

# WHEN A LOVED ONE HAS OVARIAN CANCER



"a ribbon we  
use to tie us  
together"

TM



## ABOUT THE NATIONAL OVARIAN CANCER COALITION®

Since its inception in 1995, the National Ovarian Cancer Coalition (NOCC) has been committed to raising awareness of ovarian cancer in communities across the country through education and support. As the first and only national ovarian cancer organization with a network of local chapters located throughout the United States, the NOCC has established itself as the leading advocate for patients and families coping with ovarian cancer. The NOCC works to advance its mission through national awareness and survivorship programs, a comprehensive website, a toll-free information line, peer support, professional education, and publications like this one.

### **The NOCC's national programs include:**

- The *Take Early Action & Live (TEAL)* initiative provides education and increases awareness of ovarian cancer.
- *Faces of Hope* provides up-to-date information, hope, and support to women with ovarian cancer, their families, friends and loved ones.
- Together in TEAL® - *Ending Ovarian Cancer* raises awareness, celebrates survivors, and remembers those lost to the disease.
- NOCC *CancerConnect* provides an online, HIPAA compliant platform to find peer-to-peer support, share experiences, and build community.
- The NOCC *Research in Action*® initiative provides critical funding to help support the progress of new treatment, and ultimately a cure, while supporting research initiatives such as clinical trials that save and extend lives.

For more information about the NOCC, visit [ovarian.org](http://ovarian.org) or call 1-888-OVARIAN (1-888-682-7426).



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# THE JOURNEY BEGINS

## **FROM THE MOMENT YOUR LOVED ONE WAS DIAGNOSED**

with ovarian cancer, you've probably gone through an entire range of emotions. Family members and friends of women with ovarian cancer have said that they feel angry, sad, anxious, scared, and lonely. One or more of these feelings may come and go, or you may have all of them at once. They may continue as your loved one goes through treatment and even after treatment has ended. Family members have said that they want and need to do something to help, but they don't always know what to do or how to do it. This guide is intended to provide information and answers to help you help your loved one as she adjusts to life after a diagnosis of ovarian cancer.

With support and encouragement,

**National Ovarian Cancer Coalition**



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## HELPING YOUR LOVED ONE

Family members and friends often do not know where to begin to help their loved one. Following are some tips that others in your situation have found helpful:

- Spend time and talk with her. Let her take the lead. If she wants to talk, be a good listener.
- All it takes sometimes is a touch or a hug to let someone know you care. It doesn't have to be a long conversation. Just being there is important.
- Try to feel comfortable when there is a lull in the conversation. Silence can often be comforting.
- Remember that she may not always want to talk or think about cancer.
- Help put ovarian cancer in perspective by obtaining accurate, factual, and honest information.
- Be an educated family member or friend. Know what resources are available. Seek out new, reliable information from your healthcare provider, from the National Ovarian Cancer Coalition, the National Cancer Institute, the American Cancer Society, your local library, and local support groups.
- Help her find a healthcare provider who understands her and meets her needs.
- Try to involve her in as many shared activities as she would like. Play cards, watch movies, go out to dinner, or go shopping.
- If you don't live with her, continue to visit, call, email, or write.
- Keep your promises. If you say you are going to stop by, follow through. Understand if she tires quickly and you can't stay as long as you expected. Learn to read signs that she needs rest or time alone.
- Encourage her to do things with others.
- Run simple errands. Often these small tasks seem insignificant but can provide great relief to her and her family.
- Write a little note to let her know you are thinking about her or make a quick phone call.

### BE AN EDUCATED FAMILY MEMBER OR FRIEND.

Know what resources are available. Seek out new, reliable information from your healthcare provider, from the National Ovarian Cancer Coalition, the National Cancer Institute, the American Cancer Society, your local library, and local support groups.



- Allow her privacy.
- Discuss needed changes in family roles and activities.  
Decide what is important, what needs to be done, what can be delegated, and what can wait.
- Don't minimize the effect of the cancer, but don't be overprotective.
- Most importantly, be yourself!

## COMMUNICATING WITH YOUR LOVED ONE ABOUT OVARIAN CANCER

Why is it hard to talk about ovarian cancer? Many people feel that it is very hard to talk honestly with their loved one about ovarian cancer. You may feel like you have to protect her. Or you may feel like she has enough to worry about without worrying about your stress, your problems, or your emotions. You may worry that if you talk about your fear or anxiety, you may make her scared, anxious, or make her lose hope. It's important to communicate effectively with your loved one. Below are some tips others have found helpful:

- **Express your feelings and try to communicate openly.** This is crucial to create a healing environment and to help each other gain the strength necessary to deal with ovarian cancer.
- **Give your loved one permission to openly express her feelings.** Some patients may keep feelings bottled up for fear of worrying or scaring their family and friends.
- **Let your loved one know that it is OK to cry** in front of you and that expressing emotion is not a sign of weakness.
- **Try to set aside time every day to talk to each other without interruptions.** Turn off the ringer on your phone; turn off the television; don't answer your doorbell.
- **Use "I" statements**, such as "I feel angry when\_\_\_\_" or "I feel frustrated because\_\_\_\_" or "I feel sad because..."
- **Clarify statements with each other:** "I heard you say\_\_\_\_is that right?" If you think your loved one misunderstood something you said, try saying it a different way.
- **Try to avoid serious discussions when you are tired or angry.** Messages are more likely to be poorly communicated.
- **Don't stop making plans for the future.** Discuss life goals and plans for when recovery goes well, but also for if the cancer takes a turn for the worse. Talking about this can help both of you prepare for whatever the future holds.
- **Make sure you know your loved one's wishes should the cancer get worse.** Let her know you can handle these discussions. Talk about things that both of you may be worrying about but may be afraid to talk about: finances; hospice care; who will make decisions for her if she is not able to make them for herself.

## COMMUNICATING WITH OTHERS ABOUT YOUR EXPERIENCE

Why is it important to communicate with others about what you're going through? The experience of ovarian cancer affects the entire family, as well as friends and co-workers.

As a family member or friend of a woman with ovarian cancer, you are not alone. Just as you are working to cope with the cancer of your loved one, friends, coworkers and other family members are affected too. Children and parents face uncertainty and fear. Co-workers worry and may also have to deal with crises and interrupted schedules. Everyone needs support - learn to ask for help and encourage others to do the same.

With permission from your loved one, explain what is going to friends and coworkers so they can understand if you have to change your plans. There are no disadvantages to having support in place, in case you need it. Keep in touch with your friends, family, and anyone else who supports you. Most importantly, in your role as a support person for a loved one who has ovarian cancer, you may find that you need help in helping her. Asking for help is a sign of strength and taking control.

# LEND A HAND

### YOUR FRIENDS AND FAMILY CAN:

- Accompany your loved one to doctor and treatment (chemotherapy or radiation therapy) appointments.
- Babysit, or take children to activities.
- Create a list of "how family and friends can help" and see if they can come up with their own ideas.
- If appropriate, offer spiritual help - prayers, meditation, rituals, getting her to place of worship.
- Provide emotional support - sharing, crying, laughing.
- Offer practical help - chores, transportation, researching information.

### YOU CAN:

- Appoint one of your friends or family to organize everyone else. You may not have to identify needs - they may do it for you.
- Have one friend or family member be the contact person for information and news. Then he/she can pass on information to the rest of your support network.
- Seek the assistance of a licensed counselor or a therapist if communication is difficult.



**Lotsa Helping Hands** is an organization that provides an online tool to assist in organizing support. This free web-based service helps manage and simplify everyday tasks of family, friends, colleagues, and neighbors wishing to help loved ones in need. For more information go to: [www.lotsahelpinghands.com](http://www.lotsahelpinghands.com).

## KNOWING HOW AND WHEN YOU SHOULD ASK FOR HELP FROM OTHERS

It's never too early to ask for help from a variety of sources. Ask in advance of needing the help, if you can. This gives people time to plan too.

## HERE ARE SOME SUGGESTIONS ON WHAT YOU COULD ASK FOR:

- "Please help us with our shopping."
- "We need a hug."
- "I would like you to help by inviting my loved one out and taking her places."
- "We would love it if you'd water our flowers!"
- "Please pray for us and share your faith with us."
- "Talk to us about the future; hope is important to us."
- "I/she would love a call when you have a minute to just talk."
- "We enjoy getting mail or email."
- "Could you help me (or my loved one) with chores? We still have dirty dishes, clothes and a house that needs cleaning."
- "Bring a positive attitude, it's catching."
- "Please help me/her feel good about my/herself."
- "Can you take our children or us somewhere?" (Be specific).
- "We might need transportation to her treatment, to her doctor's office, or the store."
- "Can you walk or feed our pet?"
- "I'd like you to just listen to me/her."
- "Make us laugh, tell us jokes and funny stories. Ovarian cancer has not taken away our sense of humor."
- "Talk to me about my concerns about her dying and how the cancer has changed me, without thinking I have a negative attitude."

## COMMUNICATING WITH CHILDREN ABOUT OVARIAN CANCER

### WHY IS IT IMPORTANT TO TELL CHILDREN ABOUT A LOVED ONE'S CANCER?

Cancer is a very difficult secret to keep from children. Often children will know something is wrong. They may sense your worry, overhear your conversations, or unknowingly, friends may talk to them before you do. Without appropriate, accurate information, children may imagine the worst. In addition, if you keep information from them at first, they may not trust that you are telling them the truth later on.

### WHAT SHOULD CHILDREN BE TOLD ABOUT CANCER?

What and how you tell children about cancer depends on their age. The goal should be to talk to them at a level they can understand and in a way that they can be prepared for the ways they may be affected.

According to the American Cancer Society, all children need to know:

- The name of the cancer including the part of the body that is affected – “ovarian cancer.”
- How it will be treated.
- How their own lives will be affected.

It is also important to talk with them and reassure them about other worries they might have. Some common concerns that children have voiced include:

- Concern that something they did or said may have caused their loved one's illness.
- Concern that cancer is contagious.
- Concern that everyone who gets cancer dies.

## Most children blame themselves at some point in their loved one's illness.

Unfortunately, most children will not bring this up on their own, so it's important to reassure kids about this rather than waiting for them to share their worry. The American Cancer Society suggests saying “The doctors have told us that no one can cause someone else to get cancer – it's nothing that any of us made happen.”

## HOW SHOULD CHILDREN BE TOLD ABOUT CANCER?

- Include your loved one in the conversation if possible.
- Choose a time when you are feeling calm and your emotions are feeling under control. There is nothing wrong, however, with letting them know that you are sad or upset or worried.
- Encourage them to express their feelings and emotions – anger, fear, and guilt.

Many children will ask whether their loved one is going to die. This is a very difficult question to answer and depends on many things. With ovarian cancer, the answer will depend on how advanced the cancer was at diagnosis and how well your loved one responds to treatment. Even if the cancer comes back, many women live with ovarian cancer for many years.

Following are some examples provided by the American Cancer Society of how to respond to a child's questions about whether his or her loved one is going to die. "The doctors have told me that her chances of being cured are very good. I'm going to believe that until I have reason to believe something else. I hope you can believe that too. I'll tell you if I get new or different information."

"There is no way to know right now what's going to happen. We'll know more after the first treatments are finished. When we know more, we'll be sure to tell you."  
"Her cancer is a hard one to treat but she's going to do everything she can to get better. It's impossible to know right now what will happen down the road. What you can be sure of is that I'll be honest with you about what is going on. If you can't stop worrying, please tell me so I can make it better."

## FINDING MORE INFORMATION

The following websites, pamphlets, and books are excellent resources for more information on talking with children about cancer. Titles available from the American Cancer Society at 1-800-ACS-2345 or [www.cancer.org](http://www.cancer.org) include:

- Helping Children When a Family Member Has Cancer: Dealing with Diagnosis.
- It Helps to Have Friends When Mom or Dad Has Cancer.
- Because Someone I Love Has Cancer: Kids' Activity Book.
- Cancer in the Family: Helping Children Cope with a Parent's Illness.

### Other Publications

- When Someone in Your Family Has Cancer. Available through the National Cancer Institute at: [www.cancer.gov/cancertopics/when-someone-in-your-family/allpages](http://www.cancer.gov/cancertopics/when-someone-in-your-family/allpages).
- Can I Still Kiss You? Answering Your Children's Questions About Cancer by Neil Russell. Published by HCI, 2001.
- When a Parent Has Cancer: A Guide to Caring for Your Children by Wendy S. Harpham. Published by HarperCollins, 2001.

Additional information about resources and services available for children in your community may be found at your local library, physician's office, or cancer treatment center.

## IMPORTANT INFORMATION TO TELL THE DOCTORS AND NURSES

- Symptoms: Tell healthcare professionals about the symptoms your loved one is having. Be specific.
- How severe are they? (Use a 0-10 scale where 0 = don't have any and 10 = it's bad as they could be.)
- How often throughout the day/week do they occur?
- What makes them worse or better? What are you and she doing for symptom relief? How well do those things work?
- Do they cause her to have any problems performing her usual daily activities?
- Medications: Be sure that the healthcare team knows about all the medications, vitamins, supplements, herbal medications, or alternative therapies that your loved one is taking.
- Financial problems resulting from of your loved one's treatment.

## COMMUNICATING WITH HEALTHCARE PROVIDERS

In order to maintain your loved one's privacy, healthcare providers are required to ask permission from your loved one before sharing any of her healthcare information with you.

Why is it important to communicate with healthcare professionals? Almost everyone feels better and more in control when they understand an illness, how and why it is being treated, and what kinds of side effects may occur. However, many people have a difficult time talking with doctors or nurses. Some feel uncomfortable asking questions or talking about their loved one's cancer and treatment because they are afraid they might look foolish or ask a silly question. Others are afraid if they report too many things, their loved one's treatment will be stopped.

You will need a great deal of information to be informed and make decisions. Some of this information is complicated, and often it must come from a wide variety of healthcare providers caring for your loved one. Talking with doctors and nurses is important to get the information you need. Here are some tips that others have found to be helpful:

- Approach medical staff with the assumption that they want to help you and would like to give you the information you need.
- Buy a notebook and write down all the questions you and your loved one want to ask at the next doctor visit. Writing down your questions beforehand is one of the best ways to be sure you are being clear. If you get flustered, which happens to many people, you can read your questions.
- Help your loved one speak frankly with her healthcare providers. Help her to express her feelings and to let them know her concerns.
- Ask your healthcare provider to repeat anything you or your loved one don't understand. Repeat it back to make sure you have got it right.

- Take notes during the appointment and ask permission to tape record the visit so you can use it as a reminder at home.
- Let the healthcare providers know when your loved one's needs are not being met.
- Appreciate what the healthcare providers are doing to help your loved one and tell them from time to time.

## WHAT YOU SHOULD KNOW ABOUT YOUR LOVED ONE'S TREATMENT

People need to have sufficient information so they can provide the best possible care at home. It's important to have an understanding of:

- The ovarian cancer diagnosis and stage of disease.
- Medicines involved in your loved one's treatment, and possible treatment side effects.
- How to best keep track of treatment and side effects.
- Other treatments that might be available.
- When you should call your doctor or nurse.
- Where you can go to get more information and support.

## CALLING THE DOCTOR

If you feel the situation is an emergency or urgent and you cannot get the information you need, then call the doctor or an emergency room. To do this, use the word "emergency" in your question, and then be persistent until you have the information you need.

Here are some examples of phrasing you might use:

- "I have an emergency (or urgent need) and need to talk to a doctor."
- "I have a question about \_\_\_\_\_ and I'm not sure if this is really an emergency. Who can help me?"
- "I'm very concerned about \_\_\_\_\_. It is urgent."

# IMPROVING COMMUNICATION

## **There are many things you can do to improve your ability to get information you need:**

- Be sure you know who you need to reach and how to reach them. If your loved one sees many different doctors, know who you should call for which problems.
- Learn who can answer your questions. Learn which staff members give different kinds of information to people.
  - Example: “Who can tell me when my wife will be discharged?”
- Ask the questions yourself.
- Be sure your statements or questions are phrased clearly and know exactly what information you need.
  - Example: “My wife’s pain medication is not effective.”
  - Example: “My mother’s pain is at level \_\_\_\_.”  
(0 = none to 10 = as bad as it could be)
- Focus your attention on what is most important.
- Say the reason you are concerned.
- Get to your question immediately.
- If you and your loved one have a long list of things to talk about, make a consultation appointment, so the doctor can allow enough time.
- Educate yourself about your loved one’s ovarian cancer.
- Learn the routine at her doctor’s office or clinic so you can make the system work for you.
- Accept that all questions do not have answers.
- Try to separate your anger and sense of helplessness about your loved-ones diagnosis from your feelings about the healthcare team.

## **Things that can prevent you from getting the information you need:**

- Some people are afraid to ask “stupid questions.”  
This is ovarian cancer – there is no such thing as a stupid question.
- Some people feel that healthcare providers are so important or so busy that they should not take up their valuable time with questions. This is not so! Healthcare providers are there to help people by sharing information and answering questions.
- If your loved one’s healthcare provider appears very busy, ask:  
“If this is not a good time, when would be?”
- Do not feel intimidated. Their role includes answering questions and educating patients and family members. Your loved one has a right to the information.
- Think of other obstacles that could interfere with you getting the information you need and make a plan of how you will handle them.
- Don’t be afraid to encourage your loved one to seek a second opinion, especially during times when she is being asked to share in important treatment decisions.

- Occasionally, there is a bad match between patients and doctors. If you and your loved one find that communication with the healthcare team is so difficult or unsatisfactory that it is interfering with your loved one's treatment or well-being, consider switching doctors.

## **PROVIDING DIRECT CARE TO YOUR LOVED ONE**

Providing direct care to a loved one can be difficult and stressful at first. Learning new skills, such as changing a dressing or giving an injection, takes time and practice. Taking on tasks that you have not done before such as cooking, lawn maintenance, laundry, or managing the finances can be overwhelming. Most family members agree that the most difficult thing is being able to fit these tasks into their already busy lives.

### **Following are some tips that may help you:**

- Make a list of all the healthcare tasks that you need to perform for your loved one.
- Identify tasks that you are willing to perform; circle the tasks that you don't know how to perform. Ask the doctor or nurse for information and/or training. Have them watch you do the task.
- Talk with your loved one's doctor or nurse about other providers who may be able to help by performing tasks of care that you are unable or unwilling to perform (visiting nurses, home health aides, Meals on Wheels, chore/housekeeping service, transportation service).
- Monitor the care of your loved one to make sure her needs are being met (if others are also providing assistance).
- Prioritize tasks of care that need to be performed.
- Schedule care tasks as much as possible to help you establish a daily routine. Make a list of activities and times.
- Encourage your loved one to do as much for herself as possible.
- Keep a list of signs and symptoms that need to be reported to the doctor or nurse.
- Keep a list of emergency telephone numbers near the telephone (ambulance, hospital, doctor's office, doctor's answering service).
- Find a support group for caregivers. Other caregivers will share their experiences with you and can provide tips for providing care.
- Be sure to take care of YOU. This means getting enough rest and exercise, and eating a balanced diet.
- Take time out for yourself each week to go have lunch or dinner with a friend, go to a movie or sporting event, take a walk, or read for pleasure.

### **If you need more information, the following two books provide helpful information:**

- American Medical Association Guide to Home Caregiving. American Medical Association. New York: Wiley, John & Sons, Inc., 2001.
- Coping: A Practical Guide for People with Life-Challenging Diseases and Their Caregivers. Rubin Battino. Bancyfelin, Carmarthen, UK: Crown House Publishing, 2001.

## TAKING CARE OF YOURSELF WHEN YOUR LOVED ONE HAS CANCER

- **Do you look like you feel?**
- **Are tears just under the surface?**
- **Are you turning down opportunities to go out for fear of being away from your loved one?**

Many friends and family members spend so much time worrying about and caring for their loved one that they forget to take care of themselves. It is critical for you to maintain your own health and well being because it makes you better equipped to take care of your loved one. Proper diet, adequate sleep and regular exercise is important for all of us and more so when someone you love has cancer.

### Following are suggested strategies for taking care of yourself:

- Participate in physical activity at least three times a week for at least 30 minutes. Exercise promotes better sleep, reduces tension and depression, and increases energy and alertness. If finding time to exercise is a problem, try to incorporate it into your usual day (take the stairs, walk, play with your kids).
- Get enough sleep so that you feel rested in the morning – try for at least 7 hours every night.
- Eat balanced, nutritious meals (5 servings of fruits and vegetables). Take time to sit down and eat your meals. Do not skip meals.
- Take care of your own physical health (get regular medical check-ups: blood pressure, cholesterol, cancer screening).
- Participate regularly in recreational/leisure activities.
- Drink at least eight glasses of water daily.
- Limit alcoholic beverages. Avoid using alcohol, medications/drugs, or cigarettes to calm your nerves.
- Maintain a healthy weight.
- Set limits to your life. Learn to say NO! Make choices.
- Find a hobby that takes your mind off your worries for a while: fishing, boating, painting, woodworking, knitting, reading, etc.
- Take long, warm baths.
- Look for things to laugh about.
- Get a massage.
- Wear colorful clothes; seize every opportunity to dress more “up” than “down.”
- Give yourself permission to take a break from worrying and caregiving.
- Go out for lunch or dinner with a friend or relative.
- Go to the movies, a play, or a concert.
- Find a place to cry and let out the grief and worry.
- Read non-stressful books and magazines.
- Do anything that diverts your mind – e.g. crosswords, puzzles, jigsaws or gardening.
- Telephone friends, go visit someone you like.
- If possible, stay at work as long as you normally would. Try not to start leaving or interrupting your work.
- Take long walks and enjoy the sounds, smells, and beauty of nature.

Part of the success of taking a break is ensuring that your loved one is content and cared for in your absence. If you can relax during your time away, then the break will work wonders for you.



## IDENTIFY AREAS WHERE YOU NEED TO TAKE BETTER CARE OF YOURSELF

**Rest** - Be sure to get enough rest.

Your body needs rest to face everyday challenges. As you adjust to life after your loved one's diagnosis of ovarian cancer, your sleep patterns may be disrupted. If you find that you can't get to sleep or can't stay asleep, seek out advice from your doctor about what to do.

**Medical check-ups** - Regular check-ups by your doctor, dentist, and optometrist are essential parts of maintaining your health. Visits with such doctors also help in identifying health problems in their early and most treatable stages. Going to the doctor also helps verify that the positive things that you are doing to help your health are working.

Call your doctor and schedule an appointment. Find out how often you should be going to the doctor, as this changes with age. Write reminders to yourself on your calendar to schedule appointments.

Think of some of the ways that you have taken care of yourself in the past (before your loved one was diagnosed with cancer) and try to start doing them again.

**Balancing multiple demands** - Many family members need to continue working when their loved one is diagnosed with ovarian cancer. This may cause you to experience competing demands and distress. Work is a financial necessity and/or a source of satisfaction for many, yet the responsibilities of caring for and supporting a loved one often conflict with responsibilities at work. People who strive to do both well can feel caught in the middle.

## If you have trouble sleeping:

- Read a book before bed; it may relax you and help you to fall asleep faster.
- Avoid loud noises and turn on slow, relaxing music.
- Avoid alcohol. A few glasses of wine may make you drowsy at first, but it will cause you to be awake during the night.
- Avoid caffeine and sugar before bed.
- Try to maintain a regular sleeping schedule.
- Don't take frequent naps during the day.
- Use your bed only for sleeping (don't work, watch TV, eat in bed).
- Exercise during the day, but avoid exercising two hours before bed.
- Consult your doctor if you think a medication is causing your sleep problem; some prescription drugs can cause sleep problems.
- Make your room a good place to sleep; use room-darkening shades and keep it at a steady temperature.

## HOW YOU CAN COPE WITH COMPETING DEMANDS

The following tips offer ideas and resources that can help you manage your responsibilities efficiently and balance both work and the caring roles more effectively.

- **Look in the personnel manual or other human resources publication to find out your company's policy on caregivers.** Does it offer benefits or services that could help with your situation?
- **Talk with your work supervisor about your issues.** It is better he/she knows the reasons for your late arrivals or seeming preoccupation rather than drawing his or her own conclusions. Before having the conversation, come up with some strategies about how you will cope with absences and time away from work.
- **Ask your employer if there is an employee assistance program.**
- **Ask your Human Resources or Personnel Department to give you information on the Family and Medical Leave Act.** This law entitles eligible workers a maximum of 12 weeks a year of unpaid leave for family caregiving without loss of job security or health benefits. There are a variety of restrictions, however, such as company size and the amount of time the worker has been employed.
- **Take advantage of flextime policies if that would help your situation.**
- **Offer to work a less desirable shift or be willing to make up time taken for caregiving by working days or shifts when most people want to be off.**
- **Check for information and referral resources in your workplace.**
- **Consider job sharing or working part time if possible.**
- **Avoid mixing work and time with your loved one.** Do your best to avoid interruptions and distractions at work from your loved one's health issues. If you need to make phone calls or search the internet for information related to your loved one's needs, do it on a lunch break.
- **Manage your time.** When you must take time off for caregiving, set priorities and accomplish the most important things first.
- **Delegate responsibilities when you can.** Pace yourself, as these demands may extend over a prolonged period of time.
- **Accept help when you need it.** Consider community resources for yourself and your loved one.
- **Get all the support** you can from family members, friends and community resources.
- **Take care of your own needs.** Take a break when the pressure gets too great.
- **Be sure to thank those at work for the consideration and assistance you receive.**

### THE FOLLOWING ORGANIZATIONS CAN BE CONTACTED FOR MORE INFORMATION:



- The Family Caregiver Alliance has information helpful to caregivers. Their website has a resource center that offers practical information: [caregiver.org](http://caregiver.org)
- The AARP website caregiving section: [aarp.org](http://aarp.org)

## TIME MANAGEMENT

### WHY TIME MANAGEMENT?

Ovarian cancer and treatment-related activities often are overwhelming and require much time of family members and friends who are juggling multiple roles. It is important that you manage your time wisely so that you can carry out these multiple roles and maintain your own health. Managing time effectively puts you in control of your life. If you get a handle on how you spend your time, you'll work smarter, have more time to get things done in your multiple roles, and enjoy life more with less stress. How to cope with all the different demands on your time Below are some tips on how to save time and reduce stress:

- Know how long it takes to complete tasks. Take advantage of small bits of time. Set priorities, delegate, or ask others for help.
- Focus on one task at a time.
- Create a manageable list of things to do each day. Check off tasks as you complete them so you can see your accomplishments.
- Make a weekly schedule of tasks that need to be done.
- Set realistic goals. Break large tasks into small ones.
- Set and follow priorities. What are your real priorities each day? Make your lists in order of priority and start with the high priority tasks. Other things can be delayed or put off.
- Set aside an hour a day to make phone calls and check email.
- Set aside time each week to do errands.
- Say “no” to things you do not want to do or that are not really necessary.
- Use your high-energy time of day to work on important tasks so that you are in charge of your day.
- Establish routines and stick to them.
- Some time will be spent on things beyond your control. This is just a necessity.
- Delegate what you can to others; you do not need to do everything.
- Ask for help when you need it; accept help when others offer.
- Set time limits for tasks.
- Don't waste waiting time. Use that time.
- Take time for yourself each day.

## RECOGNIZING WHEN YOU'RE STRESSED OUT OR ANXIOUS

Too much stress can lead to more serious health problems. Learn to recognize signs of stress in yourself, and contact your healthcare provider if you experience the following on a regular basis:

- Denial about the disease and its effect on your family member.
- Anger at your loved one.
- Social withdrawal from friends and activities that once brought you pleasure.
- Anxiety about facing each day and the future.
- Depression and feeling unable to cope.
- Exhaustion that makes it impossible to complete necessary tasks of the day.
- Sleeplessness caused by constant concern and worry.
- Irritability that triggers negative responses and reactions in others.
- Lack of concentration making it difficult to perform usual daily tasks.
- Health problems which take their toll, both mentally and physically - worsening chronic disease, colds.

### WHAT IS ANXIETY?

Anxiety is a vague feeling of uneasiness, unpleasant feelings, or fear resulting from expecting some bad news or harm. Anxiety can happen to anyone, but family members and friends facing the serious illness of a loved one may get anxious more easily than others. Anxiety and fear are common and normal feelings when coping with a diagnosis of ovarian cancer.

### RECOGNIZING ANXIETY

People who have anxiety say they feel uneasy, tense, apprehensive, wary, or agitated. They have a feeling of restlessness, uncertainty, and are fearful or have a sense of dread or impending doom. People tremble, sweat, have rapid breathing, rapid heart rate, or can feel their heart pounding in their chest. In addition, some people experience shakiness, or difficulty falling asleep. Sometimes people may become overly fearful and may no longer cope well with their day-to-day life.

### COPING WITH ANXIETY

No two people experience anxiety in the same way. Here are tips other people have found helpful:

- Try to identify what “triggers” your anxiety.
- List coping strategies that have helped you in the past.
- Talk with others (such as a support group) about your anxiety.

- Increase pleasurable, distracting activities such as listening to your favorite music.
- Use relaxation techniques such as controlled breathing or guided imagery (picture a pleasant scene in your mind).
- Be around others as much as possible, if this is relaxing.
- Use prayer or other types of spiritual support, such as meditation.
- Talk with your doctor or nurse about prescribing medicine to help reduce your anxiety.
- Use relaxation tapes.
- Express feelings and concerns to others.
- Limit your caffeine intake by decreasing your intake of coffee, caffeinated colas, tea, and chocolate.
- Ask your doctor for a counseling referral if these tips are not helpful. Family members and friends can help you with anxiety.

### **ASK FAMILY MEMBERS AND FRIENDS TO:**

- Help you with relaxation exercises such as deep breathing or visualizing pleasant scenery.
- Help you with situations or chores that you've identified as stressful.
- Bring home books from the library or bookstore about teaching relaxation exercises or imagery.

### **TALKING WITH OTHERS ABOUT YOUR ANXIETY**

- Be open and honest about your feelings and concerns with your family members.
- Try to describe your feelings when you're experiencing them (racing thoughts, lump in your throat, nausea, shortness of breath, dizziness or fear).
- Ask your family members and friends how your anxiety is affecting them.

## **CALL YOUR DOCTOR OR NURSE IF YOU EXPERIENCE ANY OF THE FOLLOWING PROBLEMS:**

- Panic attacks.
- Problems with anxiety that last beyond two weeks.
- Persistent fearfulness.
- Shortness of breath that lasts beyond two weeks.
- Shakiness, agitation or restlessness that lasts beyond two weeks.
- Heart racing and beating hard.
- Excessive sweating.
- Persistent problems sleeping or getting to sleep.

## MANAGING DEPRESSION AND SADNESS

### WHAT IS DEPRESSION AND SADNESS?

Depression is sadness that happens in response to an event or due to changes in your body chemistry. Depression is sadness that is greater than normal, lasts two weeks or more, and significantly impacts your daily life.

### RECOGNIZING DEPRESSION AND SADNESS

People describe depression as the darkest time in their life. Many people report crying spells, or problems with sleep (either sleeping all day or not sleeping enough). Others describe problems with eating (too much or not enough), feeling hopeless, helpless, worthless, or even feeling like they want to hurt themselves. People may have trouble experiencing any pleasure or interest in daily life, and they may not want to talk to family or friends.

Depression is not the same as an occasional, short-lived period of sadness. In depression, these low feelings are severe, and last for two or more weeks.

### THE CAUSES OF DEPRESSION AND SADNESS

Depression can occur as a result of specific events, such as a loved one being diagnosed with ovarian cancer. It can also be caused by medications, or fatigue, or from chemical changes in the brain. Generally, most people can cope with short-term feelings of depression. Persistent depression (greater than two weeks) should be evaluated by a healthcare provider for possible counseling and/or medication.

### COPING WITH DEPRESSION AND SADNESS

Every person uses different approaches when they are depressed and sad.

#### HERE ARE SOME TIPS OTHER PEOPLE HAVE FOUND HELPFUL:

- Try controlled breathing and relaxation exercises; these help release mood-enhancing substances from the brain.
- Express your feelings through journal writing or creative expression (dance, cooking, exercise, painting or music).
- Avoid alcohol consumption; it can make you feel more depressed.
- Try to get enough sleep at night; avoid napping during the day.
- Try to identify something that brings you pleasure every day.
- Be with other people as much as possible, if this helps you relax.
- Participate in regular, routine exercise. Exercise has been shown to improve mood and well-being.
- Make an appointment with your doctor and tell him/her exactly how you feel and that you need help.
- Make a list of all the medications you take; show this to your doctor or nurse. Some medicines may have to be stopped or changed.
- Join a support group. This can help relieve the isolation that is often felt by those who are depressed.
- Make an appointment with a counselor, psychologist or spiritual advisor.
- If medicines have been ordered for your depression, take them as directed.



If you ever have feelings (or actions) that you want to hurt or kill yourself or others, call your doctor immediately, or call a national suicide hotline at:

1-800-SUICIDE (1-800-784-2433)

1-800-273-TALK (1-800-273-8255)

## **FAMILY MEMBERS AND FRIENDS CAN HELP YOU WITH DEPRESSION**

### **Ask family members and friends to:**

- Talk with you about what you're going through.
- Engage in enjoyable activities with you.
- Stay with you during difficult times. Sometimes just having someone there with you is enough.
- Help you with your daily needs until you are able to care for these on your own.
- Help you with situations or chores that you identify as stressful, such as going to your doctor visits, writing out bills, or helping with household chores.
- Notify your doctor or nurse for you when needed.

### **Talk with others about your depression and sadness**

- Try to describe your depression and how it affects you.
- Ask your family members and friends for ideas to help you deal with your depression.
- Be open and honest about your feelings with your family members.
- Seek peer-to-peer support, for example, from the National Ovarian Cancer Coalition. Call 1-888-OVARIAN.

### **Call your doctor or nurse if you experience any of the following for more than two weeks:**

- Depressed mood every day for most of the day.
- Very little interest or pleasure in most activities nearly every day for most of the day.
- Noticeable weight loss or weight gain – or a major change in appetite.
- Sleep disturbance: not being able to get to sleep, waking early, or being very sleepy.
- Feeling agitated, or feeling slowed-down.
- Feeling excessively tired or lacking in energy.
- Feeling worthless or guilty.
- Feeling unable to concentrate or make decisions.
- Feelings of hopelessness and/or helplessness.

## FINDING SUPPORT

Everyone needs support to get through stressful situations. Half the battle is recognizing that you need help, the other half is asking for it. Here are some strategies to help you get the support you need:

### 1. Tap the natural support system that you may have among family and friends for emotional support, companionship, and practical help.

- Seek out family members and friends who are willing to give you support.
- When people offer to help, accept their offer.
- Set aside a specific time within the week to talk with important people in your life.
- Think of things that people could do to be of assistance. Be specific about your needs.
- Plan a time to talk to someone or seek support. Make it happen.
- People are willing to help if they know that you are willing to receive help.

### 2. Join a support group.

- Support groups help you realize that others are going through a similar situation. You are not alone. Others can verify that your worries and fears are “typical” or “normal”.
- Ask your loved one’s doctor or a nurse for help in finding a support group.
- Not all support groups are the same. Pick one relevant to your situation.
- Support groups are good forums for exchange about resources, coping strategies, and friendship.

### 3. Seek professional help from a psychologist, counselor, or spiritual advisor.

### 4. Practice effective communication with family and friends.

- Try to be open about your feelings. Let them know how you feel
  - what bothers you, and what concerns you.
- If you need a specific kind of help or support, ask for it. Be straightforward.
- Don’t assume family and friends know what you need or want
  - you have to tell them.

### 5. Spend time with people who support you.

- Avoid people who are critical or negative.
- Surround yourself with positive people.
- Optimism and a positive outlook are contagious.

### 6. Plan for social interactions.

- Disclose only those aspects of your loved one’s illness that you are comfortable disclosing.
- Plan ahead and consider both positive and negative responses that you may get from others. Be ready for both.
- Think about how you want to respond to questions about your loved one’s illness.
- Role-play the responses you would give with a friend.



## OBTAINING ACCURATE INFORMATION ABOUT OVARIAN CANCER

The first and most important step in getting accurate information is for you and your loved one to find a skilled physician. Ovarian cancer requires treatment by a physician who has been specially trained. These physicians are called “gynecologic oncologists” and they have received extensive training in the surgical, medical, and supportive care of women with ovarian cancer.

### Several organizations have information to help you find a good gynecologic oncologist:

- The Society of Gynecologic Oncologists and its consumer group, Gynecologic Cancer Foundation maintain a membership directory of gynecologic cancer specialists. You can reach them by phone at 1-800-444-4441 or via the internet at [www.sgo.org](http://www.sgo.org) or [www.wcn.org](http://www.wcn.org).
- The National Cancer Institute also offers important suggestions and information resources to help you with important decisions at [www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility](http://www.cancer.gov/cancertopics/factsheet/Therapy/doctor-facility)

### Doing your own research

Tap into organizations that have been created specifically for women with ovarian cancer. They often serve as a hub for important information as well as a way to connect with others who have gone through the same experience you are going through. Some of the best resources include:

- National Ovarian Cancer Coalition: [www.ovarian.org](http://www.ovarian.org), 888-682-7426
- Ovarian Cancer Research Fund Alliance: [www.ocrfa.org](http://www.ocrfa.org), 800-873-9569
- Ovarian Cancer National Alliance: [www.ovariancancer.org](http://www.ovariancancer.org), 202-331-1332
- FORCE: Facing our Risk of Cancer Empowered: [www.facingourrisk.org](http://www.facingourrisk.org), 954-255-8732
- Women’s Cancer Network: [www.wcn.org](http://www.wcn.org), 312-573-1439
- American Cancer Society: [www.cancer.org](http://www.cancer.org), 800-ACS-2345
- CancerCare, Inc.: [www.cancercare.org](http://www.cancercare.org), 800-813-HOPE
- Visit the National Cancer Institute (NCI) homepage - [cancer.gov/cancertopics/types/ovarian](http://cancer.gov/cancertopics/types/ovarian). It is an excellent site for accessing information about ovarian cancer, current treatment, and cutting edge research and clinical trials.
- Realize that you are not going to find the definitive cure for ovarian cancer. You will find, however, information about the best current treatment options.
- Decide in advance how much or how little research you want to do.
- Try to set limits on how much time you devote to research. It’s important to be well-informed, but be aware of how it is making you feel and whether it interferes with other things in your life.
- Share your findings with your loved one’s doctor. They can help you relate the information you find with your loved one’s particular situations.

### If you want to find original research articles, there are two medical databases available online:

1. Medline/PubMed: [nlm.nih.gov](http://nlm.nih.gov) allows you to search abstracts from 4,500 medical journals.
2. CancerLit: [cancer.gov/search/cancer\\_literature](http://cancer.gov/search/cancer_literature) allows you to search from over 4,000 sources. You can also chat online with information specialists who can help you with your search. Evaluate the quality of the information you find on the internet.

## TOP 10 WAYS TO HELP REDUCE YOUR STRESS WHEN YOUR LOVED ONE HAS BEEN DIAGNOSED WITH OVARIAN CANCER

Programs, services and care techniques can help reduce the burdens and stress after a loved one has been diagnosed with ovarian cancer.

### 1. GET A DIAGNOSIS AS EARLY AS POSSIBLE.

Understand usual patterns of disease and treatment so you know what you are dealing with. Help find a good gynecologic oncologist to perform your loved one's surgery, and direct her care.

## Consider the following criteria when accessing information:

- What is the mission of the site? Is it to provide information, support, advice, or to sell a product?
- Who produces the site? Is it an academic center, a government agency, a private citizen, a non-profit group, or a for-profit organization?
- What is the reputation of the resource?  
How long has it been in existence?
- Are sources of funding for the site disclosed and do they reflect any potential for bias?
- Is there an editorial board or a review process? What are site authors' or site editors' qualifications?
- Is the material up-to-date? Does the site post a current date and a last revision date?
- Does the information make sense and is it consistent with information you have read elsewhere?

Find a good guidebook for ovarian cancer. Much of the above information can be found in more detail in the book: *Ovarian Cancer: Your Guide to Taking Control* by Kristine Conner and Lauren Langford. Published by O'Reilly and Associates, 2003.

## **2. KNOW WHAT RESOURCES ARE AVAILABLE.**

For your own well-being and that of your loved one, become familiar with resources available in your community. In-home assistance, visiting nurses and Meals on Wheels are just some of the community services that can help.

## **3. BECOME AN EDUCATED FAMILY MEMBER/ FRIEND.**

If the cancer progresses, different skills and capabilities will be necessary. Care techniques can help you better understand and cope with many of the challenging issues that may arise.

## **4. GET HELP.**

Trying to do everything by yourself will leave you exhausted. The support of family, friends and community resources can be an enormous help. If assistance is not offered, ask for it. If you have difficulty asking for assistance, have someone close to you advocate for you. If stress becomes overwhelming, don't be afraid to seek professional help. Support group meetings and helplines are also a good source of comfort and reassurance.

## **5. TAKE CARE OF YOURSELF.**

Family members frequently devote themselves totally to their loved one with cancer, and in the process, neglect their own needs. Pay attention to yourself. Watch your diet, exercise and get plenty of rest. Take time off for a favorite hobby, shopping, a movie, or an uninterrupted visit with a friend. Those close to you want you to take care of yourself.

## **6. MANAGE YOUR STRESS.**

Stress can cause physical problems (blurred vision, stomach irritation, lack of concentration, loss of appetite). Note your symptoms. Use relaxation techniques that work for you or consult a physician.

## **7. ACCEPT CHANGES AS THEY OCCUR.**

Sometimes, loved ones may require care beyond what you can provide at home. A thorough investigation of available care options should make transitions easier; so will support and assistance from those who care about your loved one.

## **8. MAKE LEGAL AND FINANCIAL PLANS.**

Consult an attorney and discuss issues related to durable power of attorney, living wills and trusts, future medical care, housing, and other key considerations. Planning now will alleviate stress later. If possible and appropriate, involve other family members in planning activities and decisions.

## **9. BE REALISTIC.**

Neither you nor your loved one can control many of the circumstances that will occur. Give yourself permission to grieve for the losses you experience, but also focus on the positive moments as they occur, appreciate the value of each day, and enjoy your good memories.

## **10. GIVE YOURSELF CREDIT, NOT GUILT.**

You're only human. Occasionally, you may lose patience and be unable to provide all of the comfort, support, and care the way you'd like. Remember, you're doing the best you can. Being a devoted family member or friend is not something to feel guilty about. Your loved one needs you and you are there. That's something to be proud of.

# WHERE CAN I GET MORE INFORMATION?

## **NATIONAL OVARIAN CANCER COALITION, INC.**

1-888-OVARIAN (1-888-682-7426)

OR OVARIAN.ORG

## **NATIONAL COALITION FOR CANCER SURVIVORSHIP**

888-YES-NCSS (937-6277) OR

CANCERADVOCACY.ORG

## **NATIONAL CANCER INSTITUTE**

800-4-CANCER (22-6237) OR CANCER.GOV/

CANCERINFO

## **AMERICAN CANCER SOCIETY**

800-ACS-2345 (227-2345) OR CANCER.ORG

## **FAMILY CARE RESEARCH PROGRAM**

517-353-0306 OR CANCERCARE.MSU.EDU

## **NATIONAL FAMILY CAREGIVER ALLIANCE**

800-445-8106 OR CAREGIVER.ORG

## **AMERICAN ASSOCIATION OF RETIRED PEOPLE (AARP)**

888-687-2277 OR AARP.ORG



# MISSION STATEMENT

The mission of the NOCC is to save lives by fighting tirelessly to prevent and cure ovarian cancer and to improve the quality of life for Survivors.





## **NATIONAL OVARIAN CANCER COALITION**

1-888-OVARIAN (1-888-682-7426)  
**WWW.OVARIAN.ORG**

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