips with just a phone call or a click away. Any time of the day or night, every day of the year. Translation services also available.

Call 811 www.healthlinkbc.ca

Cancer Information Service, Canadian Cancer Society

The Canadian Cancer Society's Cancer Information Service offers a toll-free service by trained staff linking you with community resources for financial and home care support.

1.888.939.3333 www.bc.cancer.ca

HELPING YOUR FAMILY

“The breast cancer journey is a life-changing experience for everyone in the family, including the children.”

At times, you and your partner may get caught up in the whirlwind of appointments and treatment schedules, overlooking the needs of other family members. One helpful thing that you can do is to ensure that routines continue as much as possible. Even though there are many new things to deal with, children still need their routines, pets still need to be cared for, and family members will want to feel included in what is going on.

Communication is important. Children may have questions and turn to you, rather than the person who has the cancer. Or they may not ask questions, yet still need information. Different ages have different ways of responding. For example, young children may believe they caused the cancer. Teenagers may exhibit a change in behaviour. Speak freely and honestly with children and be prepared to answer the same questions often. As one partner stated, “We told the children not to be afraid to ask us any question. We also told them that some questions and their answers may involve tears, and that is OK.”

Other family members will find comfort in your efforts to keep them up-to-date on your partner or spouse’s treatment and plans. You may find yourself becoming the spokesperson for your family. Make sure to check with your partner or spouse to find out how much information she feels comfortable sharing. “Have a communications plan and decide in advance who you will communicate with and what information will be shared.”

The following are some ideas that have been useful to others.

- ☞ Decide together how to communicate with your family members. This will depend on ages of children and the reactions of family members. Respond to and respect all reactions to the cancer



diagnosis. Be available. As one partner reflected, “Our children reacted very differently. One took it very seriously while the other tried to pretend it did not happen.” Communication is the key. Sit down with them not once but many times and discuss how they are feeling.

- ☞ Help your children get accurate information. Sometimes children may get incorrect information about breast cancer if researching on their own via the internet or talking to their peers. Discuss what they are finding and update them regularly to ensure that they have accurate information.
- ☞ Consider approaching your children’s school to seek their assistance. Teachers and counsellors can offer valuable help and will appreciate being informed. As one spouse reported, “We informed our daughter’s high-school counsellor of the situation and she spoke to every one of her teachers. The teachers were able to better understand why she was having more difficulty in school.”
- ☞ Maintain regular routines and household chores as much as possible. Assist children in homework completion, attending sporting activities and at bedtime. Maintaining ordinary routines will help provide stability for everyone.
- ☞ Have fun with your children and encourage them to enjoy having fun. As one partner said, “We let my daughter paint my wife’s bald head – she loved it!” Another partner emphasized, “We had fun with our kids throughout the breast cancer treatment. We did things like being tourists in our own city for a day.”
- ☞ Children may want to help out more at this time to feel they are contributing. If so, encourage them to take on extra chores around the house.
- ☞ Mood swings are normal and may be expected from all members of the family.
- ☞ It is helpful for each member of the family to have a support system and people to turn to such as friends, family and colleagues.

Resources For HELPING YOUR FAMILY

Available through the BC Cancer Agency library, local book stores, public libraries and websites.

Books

You are not alone: Families touched by cancer by Eva Grayzel (2010)

Reaching out to your children when cancer comes to your family: A guide for parents by June Slakov, BC Cancer Agency (2007)

Cancer in our family: Helping children cope with a parent's illness by Sue Hailey, American Cancer Society (2011)

Website

Cancer in my Family

This site is for children aged 8 to 12. It's a fun interactive environment where children can feel safe, play games, create friendly characters – and at the same time explore how they're feeling, and learn about cancer. BC Cancer Agency

www.cancerinmyfamily.ca

Support For HELPING YOUR CHILDREN

Patient & Family Counselling BC Cancer Agency

The BC Cancer Agency centres offer programs for children

Abbotsford Centre

604.851.4710 or Toll-free 1.877.547.3777

Centre of the North (opens late 2012)

250.645.7300

Centre of the Southern Interior

250.712.3900 or Toll-free 1.888.563.7773

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Vancouver Centre

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Vancouver Island Centre

250.519.5500 or Toll-free 1.800.670.3322

YOUR INTIMATE RELATIONSHIP

“I am afraid to touch, to caress, to be as intimate as before. Will this ever change?”

Much has happened to your loved one's body and she may be uncomfortable with the physical changes resulting from surgery or treatments. These feelings will change over time. In fact, breast cancer survivors and their partners often report a newfound intimacy born out of the threat of loss. As with other aspects of the cancer journey, communication and listening are important.

Women have revealed that one of the most appreciated actions a spouse or partner can do is to hold and comfort them. To be close, to touch and to feel secure in the arms of a loved one allows for personal strength to come out. Reassuring her of your love, and statements of 'being there,' can be very powerful. Voicing words of appreciation for who she is and who she will always be to you, builds confidence.

Be aware that your partner may not have a sex drive or sexual desire before, during and/or after treatment (for a while). This is normal. The most important point is to support your partner emotionally until her sex drive returns. Others may be able and interested in maintaining an intimate relationship throughout treatments.

When you are both ready to recapture closeness and intimacy here are some options to consider.

- ☞ You may want to follow her lead and let her decide when she is ready to resume intimate relations or you may want to gently bring up the topic of physical intimacy.
- ☞ When you are ready, plan a special or romantic time away by yourselves. Have other family members take care of the children and go away to a retreat or even just cook a special dinner for the two of you.
- ☞ Offer a foot massage or back rub.

- ☞ Acknowledge the scars and the need to mourn physical changes. This mourning process can take time. As one partner confided, "After resuming physical intimacy, I found my wife crying in the bathroom. She was upset that things were no longer the same." Intimacy may be different after treatment. Everyone reacts differently. Be prepared to support each other through this time of change.
- ☞ Keep in mind there are other qualities in your partner that attracted you to her, such as a sense of humour, intelligence and other unique traits. Intimacy is mental as well as physical.

Resources For YOUR INTIMATE RELATIONSHIP

Available through the BC Cancer Agency library, local book stores, public libraries and websites.

Books

Intimacy after cancer: A women's guide by Sally Kydd and Dana Rowett (2006)

100 Questions and Answers about Cancer and Fertility by Kultuk Oktay et al. (2008)

Booklets

Sexuality and Cancer: A guide for people with cancer. Canadian Cancer Society (2011) 1.888.939.3333 www.cancer.ca

100 Questions and Answers about Breast Cancer Sensuality, Sexuality, and Intimacy by Michael Krychman et al. (2011)

Website

Fertile Future

A Canadian network dedicated to providing information, education and financial assistance to cancer patients who wish to pursue fertility preservation.

1.877.467.3066 www.fertilefuture.ca

WHEN TREATMENT IS FINISHED

“Whew! What a relief that it is over... or is it?”

Cancer has changed your lives forever. Surprisingly, couples sometimes report that the experience has brought them closer and helped them appreciate the here and now.

When treatments are finished, one of you may be more ready to move on than the other. For instance, your partner may still experience fatigue and be dealing with the emotions of having had cancer, while you may wish you could get back to normal. Or she may be ready to take on the world in new and exciting ways, while you may find you are the cautious one. There is no right or wrong way. There is just getting back into life, different or the same.

As one partner stated, “Although treatment is finished and physical healing is well on its way, there is still much emotional and spiritual healing to do.” Be prepared for highs as well as lows.

Some final thoughts from partners regarding what to expect after treatments end.

- ☞ Fears may linger well past the time treatments end, and emotions may flare up for either of you. Will the cancer come back? This anxiety may resurface as follow-up testing occurs over the next five years or so.
- ☞ Your partner may try numerous things to prevent the cancer from coming back. You may find more activity and exercise in your lives or a change in spirituality. She may make changes in nutrition. You may, for example, find more vegetables on your dinner plate. These are ways she may try to be and stay healthy and your support will make this process easier.
- ☞ Try to let go of timelines for the healing process. Each person and each couple has their own time frame for getting back to normal or “new normal” as some people call it.
- ☞ Celebrate the challenges that you have both overcome to get to this new place and relationship. Take care of yourself, take care of your partner and be patient.



“Keep supporting her – even if she no longer talks about it, it is still there.”

Resources For WHEN TREATMENT IS FINISHED

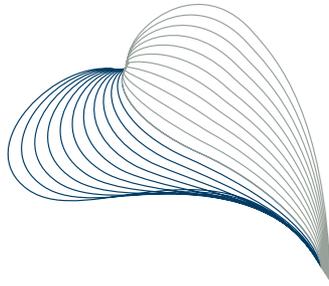
Available through the BC Cancer Agency library, local book stores, public libraries and websites.

Books

Everyone’s Guide to Cancer Survivorship by Ernest Rosenbaum et al. (2007)

Facing Forward: Life after cancer treatments. National Cancer Institute (2007)
www.cancer.gov Enter “life after cancer” into the SEARCH

After Breast Cancer: A common sense guide to life after treatment
by H. Schnipper & L. Schnipper (2006)



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