



NEW
BRUNSWICK
**Breast &
Women's
Cancer**
PARTNERSHIP



Le partenariat
du cancer du sein
et des cancers
féminins
DU NOUVEAU-BRUNSWICK



Information Guide

Gynecological Cancers New Brunswick



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Dedication

This guide is dedicated to Melinda who offered her time generously toward this project. Her dedication and spirit have inspired all those who worked with her to persist and achieve our goal.

Thank you.

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Introduction

This resource guide was created by the New Brunswick Breast and Women's Cancer Partnership to support women diagnosed with a gynecological cancer in New Brunswick. Being diagnosed with cancer can be a scary time and it is our hope that this guide will help identify resources that may help you during your cancer journey. Many women have difficulty finding reliable information when they are diagnosed. While lack of information can be a problem, sometimes when you are faced with a lot of information, it can be overwhelming. The content can be difficult – it may be written in highly technical language or it may deal with hard issues. We want to help you with this.

After much research we have compiled information that we have found helpful including available print material, useful websites and telephone services that could be a great support during your journey. Go at your own speed. At different points in the course of your illness you will have different information needs. Hopefully this guide will provide information and support that you and those close to you need during this time.

How to use this guide?

Contained in this guide are lists of resources, websites and telephone numbers in relation to gynecological cancers and making your way through the cancer journey, from diagnosis to survivorship. Attached to this information is contact information for the persons or organizations responsible for providing these resources. This tool is simply a "guide to available resources". As you make your way through the contents, check out the information listed, call or email the appropriate contact to receive print materials, visit the websites if you have access to internet and make note of telephone resources that are of interest to you.

This guide is meant to direct you to resources for information and support. However, in today's fast paced world, information and resources can change quickly. We will do our very best to keep this guide updated but in the event that a resource is no longer available we apologize in advance for any inconvenience.



Communicating with your Health care team

The first step to receiving information about your diagnosis is communicating with your health care team; they can be a great support in finding the information you need. We have supplied some notes below to help you in your communication. Communication works best when a partnership develops between the patient and her family and the health care team. Ask questions and share your feelings so that the health care team can provide the information that you need. When all parties speak clearly and listen to one another, a helpful partnership can grow. Below are some tips for communicating with your primary health care providers.

- Let your doctor/health care team know how much information you want. Some people want to hear about statistics and chances for survival. Others may prefer only the minimum in order to make their decisions.
- Speak with your doctor about whom you want with you for support if at any time there are difficult issues you will need to talk about. This can ensure that you are not alone when you need someone with you.
- Bring a family member or friend who can give you moral support during appointments. This person may also hear information that you might miss.
- Write down your questions ahead of time. Organize them with the most important ones first.
- Keep notes about your symptoms. They will be helpful when you tell your health care team what you are experiencing.
- Make notes during your appointments. Jot down any specific instructions that are given, even if they seem simple.
- Ask your doctor about tape recording conversation with him/her. You can review the tape later if you feel you missed something.
- If there are terms you don't understand, ask a member of your health care team to explain them in language you can understand.
- Ask for things to be repeated if you are not clear about them, and to also ask for explanations about possible side effects, benefits, and risks.
- Courtesy and a pleasant manner usually invite the same in return.



Resource

Additional resource, Appendix A contains a handout “Questions to ask your health care team” Canadian Cancer Society.

Print Resources

There are a number of helpful books about dealing with cancer. You can buy your own or borrow them from your public library or from the library at your treatment centre. You can obtain a depth of information from books that is not possible from other sources. Brochures usually reflect recent developments and important facts on a topic; however, they may or may not give you the depth of information you are looking for.



Internet Resources

The internet is also a source of information about health issues and it has grown by leaps and bounds. A major advantage of this medium is that the material can be the most current that is available. A major concern, however, is the reliability of the material. Since anyone can publish information on the web – medical experts as well as individuals may simply be expressing opinions. How can you be assured that you are getting reliable information?

- Check who sponsors the site. You are more likely to get reliable information from non-profit cancer organizations, from reputable medical centres, and from governmental health agencies. If it is not an organization, but rather an individual, what are his or her credentials?
- Is the date on the website recent? Most sites indicate when they were last updated.
- Does this site refer to reports from leading medical journals? Are there other references?

If you don't have access to the internet and want to use it, others may be willing to help you: friends, children, grandchildren, and partners. Ask them. You might use the computers at your local library. Their personnel are trained to help you find information.

Notes: Most hospitals have a resource centre with access to computers.

Telephone Resources

Most resources available in this guide also have accompanying telephone contact information. Using the telephone to get information and support can be a great way if you are uncomfortable using the internet or are unsure about where to get print resources. If you have questions about any resources feel free to call the number attached to the contact information to get more information.



Educational Resources

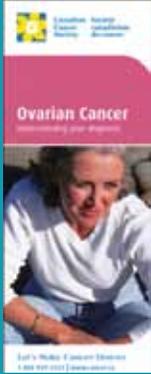
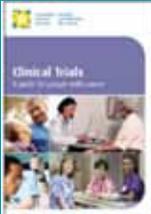
The following is a list of free brochures you may find helpful in your quest for information. Any of these items are available through the Canadian Cancer Society, or at the number indicated in the description box.

You can contact the Canadian Cancer Society's Information Service at 1-888-939-3333 or download the information on their website www.cancer.ca under "publication".

All publications are free and available in multiple languages. You may also e-mail the Cancer Information Service with any of your questions at: info@cis.cancer.ca.

	TITLE	DESCRIPTION
	You are Not Alone: A guide for women living with Ovarian Cancer	<i>A comprehensive guide for women with ovarian cancer. Over 150 pages of information about everything from diagnosis to survivorship. Free of charge. Call 1-866-825-0788 or visit www.ovariancanada.org to order</i>
	Cervical Cancer Understanding your diagnosis	<i>Explains and describes cervical cancer and its treatment.</i>



	<p>Ovarian Cancer Understanding your diagnosis</p>	<p><i>Explains and describes ovarian cancer and its treatment.</i></p>
	<p>Uterine Cancer: Understanding your diagnosis</p>	<p><i>Explains and describes uterine cancer and its treatment.</i></p>
	<p>Chemotherapy: A guide for people with cancer</p>	<p><i>This booklet is a guide to help you understand chemotherapy and its possible side effects.</i></p>
	<p>Clinical Trials: A guide for people with cancer</p>	<p><i>Explains what clinical trials are and what to expect if you decide if it may be a treatment option for you.</i></p>



	<p>Eating well when you have cancer: A guide to good nutrition</p>	<p><i>Learn what good nutrition is and how to manage side effects during treatment.</i></p>
	<p>Radiation Therapy: A guide for people with cancer</p>	<p><i>Radiation Therapy: A guide for people with cancer</i></p>
	<p>Sexuality and Cancer: A guide for people with cancer</p>	<p><i>Sexuality and Cancer: A guide for people with cancer</i></p>
	<p>Complementary Therapies: A guide for people with cancer</p>	<p><i>Information on most common therapies used by people living with cancer.</i></p>
	<p>Pain relief: A guide for people with cancer</p>	<p><i>A booklet about understanding types of pain as well as methods to reduce and control it.</i></p>



	Living with Cancer: A guide for people with cancer and their caregivers	1-888-939-3333 www.cancer.ca 1-800-455-9090
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Support Resources

	Canadian Cancer Society Cancer Information and Support Practical Transportation and Travel Assistance	1-888-939-3333 www.cancer.ca 1-800-455-9090
	Online and telephone support programs	1-866-825-0788 www.ovariancanada.org



Human Resources and Skills Development Canada	Finances	www.canadiansocialresearch.net/hrsdc.htm
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Miscellaneous:

Books:

- Harpman, Wendy Schlessel. When a parent has cancer: a guide to caring for your children. Harper Collins, 1997.
- Parker, William H. and Parker, Rachel L. A gynaecologist second opinion. (Available at Chapters)
- Béliveau, Richard and Gingras, Denis. Foods that fight cancer: preventing cancer through diet. McClelland Stewart, 2006.
- Kydd, Sally and Rowatt, Dana. Intimacy after cancer. Big think media, 2006.



Additional Canadian Resources

An effort has been made to include as many relevant resources as possible – there are still many more despite our extensive lists. Also, we have tried to assure the accuracy of the contact information. However, contact information changes and we regret any inconvenience that may result.

Here is a list of phone and website information for Canadian organization that may be helpful, some have already been referenced but this simple list may help you quickly identify with one particular support.

Anemia Institute

Phone: 416-969-7431

www.anemiainstitutue.org

Canadian Association of Psychosocial Oncology

Phone: 416-968-0207

www.capo.ca

Canadian Association of Social Workers

Phone: 613-729-6668

www.casw-acts.ca

Canadian Cancer Society NB

Phone toll free: Cancer information and Support 1-888-939-3333

www.cancer.ca / info@cis.cancer.ca

Canadian Association of Genetic Counsellors

Phone: 905-849-8299

www.cagc-accg.ca

Canadian Association of Nurses in Oncology

Phone: 604-874-4378

www.cano-acio.ca



Canadian Naturopathic Association

Phone toll-free: 1-800-551-4381

www.naturopathicassoc.ca

Canadian Neuropathy Association

www.canadianneuropathyassociation.ca

Canadian Psychological Association

Phone toll-free: 1-888-4720657

www.cpa.ca

Canadian's Women's Health Network

www.cwhn.ca

Dieticians of Canada

www.dietitians.ca

Family Caregivers Network Society

Phone: 250-384-0408

www.fcns-caregiving.org

Federated Women's Institutes of Canada

Phone: 519-448-3873

www.nald.ca/litweb/other/fwic/index.htm

Healing Journey

Phone: 416-946-2062

www.healingjourney.ca

Health Canada, First Nations and Inuit Health Branch

www.hc-sc.gc.ca/fnih



Hereditary Breast and Ovarian Cancer Foundation

Phone: 514-482-8174

www.hboc.ca

Hope Air

Phone toll-free: 1-877-346-4673

www.hopeair.org

Human Resources and Social Development Canada

Employment Insurance

www.hrsdc.gc.ca

Look Good Feel Better

Phone toll-free: 1-800-914-5665

www.lgfb.ca

Menopause Canada

Phone: 1-613-533-6430

www.menopausecanada.com

National Council of Women

Phone toll-free: 1877-319-0993

www.ncwc.ca

Canadian Cancer Society Research Institute

research@cancer.ca

Ovarian Cancer Canada

Phone toll-free: 1-866-825-0788

www.ovariancanada.org



Persons with Disabilities Online

www.pwd-online.ca **Self-Help Resource Centre**

Phone: 416-487-4355

www.selfhelp.on.ca

Self-Counsel Press

www.self-counsel.com

Society of Gynaecologic Oncologist of Canada

Phone toll-free: 1-800-561-2416 ext. 250

www.g-o-c.org

Women's Health Matters

www.womenshealthmatters.ca

Young Adult Cancer Canada

Phone toll-free: 1-877-571-7325

www.youngadultcancer.ca



Other Resources (international)

American Cancer Society (US)

www.cancer.org

Association of Cancer Online Resources

www.acor.org

Cancerbackup (UK)

www.cancerbackup.org.uk

Cancer Care, inc. (US)

Phone toll-free: 1-800-813-HOPE

www.cancercare.org

Cancerfacts.com (US)

www.cancerfacts.com

Cancer Network (US)

www.cancernetwork.com

CaringBridge (US)

Phone: 651-452-7940

www.caringbridge.org

CenterWatch, inc. (US)

Phone: 617-856-5900

www.centerwatch.com

Conversations(US)

Phone: 806-355-2565

www.ovarian-news.com



Coping Magazine (US)

Phone: 615-790-2400

www.copingmag.com

Eyes on the Prize (US)

www.eyesontheprize.org

FORCE: Facing our Risk of Cancer Empowered (US)

Phone toll-free: 1-866-288-7475

www.facingourrisk.org

Gillette Women's Cancer Connection (US)

www.gillettecancerconnect.org

Gynecologic Cancer Foundation (US)

Phone: 1-312-235-4060

www.sgo.org

Hyster Sisters Hysterectomy Recovery (US)

www.hystersisters.com

Kids Konnected (US)

Phone: 1-949-582-5443

www.kidskonnected.org

MAMM Magazine (US)

Phone toll-free: 1-877-668-1800

www.mamm.com

National Cancer Institute (US)

www.cancer.gov

National Comprehensive Cancer Network (US)

www.nccn.org



National Center for complementary and Alternative Medicine of the National Institutes of Health (US)

www.nccam.nih.gov

National Coalition for Cancer Survivorship (US)

Phone: 1-301-650-9127

www.canceradvocacy.org

National Family Caregivers Association

Phone: 1-301-942-6430

www.nfcacares.org

National Ovarian Cancer Coalition (US)

Phone toll-free: 1-888-Ovarian

www.ovarian.org

North American Menopause Society (US)

www.menopause.org

Office of Cancer Survivorship (US)

www.cancercontrol.cancer.gov/ocs

Oncolink (US)

www.oncolink.com

Oncology Forum (US)

www.oncologychannel.com



Ovacome (UK)

www.ovacome.org.uk

Ovarian Cancer National Alliance (US)

Phone toll-free: 1-866-399-6262

www.ovariancancer.org

Society of Gynaecologic Oncologists (US)

Phone: 1-312-235-4060

www.sgo.com

Vital Options (international)

Phone toll-free: 1-800-477-7666

www.vitaloptions.org

The Wellness Community (US)

Phone toll-free: 1-888-793-WELL

www.thewellnesscommunity.org

Well Spouse Community (US)

Phone toll-free: 1-800-838-0879

www.wellspouse.org



Acknowledgements

This guide was developed by a group of professionals and cancer survivors of the New Brunswick Breast and Women's Cancer Partnership whose objective is to develop, assess and distribute bilingual information kits for newly diagnosed women with breast and gynaecological cancers, in collaboration with provincial cancer agencies. It is our hope that this tool will help guide you along your road to recovery.

Committee members:

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Suzanne Roberts, MD, Saint-John Regional Hospital, NB

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Special thanks to the staff at Razor Creative for their patience and support. Their dedication to this project was inspirational to all of us.



Appendix A

Questions to ask your health care team about gynecological cancers:

At first, the information you learn about treatment options may seem overwhelming. You may ease the stress by allowing yourself the time to gather as much information as possible about cancer and its treatment. That way, you can discuss the issues with your doctors, nurses, and loved ones.

You may find it helpful to make a list of your questions before seeing your doctor. Use the list of questions below as a starting place for the questions you might ask. To make it easier to remember what your doctor says, take notes during meeting, or ask if you can use a tape recorder. It may also help to have a family member or friend with you to take part in the discussion, take notes, or just listen.

- What treatments do you think are best for me and why?
- What treatments do you think are not for me and why?
- What is the success rate of this particular treatment for my type and stage of cervical cancer?
- Can I take my other medicines during the treatment period?
- What is the length of the treatment period?
- How long will each treatment take?
- Where do I have to go for the treatment?
- Who is involved in giving me the treatment?
- Does someone need to go with me during treatments?
- How will I feel after the treatment?
- What side effects can I expect to have?
- How long will side effects last?
- Will I be able to have children after treatment?
- Will I continue to have periods after treatment?
- Are there side effects that I need to call you about?
- Will treatment cause any sexual problems
- What can I do to ease the side effects?



- Will I be able to go to work and be around my family?
- Should I change my diet? What foods can't I eat?
- What kind of follow-up care do I need?
- What can I do to reduce the chance that the cancer will come back?
- Are there any clinical trial I should look into?
- Are there support groups nearby that I can join?
- Does this cancer prevent me from taking oestrogen replacement therapy?
- What type and grade of cancer do I have?
- Has this cancer spread anywhere else?
- What is the goal of treatment?

Now is the time to be very honest with yourself about what side effects you can and cannot tolerate. It is your healthcare team's duty to tell you what those side effects might be before the treatment, but it's up to you to think about them seriously before making a decision.



