

Beginning a New Chapter: Follow-up care after your cancer treatment

Once your treatment has been completed, your healthcare team will recommend follow-up visits to identify and assist with the health issues pertaining to your cancer diagnosis. Follow-up appointments provide an opportunity to address concerns and may help to identify and/or rule out cancer recurrence.

The risk for cancer recurrence is different for each cancer survivor. Many factors influence the risk for cancer recurrence. Cancer treatment side effects may continue or present themselves months or even years after treatment has completed. Learning about these changes may help you to understand both the disease and treatments.

Information needs vary from individual to individual. Although you may remember discussions about your cancer and the treatment in the past, you may not recall all of them. Perhaps you had particular concerns that were a high priority at the time. What you may remember is regular appointments when there was discussion about your health care concerns and the activity based on your treatments. You may also remember celebration and relief when the initial treatment was over. You likely hoped that the cancer was gone or would not cause you problems for a long time. You may also have felt that you were really cared for, supported and reassured during your treatments. The cancer was being “actively fought.” Now you may find that living with uncertainty does not stop when treatment finishes.

Getting your life back together after the first line of treatment for ovarian cancer may not be as easy as many would think. It may have surprised you what a challenge it has been. The post-treatment phase has been described as a “new normal.” After being diagnosed with a serious disease such as ovarian cancer and dealing with treatment that is very taxing on one’s whole being, many women with ovarian cancer may find the experience has made a deep impact and has changed their view of life. They are not the person they used to be before the diagnosis.

In their book, *Picking Up the Pieces* (<http://www.pickingupthepiecescancer.com/>) authors Dr Sherri Magee and Kathy Scalzo examine this recovery phase and provide a framework for building bridges after cancer: bridges to oneself, to relationships that may have changed and to the new and possibly bewildering place a woman may find herself.

The following Ten Tools to Recovery are explored in *Picking Up the Pieces*:



1. Assess your strengths. *What's changed? What's the same?*
2. Grieve the loss.
3. Take an active role in your healing. *Is this choice healthy?*
4. Identify your intentions and decide on actions. What do I need to heal?
5. Prepare for resistance and gather support.
6. Explore possibilities.
7. Grab second chances. *Am I living the life I want to live?*
8. Harvest the strengths and new insights.
9. Live in the now, but plan for the future.
10. Reframe the fearful "*what if*" into a curious "*what's next?*"

Perhaps you will find using these tools helpful to gain strength and confidence in the recovery phase after your treatment.

Find more helpful information about being a survivor is at the Livestrong website (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics>)

Can I Prevent Ovarian Cancer from Recurring?

After some women have been diagnosed with ovarian cancer and have been treated for it, they make changes in their life style—or aspire to. As yet, there is no research to indicate that exercise, changes in diet, meditation, etc. can prevent ovarian cancer from recurring. But there is research that supports the positive effects on overall health of eating a healthy diet, of regular exercise, and of practices such as meditation, relaxation, prayer and Yoga. The authors of *Picking Up the Pieces* indicate one of the tools to recovery is to take an active role in your healing. Making changes to benefit your health is one way to do this.

The Possibility of Recurrence

Some women who have been diagnosed with ovarian cancer may not realize or may not have been informed that the disease may recur, so may not consider this possibility. When they do learn about it, it is a bitter surprise. At the other end of the spectrum, some women who understand the cancer might recur may find themselves preoccupied with, almost obsessive about, the possibility. They may find it hard to appreciate their daily lives because of the anxiety. Sometimes women wonder if there is anything they might have done differently to keep the cancer from recurring. They may almost feel guilty when it returns. It is not known what causes ovarian cancer to recur.

In the months and years following treatment, regular visits are scheduled with the gynecologic oncologist. They are likely to include a physical examination, possibly a CA125 blood test, possibly an ultrasound. There is a trend away from using the CA125 since studies indicate there is no improvement in survival when the CA125 is used in comparison to monitoring symptoms. Also the CA125 is not sensitive for all women and may not be helpful in a recurrence situation. For some women, tracking the CA125 counts can cause a lot of anxiety, but there are those who may find that watching for symptoms is stressful too. You may wish to discuss the use of the CA125 or monitoring symptoms with your gynecologic oncologist or the oncology nurse.

In between appointments, women monitor or watch for symptoms, particularly abdominal symptoms such as swelling or bloating and changes in the bowel pattern. This can be anxiety producing: How can

you be sure when indigestion is a result of what you ate? Or is it a sign that the cancer has recurred? Eventually one gets a clearer sense of what symptoms mean. If symptoms persist or get worse, you should discuss this with your doctor.

For an excellent discussion about fear of recurrence, go to the Livestrong website (<http://www.livestrong.org/Get-Help/Learn-About-Cancer/Cancer-Support-Topics/Emotional-Effects-of-Cancer/Fear-of-Recurrence>)

Remission: What does it mean?

After treatment you may enter a period of remission. The American Cancer Society describes remission as there being no sign of cancer. In a complete remission, all the signs and symptoms of the cancer disappear and cancer cells cannot be detected by any of the tests available for that particular cancer. A patient may have a partial remission when the cancer shrinks but does not completely disappear. This is most often what happens with ovarian cancer because microscopic disease is likely to remain even after a good response to first line treatment. Remissions can last anywhere from several weeks to many years. Complete remissions may go on for years, even with cancer inside the body. If this period goes on long enough it may be considered cured. If the disease returns (recurs), another remission may be possible with further treatment.

You may see on your medical chart: NED. This means “no evidence of disease.” Sometimes survivors talk about “dancing with NED.” This is the period after treatment when there are no symptoms.

You may see recurrence statistics about ovarian cancer. Statistics deal with groups of people, not with individuals—and you are an individual. When one hears recurrence statistics, there may be a tendency to put oneself into the more pessimistic place. Always remember we do not know what the future holds and no one can accurately foretell what will happen—not even doctors. If statistics will be helpful to your journey, use them; if not, close the door on the tyranny of those numbers. New developments, new drug options and personal factors unique to you can be more powerful than statistics.

Ovarian cancer is often chemo-sensitive—that is, it is beaten back by chemotherapy—and many women will achieve a remission. However, a fair number of women may experience a relapse of their ovarian

cancer. Ovarian cancer survivors may face a recurrence of their disease. For some, a recurrence may come much sooner than hoped. This is also the time when the woman with ovarian cancer may realize that a cure likely is not possible. You have already lived the cancer experience: diagnosis, treatments, side effects either short-term or long-term. You may or may not have decided what you might do if faced with the reality of recurrence. What may have seemed like an easy decision can shift if the cancer relapses. You may find yourself changing your mind and looking for more options.

If there is evidence that your cancer has recurred, you and your health team will need to consider the next steps. It is understandable that you may want to get the cancer treated as soon as possible because you are concerned that it will spread. However, give yourself time to consider the treatment options and how the goals of treatment balance with toxic side effects (such as neuropathy). For instance, neuropathy is a side effect of some chemotherapy drugs and because it is cumulative, may have a big impact on your quality of life.

Treatment for Recurrence – Considerations

When they are being treated for recurrence, most women aim to extend their lives. But this is part of a bigger picture.

- You may need to think not only about how to balance treatment that will stop or slow the spread of the cancer, but what drugs will be most helpful in doing this and what the side effects that they carry for you.
- The symptoms of ovarian cancer can be distressing—bowel issues as a result of bowel obstruction. How can such symptoms be minimized?
- How best can the time before symptoms develop or get worse, be increased?
- What treatment options are best to increase time before disease progresses?
- How can the quality of life for a woman with ovarian cancer be enhanced or maintained?

Some gynecologic oncologists prefer to restart treatment for ovarian cancer recurrence on the basis of the symptoms a woman experiences. Others may use a rising CA125 level as a trigger to do further tests. Then, if the test (for example an ultrasound) shows measurable evidence of disease spread, then the doctor would offer treatment. Talk with your doctor and the health care team about the pros and cons of the different approaches in your particular situation.



There are multiple chemotherapy treatments, but not all of them may be right for you. Your medication will be individualized for you and the doctor will discuss your best options with you. It is important to understand your overall goals, your quality of life, the side effects caused by the medications and how badly the cancer makes you to feel.

When you are being treated for recurrence, chemotherapy treatments are often referred to as a palliative treatment: the goal is to provide relief of symptoms and to achieve a temporary remission.

When you restart chemotherapy, it is not the same as when you were first diagnosed with ovarian cancer when you may have sensed an urgency to begin treatment. With a recurrence, decisions are based on individual circumstances. Once a recurrence occurs, it is possible but not likely there will be a cure. When restarting chemotherapy or other treatments, the goal is to improve your quality of life and hopefully to achieve a period of time when a drug holiday can occur. A drug holiday is a period during which a drug (which is typically taken) is not taken in order to reduce certain side effects.



Some considerations about treatment

Platinum Sensitivity

If your ovarian cancer initially responded to a specific treatment program, chances are it will respond again if the cancer recurs. The longer the duration since the first line of treatment with a platinum drug (carboplatin, cisplatin) or any agent, the better the chances that the recurrence will respond.

Platinum agents either alone or with other drugs are the most common chemotherapy drugs for ovarian cancer. If a woman received carboplatin during her first line of treatment and the **ovarian cancer recurs after a year or more**, the ovarian cancer is referred to as platinum sensitive—it initially beat back the cancer. In this case, carboplatin will be a powerful agent to deal with the ovarian cancer recurrence. And if a platinum agent is given, then it may be given alone or with another non-platinum drug.

If the ovarian cancer recurs after six months, it is partially platinum sensitive and a platinum agent may or may not be the best choice of drug to treat recurrence.

If it is less than six months before the ovarian cancer recurs, it is called platinum refractory and platinum chemotherapy will not be a good choice to deal with the recurrence. There are other drug options that will be used.

It has also been shown that a woman's ovarian cancer, if she initially responded to platinum agents, may respond a second or third time to those same chemotherapy drugs.

If platinum therapy will be used to treat the recurrence, whether it is used alone or with other drugs, the woman will need to discuss an important issue with the doctor. With repeated use of platinum agents, there is the risk of hypersensitivity reaction. . These allergic reactions or hypersensitivity reactions can be as serious as a bee sting reaction or a nut allergy. Symptoms range from mild rash to difficulty breathing, chest pain and serious cardiovascular or respiratory arrest. Her family should be aware of this possibility as well. The health care team will make decisions regarding future treatments based on the type of reactions or side effects that occurs with your treatments.

So, you may ask yourself, "what agents are right for me?"

The following treatment drugs have been used in recurrent and platinum-resistant ovarian cancer:

Chemotherapy:

Cyclophosphamide

Etoposide

Docetaxel (May not be approved for funding in all provinces)

Gemcitabine

Liposomal Doxorubicin (Caelyx)

Melphalan

Paclitaxel (Usually used with carboplatin if cancer recurs one year post treatment)

Topotecan (May not be approved for funding in all provinces)

Vinorelbine

Hormonal Therapy:

Tamoxifen interferes with the activity of estrogen and may be helpful for advanced ovarian cancer although there is not strong research evidence to support its use.

Biologic Agents:

Biological therapies (also called immunotherapies) use substances that occur naturally in the body to destroy cancer cells.

Bevacizumab (Avastin) is a type of immunotherapy called a monoclonal antibody. It has shown promise in clinical trials.

These agents may be given alone or in combination. Some of these drugs are used to treat particular types of ovarian cancer. When they used in combination, it is difficult to establish which drug or drugs are actually helping you. Some physicians prefer to try one at a time in order to get a better picture if the medication is helpful for you. These drugs are given on different schedules. Some are given only intravenously; others are in pill form. There are different response rates or chances that these drugs can help you. Some or all of them may not be appropriate for your situation. Discuss these options with your doctor and healthcare team. Sometimes these medications can cause powerful side effects and living with the cancer may be preferable.

Instead of the usual chemotherapy agents, hormonal therapy such as Tamoxifen may be used. Targeted therapies such as Bevacizumab or other chemotherapy drugs may be recommended for women who have had previous chemotherapy.

In some cases, clinical trials may be offered to test new agents to treat recurrent ovarian cancer management. Participating in a clinical trial may be an option for you. Discuss this possibility with your healthcare team.

Targeted therapy is a fairly new development in cancer treatment. The focus of many targeted therapies is based on signals and pathways within the cancer cells to block or stop the growth or spread of cancer cells. Targeted therapies work differently from chemotherapy. They may be used alone or in combination with other treatments. As healthcare providers use these new treatments, they learn more about their safety, side effects and symptom management.

An online resource that you may find helpful is the National Comprehensive Cancer Network (NCCN) Guidelines for Patients <http://www.nccn.com/patient-guidelines.html#ovarian> . Although developed in the US, it gives clear and helpful information about treatment options. You may find it useful to have this information when you are speaking with your gynecologic oncologist about possible agents that can be used for your treatment.

To learn more about the specific treatment agents and their side effects, you can go to the British cancer site, MacMillan Cancer Support <http://www.macmillan.org.uk>. You will find lots of information about the agents that might be used in your treatment. Knowing more about them can help you prepare, watch for possible side effects and plan what questions to ask your doctor. You will need to think about and discuss with your doctor how your treatment can be balanced so that side effects do not interfere with the quality of life that you want.

Some women recur once and then go for many years in remission; others have brief respites between recurrences but with treatment have a satisfying quality of life for an extended period. Many women have had a number of recurrences and have been treated for long periods and have had a quality of life that was meaningful and satisfying. Some women choose not to continue with treatments. These decisions are made based on your individual priorities.

- Surgery

Surgery to remove recurrent ovarian cancer is used with caution. Surgery on its own is a serious procedure and carries risks. It is more complex to repeat abdominal surgery in ovarian cancer, partly because of the effects of previous surgery. There is no strong evidence that it helps women live longer. The decision to perform surgery on a woman whose ovarian cancer recurs is a very individual one.

An exception may be for women who recur after more than 12 months and who meet specific criteria. This is rare and requires individual assessment.

If there are several sites where there is tumour growth, if the ovarian cancer is “bulky” and if there is ascites (fluid in the abdomen), repeat surgery is not likely to be used. Exceptions to this would be specific issues like a bowel obstruction.

- Radiation

While radiation is not often used in recurrent ovarian cancer, it may be helpful when there is localized tumour that does not require a large part of the bowel to be exposed to radiation. While radiation destroys cancer cells, it can also damage or kill healthy cells. It might be used to control a specific localized issue such as tumour recurrence at the vaginal vault (internal end of the vagina) that causes bleeding.

Radiation may be used to reserve chemotherapy treatments for later use or to manage an isolated mass. There are pros and cons to using radiation therapy treatment. It causes side effects which vary, depending on the site being treated. Speak with your healthcare team regarding this option for you.

There is information about radiation in *You are Not Alone* (hyperlink), pages 48 – 51. And the Canadian Cancer Society has a booklet available about treatment with radiation and its side effects. Go to www.cancer.ca.

- Clinical trials

Participation in a clinical trial to treat your recurrence may be an option for you to consider. Speak about this possibility with your gynecologic oncologist.

A clinical trial is a research study, in this instance to help find better ways to treat ovarian cancer. While many clinical trials are related to treatment of the cancer, other trials may deal with reducing side effects such as nausea or sleep disturbances.

Trials are run according to a clear and strict protocol. To participate in a clinical trial one needs to meet certain criteria and these depend on what the clinical trial is investigating. There are different phases of clinical trials and each phase answers specific questions.

A Phase I clinical trial determines the dose and side effects of the drug being studied. Although there is some risk, a Phase I trial may be an option for those who are willing to try something new and with positive potential. There is only a small group of participants in a Phase I trial and they are closely monitored. The dosage of the drug is gradually increased for safety and to balance the side effects that it may cause.

A Phase II clinical trial determines if the drug works in a specific cancer and how well. The number of participants for a Phase II trial is also small.

A Phase III trial looks at a new treatment in comparison to a standard one. There are a large number of participants usually and all participants get treatment. Participants and the doctors are not likely to know who receives which treatment.

Ovarian Cancer Canada's website has information about clinical trials and ovarian cancer (<http://www.ovariancanada.org/KnowledgeAwareness/Treatment-And-Recovery/Clinical-Trials>). The Canadian Cancer Society has a publication with basic information about trials. Go to www.cancer.ca.



To get details about ongoing clinical trials in your province, go to: <http://www.canadiancancertrials.ca>.

The Society of Gynecologic Oncology of Canada also provides information about clinical trials by cancer centre. Go to www.g-o-c.org.

Some clinical trials are conducted only at one location whereas others may be at a number of cancer centres.

If you find a study that you may qualify for, take the information with you to discuss with your doctor the pros and cons of participating in a clinical trial.

Talking with the Doctor

A document prepared for the Canadian Breast Cancer Initiative helped provide some of the information that follows. While “the doctor” is referred to here, you can use this information to help communicate with all the members on your health care team: nurses; pharmacists; social workers, etc.

Although the doctor is just another human being, he or she plays an important role in helping you deal with recurrence. Since it is your life and you live it, think about what role you want to play in the treatment discussions and decisions.

- Do you want to be an active partner in the decision making?
- Would you like the doctor to make the decisions for you?
- Are there times when you want to be the active partner and other times when you find it preferable to take a less active role?
- To what extent do you want your family involved?

Since neither you nor your doctor can read minds, communication needs to be clear. Unspoken attitudes and feelings can complicate things, so it is helpful to look at those you bring to your interaction with your doctor. You may feel at a disadvantage since you do not have the knowledge the doctor has. It may seem as though doctors wield a lot of power and that you should not question what they say or disagree with what they advise. Courtesy and openness can help you, and so can being prepared for your appointments.

- Before your appointment
 - Set some goals for the discussion. Know what you need. Do you need to get information from the doctor or to give information? Do you need to make a decision? Get help and support?
 - Give some thought to what the doctor’s priorities may be. How can you best communicate with this professional?
 - Identify topics that you need to discuss and how. Formulate specific questions.
 - Concentrate on what is most important to you at this time and set priorities.
 - Perhaps it is helpful in your situation to speak with others on your healthcare team such as the oncology nurse, social worker, dietician or pharmacist.



- Take a friend or family member that you trust with you to support you at your appointment. That person can listen, take notes, and ask questions you may not have thought of.
- It might be helpful to send your questions to your doctor before your appointment.
- Be prepared for your appointment. Brainstorm with a friend to make sure all important topics will be covered. Group your questions into topics. You might want to role play with your friend to boost your confidence.
- Give yourself time—not everything has to be decided right away. Schedule special appointments to discuss an issue further.
- When you meet with your doctor
 - Review your agenda and priorities with the doctor early on. Agree on what you both need to discuss.
 - Listen carefully and use body language to convey this.
 - Ensure that you understand. Repeat to the doctor, in your own words, what you heard (“If I understand you right, you’re telling me ...” or “I’ll tell you what I heard so we can make sure I’ve got it ...”) Ask the doctor to confirm or clarify. This way any misunderstandings can be cleared up. It can also help you remember the information or instructions the doctor gave you.
 - Use “I” messages (“I feel that ...”, “I am concerned that ...”, “I need more time to think ...”). Share with the doctor what is important to you in planning your care.
 - Share what you are feeling (“I feel confused, overwhelmed, calm, embarrassed, frightened...”). If you show your anger, frustration, fear, or embarrassment, talk about it.
 - Ask your doctor and other healthcare professionals to repeat anything that you do not understand using simpler terms. If a picture might help, ask them to show you one or to sketch it.
 - If you feel that there is something that blocks communication, raise it courteously and work towards a common solution.
- After your appointment



- Take time to absorb what was said. Review your notes and reflect on what your doctor said, as well as your own views and feelings. If someone came with you to the appointment, get their perspective.
- New questions may arise that you will want to follow up with the next time you talk with the doctor.
- Reflect on your meeting with the doctor. Were you able to express yourself? Did you learn what your doctor was thinking and feeling? Is there something that you might change for next time?
- Record in a journal what you learn from your doctor, other caregivers, other patients, or your own reading.

Second Opinions

Ovarian cancer treatment is a complicated thing; the information about treatment options keeps growing. You have the option to get a second opinion. You may want this to confirm that the course that has been chosen is the right one for you; or you may want to learn about other options available. Second opinions are a normal part of cancer care.

It may feel difficult to ask your gynecologic oncologist for a referral for a second opinion. You may be afraid that it conveys mistrust and that perhaps it will hurt your relationship. On the other hand, you may strongly disagree with the treatment plan the doctor proposes and look for someone who is more in line with what you believe needs to be done. Referral for a second opinion is a part of a doctor's professional practice. A polite and matter of fact approach on your part will help.

Your health information such as test results and pathology reports will be forwarded to the doctor. Take the time that you need, days or a few weeks to get a second opinion so that you can choose a treatment that seems right for you. You may be asked to sign a release form to share your health records with the consulting doctors especially if this is doctor from another healthcare facility.

Ovarian Cancer Canada addresses the topic of second opinions in more detail in one of our teleconference sessions archived on www.youtube.com/OvarianCancerCanada.



Support that You Need - Considerations during Recurrence

Support and Your Health Team

While it does not happen in all cases, many women feel support from members of their health team at the cancer centre—this may include the doctor, the chemo nurse and social worker or psychologists who are part of the psychosocial department and others. Clear and friendly communication helps create a supportive atmosphere.

Quality of life—how to make it better or how to keep it—is likely to be a prime concern for you. You might wish to talk with the staff about quality of life issues so that they can best support you. Some of those issues are:

- Balancing the best treatment with the side effects that it may cause
- Minimizing the symptoms of ovarian cancer
- Increasing the time before symptoms develop or get worse
- Increasing the time before the disease progresses

Support around you

It may be difficult for you to share with those close to you that the ovarian cancer has recurred. You will need to decide how much to tell them and when. Perhaps there is someone whom you trust that might help you with this: a family member, a friend, a health professional, someone from your faith community, etc.

Many feelings may come up—in you and in those close to you when they learn that the ovarian cancer has recurred. These may include disappointment, shock, fear, anxiety and others. Keep lines of communication open for mutual support.

Sometimes it is not easy to know what you are feeling. It is worthwhile to share this—it is OK not to know what one feels. And it is helpful information for those around you.

When women are first diagnosed with ovarian cancer, relationships may change. Those individuals you that you thought would be there for you the first time you were diagnosed might have disappeared. Perhaps you are afraid this might happen again with recurrence.

But others may have appeared to help you out.



Different people are helpful in different situations. Especially during this tough time, be with people who you feel good to be with.

If people ask how they can help you, be prepared with some errands that they might do for you such as driving you to your appointments, picking up kids after school, or walking the dog. Make use of the willingness of others to be of service to you.

You may be afraid of becoming a burden to those close to you. If you are a woman without a partner, you might feel especially vulnerable, feeling as though there is no one you can count on. Ask for help among those you can trust in your circle and take advantage of offers to help you.

You may wish to discuss your concerns with your healthcare team. They may be aware of other supportive strategies to help you.

Support Groups

An important source of support and information may be other women who have gone or are going through ovarian cancer recurrence. Many women have found that in support groups there are others who understand and are in the same boat. In a support group there are likely other women who have gone through what you are going through and who want to share what they have learned.

- In some cancer treatment centres there may be an ovarian cancer support group that one can join. Often these are led by health professionals such as psychologists or social workers.
- Other support groups may be peer-led (that is, led by a cancer survivor) and be sponsored by a cancer organization. These are likely to be away from the treatment centre.
- Where there is no ovarian cancer support group, a woman may be able to find what she needs in support groups for people with any cancer. There are many concerns that people with cancer share. Often groups like these are led by the Canadian Cancer Society.
- There are online chat groups for people with cancer and for caregivers provided by CancerChatCanada. These are led by health professionals. This important project is hosted by the BC Cancer Agency and funded by the Canadian Partnership Against Cancer. For more information go to the website at <http://cancerchatcanada.ca/> or call 1-800-663-3333 ext. 4965 or 4966. They take referrals to support groups anytime.
- Another kind of online support is also provided by the www.acor.org. It offers a mailing list for those affected by ovarian cancer. Many women have found the support, information and the sense of community provided by this list very helpful. Although it is based in the US, it connects women around the world.

Getting Connected / Staying Connected



There are sources of information and support that may be helpful for you during the recurrence.

- If you have not received it already, order a free copy of the *You are Not Alone* resource book that Ovarian Cancer Canada provides for women with ovarian cancer. Although it was designed for women when they are first diagnosed, you may find helpful information for this phase of the cancer journey as well.
- If you have not already subscribed but would like to, get on the Ovarian Cancer Canada Seeds of Hope Newswire mailing list. You can register on-line for your free electronic support newsletter at www.ovariancanada.org. The newsletters will provide you with inspiring stories, updates about ovarian cancer research and events going on in the ovarian cancer community in your region and across the country.
- If you have not contacted her already, connect with Ovarian Cancer Canada's regional manager in your area. She can help to keep you informed about activities and resources in your area.
- Ovarian Cancer Canada has a number of excellent audio presentations archived at www.youtube.com/OvarianCancerCanada, including a presentation by a gynecologic oncologist on recurrence.



Side Effects of Treatment

There are a number of side effects that result from treatment and are discussed in *You are Not Alone*.

There is also helpful information available about dealing with side effects in the Canadian Cancer Society's booklet, *Chemotherapy and other drug therapies: A guide for people with cancer*. It is available in the publications section of their website www.cancer.ca or you can order it by calling 1 888 939-3333.

Peripheral neuropathy and Chemo brain will be discussed here.

- Peripheral Neuropathy

A number of chemotherapy agents (such as carboplatin, cisplatin and paclitaxel) alone or in combination can contribute to neurological side effects during cancer treatment.

These side effects may be short- or long-term. It depends on factors such as your age, how much is given in a dose, the cumulative (total over time) dosage of chemo drugs, how long one has been treated, combinations of neurotoxic agents and other factors.

Peripheral neuropathy can vary: when it might begin, how severe it is, what it is like and how long it is likely to last. Often, it may be a glove-and-stocking distribution in the hands and feet. The hands and feet may be numb or very sensitive. There might also be sensations such as tingling, pain from stimuli that are not usually painful (such as touch), exaggerated pain, diminished pain, or burning, shooting, or electric-shock-like pains. It may also be felt as severe itching.

Peripheral neuropathy might dull temperature sensation, decrease awareness of body position, and lessen the ability to feel vibrations. Arms and legs may feel weak. There may be loss of balance.

Sometimes women may not be aware of these are side effects or may not talk about them with their treatment staff because they believe they will go away. Talk with your team about these side effects early to help prevent the discomfort and prevent them from getting worse.

Antidepressants (duloxetine) or anti-convulsants (gabapentin) may help relieve the nerve pain. A lidocaine patch or some other topical analgesic may provide relief from discomfort. Acetaminophen and non-steroidal anti-inflammatory drugs (NSAID) may be helpful. Talk with your doctor about these options. Some women have consulted naturopaths for help.

Things you can do to manage peripheral neuropathy and keep yourself safe:

- Protect hands and feet from injury—use oven mitts when cooking; gloves when gardening; wear properly fitting shoes
- To protect your self from extremes of temperature, wear protective clothing in the cold, assess water temperature carefully



- For safety related to balance, prevent falls with well lit rooms, clear walkways, and nonskid mats in your shower or bath
- Ask others to help you with any changes in daily routines in activities where you might lose balance or require motor skills: picking things up, buttoning clothes, opening jars, or inserting keys in keyholes.
- Consider eliminating throw rugs, as they may increase your risk for falls.
- Fatigue and depression may go along these side effects. You and those close to you should report this to your treatment team.

Although many prevention strategies have been studied to prevent peripheral neuropathy, these have not proven to be very effective. Vitamin E has shown some promise for prevention of neurotoxicity in cisplatin-based compounds and paclitaxel.

Exercise to help restore function in the arms and legs may be of help. Exercise can also improve balance, strength, and safety. Specific stimulation exercises for the hands and feet may be used by physiotherapists and exercise therapists. Ask for referral to physiotherapy and/or to occupational therapy if braces and other assistive devices may be needed.

Controlling diabetes, limiting alcohol intake and avoiding repetitive activities such as extensive walking, playing instruments, knitting, typing may decrease symptoms.

There is helpful information on the MacMillan Cancer Support site about peripheral neuropathy <http://www.macmillan.org.uk/>

- Chemo Brain

Studies show that “chemo brain” or chemotherapy induced cognitive impairment is fairly common. It refers to memory problems, problems in thinking and poor concentration that seem to result from treatment. Some people will refer to this problem as “chemo fog”. Other symptoms include confusion, fatigue, short term memory problems, difficulty learning new tasks and other problems. Trouble paying attention, finding the right words, and doing math may also be part of chemo brain.

It is uncertain what causes these problems with memory and concentration or makes them worse. Contributing factors may be treatment (chemotherapy, radiation, hormonal, etc.), poor nutrition, anemia, infection, and sleep problems. Anxiety, stress and depression may also play a role. Side effects of other drugs used to deal with side effects of treatment and/or changes in hormones may also play a role in chemo brain.

Talk with your doctor if you are concerned about chemo brain. It is helpful to keep a journal of any memory lapses and to bring it to your appointment. Keep track of the situations in which you experience



memory problems: what you were doing and what type of trouble had. Also bring along a list of all medications, vitamins or supplements that you take.

At present there are no effective medications to deal with or prevent chemo brain. You can do things to help yourself:

- Minimize distractions so that you are able to focus.
- Use a day planner and record everything that will help you be organized.
- Create "to-do-lists"
- Consider using a pill box/organizer for your medications.
- Keep your living and work space simple and organized.
- A healthy life style will be of benefit: eat well, get the rest you need, get regular exercise; relax.
- Ask your family and friends to help you keep on track with specific reminders.
- Work your brain. Do crosswords, puzzles, and math calculations/problems.
- Be patient with yourself and keep a sense of humour.

Chemo brain may make it difficult for women to work: they may be unable to work when tasks take more concentration or take longer to finish. Multi-tasking may be more of a challenge. If symptoms make it difficult to do your job, let your doctor know. With the help of an occupational therapist or vocational rehabilitation counsellor, it may be possible to make changes in your current job. Or, it may be time to find a new job using other strengths and skills that you have.

Although it is rare, a woman may be unable to return to work because she is unable to concentrate and/or has memory problems. In this case, she may need to apply for disability benefits. She will need the help of her oncologist and social worker to do this.



Complementary and Alternative Medicines (CAM)

Many people with cancer have questions about complementary and alternative medicines. Are they safe to use? Do they work? How might they help me? Do they work with the treatment that I am using?

Complementary treatments are used along with conventional medical treatments; alternative therapies are used instead of conventional medical treatments.

People who choose CAM may believe CAM treatments are more “natural” and less toxic than medical treatment. They may have found CAM helpful to reduce cancer symptoms or the side effects of conventional treatments. Some CAM may also help relieve the stress of cancer and its treatment. Some CAM may help the body heal.

In general, types of CAM are:

- Biologics and Natural health products. “Biologics” include special diets and foods. Natural health products are vitamins and minerals, herbal remedies, homeopathic medicines, probiotics, amino acids, essential fatty acids and other products.
- Mind-body practices that include meditation, prayer, relaxation, visualization, and art and music therapy.
- Manipulative and body-based practices that include therapies such as spinal manipulation and various kinds of massage.
- Energy therapies that include therapeutic touch, reiki, and acupuncture.
- Whole Medical Systems that are based on specific theories. Examples include traditional Chinese medicine and naturopathy.

Since there is a risk that CAM can affect your conventional cancer treatments or interact with medications you take for other medical conditions, let your doctor know about your use of CAM.

Some of the challenges about the use of CAM are:

- How to choose which CAM therapy will be most helpful for you
- How to find a reputable therapist
- Paying out of pocket costs (although some services may be covered by your private insurance)
- CAM therapies may not be regulated.



Using CAM may bring a sense of hope, partly because women may feel more in control of their cancer experience.

Excellent information about CAM can be found at:

- BC Cancer Agency's Complementary Medicine Education and Outcomes (CAMEO) Program provides information to help you choose a safe and helpful CAM therapy. <http://www.bccancer.bc.ca>
- The Canadian Cancer Society provides a downloadable booklet entitled Complementary Therapy in the publications section of their website www.cancer.ca or you can order it by calling 1 888 939-3333

A new and growing field is Integrative Medicine which incorporates CAM into mainstream medical practice.

Some CAM resources created for people with cancer:

- The Healing and Cancer Foundation offers integrated programs for the mind, body and spirit that are aimed to "transform the experience of illness into a journey toward wholeness." <http://www.healingandcancer.org/>
- Inspire Health is based in BC and guides patients "to integrate research-informed natural approaches to health into their cancer treatment and recovery." <http://www.inspirehealth.ca/>
- Cancer Decisions – Dr. Ralph Moss PhD provides recommendations of the most successful cancer treatments in North America and Europe, as well as innovative therapies given at cancer centres. <http://www.cancerdecisions.com/>
- Life over Cancer – is a book by Dr. Keith Block who specializes in integrative oncology. <http://www.lifeovercancer.com>
- Although it is biochemistry and not integrative medicine, Canadian researcher and biochemist Dr. Richard Béliveau and co-author Denis Gingras describe the science of food and which properties of particular foods are the active cancer-fighting elements in their book *Foods That Fight Cancer*. <http://www.richardbeliveau.org>



Caring for Yourself

Going through recurrence has been described as walking through a swamp—there may not seem to be a step you can take onto solid ground. Nothing is certain and there may be a lot of fear and anxiety. It is an effort to wrap your head around the uncertainty that comes with the journey through the swamp. But many women have found it possible to carry on and to feel better. The anxiety is likely to lessen with time.

Here are some thoughts from women with ovarian cancer that may help you through the swamp. They are personal perspectives and might give you food for thought:

- *How much am I willing to change my lifestyle?* If there is a lot of pressure to conform to certain behaviours regarding diet, self-care, healthy living, etc. what needs to stay the same in your life? What do you want to change?
- *I will preserve my boundaries and tell my story in my own way to the people that I choose.* It is up to you who you tell and what information you share about your situation.
- *This time it is different.* Being diagnosed with a recurrence can best be described as sobering. What do you need to do in the face of it? What do you need to do differently; what do you need to keep doing?
- *If I choose to go off treatment for a while, I will not likely die tomorrow.* Family members, support group members and others can pressure you to stay on treatment when it doesn't feel right to you. Give yourself the opportunity to think about it and figure it out. Maybe take a break from treatment. Talk with someone you trust on your treatment team about how you might do this.
- *I trust my doctor and I have to honour my own needs.* Perhaps your doctor gives you too much or too little information. Perhaps he/she, even with your best interests in mind, has another agenda for you. Refer to the section on communicating with your doctor and speak your needs.
- *Staff should not write a patient off because she has recurred.* Sometimes treatment staff tries to be “realistic” and it comes out harsh and not very sensitive. Challenge them gently—they do not really know you and they can't read the future.
- *They want me to keep a positive attitude.* When you have a positive attitude, the people around you are likely to feel more comfortable. Only you know the truth of what you feel. About 25 per cent of people with cancer suffer clinical depression. It may not be



easy to recognize depression since anxiety, a sense of loss, and sadness are “normal” reactions to a diagnosis of recurrence. While your job isn’t to keep others comfortable by being positive, seek help if these feelings last longer than a few weeks.

- *I have two faces: a personal one and a public one. People tell me, “You look great; you're so strong!” Well, don't judge a book by its cover! Sometimes friends may seem insensitive when they tell you look good, because you may feel awful and believe you look ugly. If they say that you are strong, it may feel hard to take if you feel you are just dragging along. Often these things are said with the best possible intentions. Take a deep breath, say “thank you” and gently tell them what is going on with you.*

Recurrence and Your Children

Recurrence is bound to bring up feelings of uncertainty. You will likely also go through changes, physical and emotional, that occur because of the disease or treatment. This is bound to have an effect on your children. Although you may have discussed cancer with them when you were first diagnosed, the situation has changed. Children at different ages have different needs but it is still important for them to be connected to what is going on in their family.

The American Cancer Society devotes a section on their website about how to talk with children at various ages about recurrence. It is also available as a downloadable document. Go to www.cancer.org.

BC Cancer Agency has developed a website (Cancer in my Family – My Anything but Ordinary Journey) to help children explore their feelings about cancer in the family and to help parents stay connected to their children as they work through questions, emotions and understanding of their family's journey. Go to www.cancerinmyfamily.ca.



For Family Members—When ovarian cancer recurs in a woman who is close to you

When a person close to you is first diagnosed with ovarian cancer, it may be a shock. But after she (and you) has (have) made it through that rocky treatment journey, there may be a short or long period when she is in remission. Then, it can feel overwhelming if the cancer recurs. Then it can be a struggle as you try to figure out how to support her and to manage with what is going on.

The prospect of going through more treatment, side effects and the uncertainty of what might happen can be scary. You are scared for her and scared for the impact the recurrence will have on her, on you and on the rest of your family. Families in our busy and stressful world are often already stretched. But having the added stress of a recurrence will have an impact on things big and small in your family life— who will cook dinner? Who will do the laundry? Who will there be to care for the kids? What might happen without the second income? More responsibilities may get shifted to the partner when the cancer recurs. Tensions might rise as family members get tired with all the changes and demands when the wife and mother is ill.

Ovarian Cancer Canada has an archived presentation at www.youtube.com/OvarianCancerCanada called “Like Fish Out of Water: Men being helpful to women with cancer” based on research by Drs. Ross Gray and Karen Fergus. It is helpful to listen to. The suggestions below, on how to be helpful, come from that research:

- Just listen. Simply being with her if she is confused, hurt, or angry is an enormous help. Avoid giving advice or false reassurance.
- Offer practical help – you can babysit, drive her to appointments, get books from the library or information on the Internet for her, or buy food for her pet.
- Do research to help her. Learn as much as you can—it will also help you.
- Talk with her about the unfamiliar roles that you are taking on (caretaker, household responsibilities, and emotional support giver) and ask for her advice in how best you might carry them out.
- Understand that support group members may become very important to her and that this is not intended to push you away or diminish your importance to her.
- Sometimes a woman’s “spiritual direction” may change as a result of cancer and you may need her to talk with you about what is happening in this regard.
- Let her know that you are trying to figure out how to be supportive. Ask for her what she needs.
- If you have financial worries, give thought how to talk about them together.



- If you are troubled by your reactions to changes in her body (premature menopause symptoms, vulnerability), and to changes in your sexual relationship, find a counsellor at the cancer centre or someone else you both are comfortable with.
- Accompany her to her medical appointments.
- Let her know how much time you can give her and the kinds of things you are able to do for her. It is better to give reliable help in one area than to promise a lot and let her down.
- Enlarge and use support networks—hers and yours. Include friends as well as family. Share the care so that it doesn't all fall on the shoulders of one person.
- Find support services in the community that you or you both can use. These may include centres in the community for cancer patients and their families, as well as those which may not have cancer as their main focus (e.g., church groups) as well as professional counsellors.
- Let her know that she can express her feelings to you whether they are positive or negative. She doesn't have to act upbeat if she doesn't feel like it. And be aware that you do not have to "fix" her feelings.
- Allow her to make her own decisions. Accept that they might be very different from what you would choose.
- Consider how you might help her to keep her privacy—who should know about what.
- Recognize your own needs. Perhaps her illness makes you feel guilty about being healthy. Perhaps you feel powerless and cranky. Perhaps you become afraid of facing your own death. Perhaps you need some break time.
- When you learn about your own needs, you are in a better position to be genuinely helpful.
- Express your true feelings. "I'm scared for you," or "I don't want to lose you," that show you are concerned.
- Gently remind yourself that there are limits to what you can control and that it's not up to you to make everything better.

There are some helpful publications of the Canadian Cancer Society for those who are close to people with cancer. They help you understand what a person with cancer is going through and how you might be able to offer support. Although they do not deal specifically with recurrence, you will find them helpful:

- Living with Cancer: A guide for people with cancer and their caregivers



Ovarian Cancer Canada
Cancer de l'ovaire Canada

- When Someone You Know Has Cancer: How you can help.
- Living with Advanced Cancer

Go to the Canadian Cancer Society website (www.cancer.ca) and download the booklets. Or, for free copies, visit your local Canadian Cancer Society office, contact the Canadian Cancer Society's Cancer Information Service toll-free at 1-888-939-3333, or send an email to info@cis.cancer.ca.

- There are online chat groups for people with cancer and for caregivers provided by CancerChatCanada. These are led by health professionals. This important project is hosted by the BC Cancer Agency and funded by the Canadian Partnership Against Cancer. For more information go to the website at <http://cancerchatcanada.ca/> or call 1-800-663-3333 ext. 4965 or 4966. They take referrals to support groups anytime.



Sexuality and Intimacy

As a result of the treatment for ovarian cancer recurrence, women are likely to experience a lack of sexual desire. There are many factors that contribute to lowering libido. Side effects may sap energy or a woman may not feel comfortable about how her body has changed. Stress, worry, pain, radiation and chemotherapy, feeling ill and being tired are all powerful depressants that are likely to dampen sexual feelings.

Since sex has a great deal to do with the mind as well as the body and with the heart, communication is an essential part of it. Talking with your partner about what you are feeling and what your partner is feeling is important. If you need some guidance with the conversation, getting some help with your family doctor might be a good place to start.

Ovarian Cancer Canada has an archived session by Dr. Anne Katz on sexuality and ovarian cancer at:
<http://www.youtube.com/profile?user=OvarianCancerCanada&view=videos&start=40>

“Fish Out of Water: Men being helpful to women with cancer” is a research-based play which touches on sexuality from the male partner’s perspective. It is also available on YouTube:
<http://www.youtube.com/profile?user=OvarianCancerCanada#grid/uploads>

Dr Katz’s book about this important topic is entitled *Woman Cancer Sex*
(http://www.amazon.com/Woman-Cancer-Sex-Anne-Katz/dp/1890504807/ref=sr_1_1?ie=UTF8&s=books&qid=1245863228&sr=1-1)

Negotiating Finances

There is a lot of information about finances—resources, programs and coverage—in *You are Not Alone*.

1. Contribution programs, including Employment Insurance Benefits and Canada Pension Plan-Disability Benefits. Both of these are federal programs.
2. Asset-tested programs, which are usually municipal and provincial programs, sometimes called Social Assistance, Welfare, or Disability Benefits. Each municipality and province operates under their rules and legislation.
3. Income programs from your employment that may include short-term and long-term disability.
4. Personal assets which are unique to each person. These can include liquid assets such as savings, GICs, stocks, bonds, and RSPs, plus other assets such as investments, life insurance policy, and property.

Other resources to consider when coping with your illness include medical and drug coverage.

Helpful links:

- Wellspring, a Canadian cancer support organization, includes a program that addresses the financial issues of people living with cancer. At www.wellspring.ca, search for the Money Matters program.
- DrugCoverage.ca is designed to help Canadians access reimbursement for prescription medications. It provides information on the various types of Private Insurance plans, Provincial/Territorial Drug Benefit Programs and Federal plans available in Canada. <http://www.drugcoverage.ca/>
- On the Willow Breast Cancer Support site is a listing of resources to help address the financial challenges of breast cancer province by province. Willow Breast Cancer Support www.willow.org.

Discuss these concerns with your doctor or healthcare team. An appointment with a social worker may shed some light on your concerns and provide an opportunity to discuss coping strategies.



Ovarian Cancer Canada
Cancer de l'ovaire Canada

Work

Balancing work/career, ovarian cancer and treatment can be challenging. If the ovarian cancer recurs, many questions come up: Do I want my old job? Can I go back to it? What are my options? There is information about relationships with colleagues and bosses in *You are Not Alone*.

In recent years with more people returning to work with cancer, cancer in the workplace has become a more significant issue. A helpful website that covers many aspects of being employed with cancer is the US site is: <http://www.cancerandcareers.org/>.

Hope

Hope is a positive perspective on the future—your plans and wishes. But with a recurrence you may feel hopeless: your life may spin out of your control. The ovarian cancer, or the doctor, or the treatments may seem to control you. Focus on positive things that can be done about your recurrence. Look for things to distract you in a positive way—be with people you enjoy, do things that make you happy, watch movies that make you laugh or inspire you. Put some of those things that are fun into your life, whatever they are. Talk with the chaplain or whomever you trust to help restore your hope when it flags. Planning a trip or looking forward to an event such as a loved one's wedding or graduation can increase your sense of wellbeing and fill you with hope.

Recurrence changes your way of life, your perspective and your plans for the future. When you were first diagnosed, you may have hoped that after treatment your life would go on as usual. Perhaps that is still your hope. Be aware that family members may hope for different things for your life. This can complicate things.

In recurrence, your hope may shift from hope of cure to hope that you live the rest of your life as well as possible. Sometimes even health care professionals seem to believe that living a long life is the only hope that their patients have. But hope may change as illness progresses. You may find that hope for you resides in quality of life rather than length—you want to live well. Hope may also be spending time with those that are meaningful for you—family and close friends. Or it may be a warrior hope to fight a good fight as long as you can. Not being abandoned by the significant people in your life may be your hope. Being assured that others genuinely care about your well-being sustains hope.

Discuss with your family and with your treatment team what hope means to you. Ask them to work with you to allow this hope to grow. There is an excellent discussion of hope at www.virtualhospice.ca.



Ovarian Cancer: A chronic disease?

For some women ovarian cancer will go in and out of remission and will be treated over time; this can be considered a chronic disease. It means that you can live with a good quality of life for years. It also means that planning what therapy to take and when over an extended period of time may help women with ovarian cancer live longer and with a better quality of life. Since it can be repeatedly treated over time, you may be able to live your life and to do the things you want to do.

Advance Directives

Advance care planning is a process that includes conversations with close family and friends. It is a way to ensure that you receive the kind of care that is most important to you at the end of life.

An advance care plan describes your wishes for the end of life if you cannot speak for yourself. Your plan, which should be written, may include information about treatments that you do or don't want to have and other information about your care at the end of life and will name a substitute decision maker.

For more information about how to start the conversation about advanced care planning and about how to create your advanced care plan, go to the special website developed by the Canadian Hospice Palliative care Association: <http://www.advancecareplanning.ca/>

Palliative Care

The discussion of palliative care can be a tough one since it may carry negative connotations. Palliative care is meant to relieve suffering and improve the quality of life for persons who are living with or dying from advanced illness. It may be the main focus of care when a cure is no longer possible.

Discussion about palliative care services can be helpful in the course of recurrence since they can be a resource to help relieve pain and other symptoms. They are helpful not only when a person is approaching death but also at earlier stages in the illness. Palliative care may be combined with treatments aimed at reducing or curing the illness, such as chemotherapy. Other aspects of palliative care include caregiver support.

Speak with your doctor or other members of the healthcare team about referral to palliative care to help you manage your symptoms.

To learn about the kinds of services provided by hospice palliative care across the country, go to the Canadian Hospice Palliative Care Association website at <http://www.chpca.net>



Overall Health

While dealing with ovarian cancer may be an issue for you, it is important to pay attention to other aspects of your health.

- Keep up your visits with your family physician. Although it should not be up to the patient to do this, you may want to check that he/she is getting reports about your ovarian cancer treatment and follow up.
- Pre-existing conditions such as hypertension, diabetes, high cholesterol, arthritis, etc. need continuing follow up by your family physician.
- Although you are being followed at the cancer centre for ovarian cancer, make sure you receive the age appropriate screening for breast, cervical and colon cancer through your family physician.
- Attend to your well-being day by day: eat a healthy diet, ensure you get the rest you need and engage in physical activity daily. All of these will benefit your mind, your body and overall health.
- There are multiple aspects to your being: physical, emotional, spiritual, social. If your emotional health is in pieces, see a social worker or counsellor. If your spiritual wellbeing needs attention, find a meditation teacher or; see your minister/rabbi/priest/imam or someone else you can trust to help you work through this important area. What benefits the health of one area is likely to benefit your total health.
- Many have found that giving to others benefits one's wellbeing. Consider volunteering in Ovarian Cancer Canada programs such as Knowledge is Power or Survivors Teaching Students, if this seems right for you.