

For Partners, Family and Friends: When someone you love has gynaecological cancer

The diagnosis of cancer in someone you love can be shocking and overwhelmingly. As a family member, husband, partner or close friend of someone who has gynaecological cancer you may find it difficult to gauge how best you can be helpful. It is not easy to balance 'being strong' while at the same time 'showing how much you care'. This challenge is made even harder when you are dealing with your own sense of shock.

Just as the woman you care about may be feeling frightened and unsure of her future, you too will be dealing with fear and uncertainty. As someone who cares, a number of other factors can add to this distress. You may find that roles have to change, and you now have to balance existing commitments with added responsibilities and tasks. This can be tiring. You may also be the source of information to everyone who asks, "How is she?" at a time when you need care and support yourself. For all these reasons and more, it is absolutely normal to have times when you feel overwhelmed.

It is important that you make sure you are looking after yourself. This includes making sure that you keep well, and as physically fit as possible, by eating properly, ensuring you are getting enough sleep, and consulting your doctor if you are feeling unwell. It also includes taking time out sometimes to do something that gives you pleasure. If your feelings become too overwhelming, seek the support of other friends or family members, or discuss your problems with the health care team at the hospital.

Here are some of the emotions people commonly experience when someone they love has cancer. These feelings are only a few of the many that you may experience.

Dealing with your own feelings

Shock. A cancer diagnosis often comes out of the blue. This in itself can be very threatening, because, while we know that everyone is at risk of cancer, when it affects someone close to us we realise just how vulnerable we all are. We get a glimpse of how fragile our lives can be. When dealing with the shock of diagnosis it is not unusual to feel numb. You may also

find it hard to concentrate, have feelings of anxiety, nausea, and experience a loss of interest in everyday things.

Fear. The word 'cancer' is still associated with a sense of foreboding. Understandably, you may fear that your loved one will die from her cancer. If your loved one is related to you, you may also be worried about your own risk of cancer. Speak to your GP who can assess your risk and refer you to a Familial Cancer Service if necessary.

Uncertainty. Unfortunately, while cancer treatments are improving rapidly, it is often not possible for doctors to give precise answers to questions such as: "Will she die?" "Is she cured?" "Will it come back?" "How long will she live?" This uncertainty can be very distressing.

Anger. Anger is a common emotion when you love someone with cancer. You may be angry with the doctors because they can't give you clear answers. You may feel the world is not fair. You may resent friends and other family members for not seeing how the diagnosis is affecting you. You may at times also be angry with your loved one.

Guilt. When something unexpected and frightening happens, such as a cancer diagnosis, we often need to try to make sense of the event. People often look to the past to explain the present. In this way, you may find yourself thinking that something you did or didn't do in the past was the 'cause' of the cancer, no matter how unlikely that may be. You may also feel guilty that you can't make your loved one's pain and fear disappear.

Helplessness. Caring for someone with cancer may be the hardest thing you have ever done. Knowing exactly what will be helpful can be hard to judge, and at times it may feel that whatever you do will not be enough. Ideally you would like to make her well again, but this has largely been taken out of your hands. Not all things can be fixed, but worries and concerns, both yours and those of your partner, family member or friend can be voiced and acknowledged.

Being a Good Listener

The aim of sensitive listening is to try to understand what the other person is feeling. Everyone has their own unique way of dealing with crises, so you can never truly know what it is like for the other person, but you can try to

'hear' their concerns as fully as possible. Don't feel you have to offer solutions. Just being there, listening and caring, may be the most helpful things you can do.

Avoiding difficult topics, responding with, "You'll be fine, don't worry", can place an added burden on the woman with cancer. It can have the effect of leaving her alone to face her fears. Allow her to say it, if she feels afraid that she will die, or that the cancer may return. Be willing to talk about these difficult topics. By dealing with "worst case scenarios" she can begin to feel a sense of control over her uncertain future, knowing that her worst fears have been faced, voiced and acknowledged.

Many people believe that being positive can help to cure cancer. They also believe that thinking or talking about negative thoughts and feelings can make the cancer grow faster, or make it more likely to come back. For this reason family members and friends may find it difficult to talk about cancer related issues, especially when treatment is finished, fearing they will be encouraging their loved one to 'dwell' on their problems, or may even be making matters worse. Remember that being positive does not mean we have to feel happy and optimistic all of the time. Being positive means choosing to live as best as one can for as long as one can. To do this we need to face our fears, not hide from them.

Whilst it is important that you are a good listener, don't be afraid to talk about your own feelings. It is OK to say, "I find this difficult to talk about"; or "I don't know what to say". It is also OK to talk about your fears. You may be afraid of breaking down or crying, but by trying to be strong for each other, opportunities to talk about important issues can be missed. It may be that your loved one is afraid of burdening you with her feelings. By raising them yourself, you can open up the communication. Finally, be sensitive to her needs, there may be times when she does not want to talk about her cancer issues. Cancer is something she has, not who she is. At these times your role may be to provide a sense of normality to an otherwise non-normal event. Be respectful of this.

What else can you do?

1. Become informed. If you are to be useful to your friend, family member or partner, you may need some information about what the medical situation is. Information can help you understand better what

is happening and help you make plans. You do not need to become an expert on the subject.

2. Gynaecological cancers and their treatments bring about radical physical changes. Remember that touching, holding, hugging, and caressing are ways to express your caring. More than words, they express your continued acceptance of her as a physical being. However, also be aware there may be times when she doesn't want to be touched too much. It's OK to ask.
3. Think about other family members: Are there children who need to be taken to and from school, to be helped with their homework or ferried to and from other activities?
4. Think about what you are good at or able to do and offer specific help. This is more helpful than saying "If you need me let me know".
5. People with cancer are encouraged to take someone with them when they see the doctor. Offer to go with her, or if you can't, help her to prepare for the appointment. You might help her to think about questions she wants to ask. If you do go with her, listen to what the doctor says and make notes of essential details. During the appointment, however, do not answer for her, unless she asks you to.
6. Support yourself. Supporting a person with cancer can certainly bring you closer together. However, it can also be very demanding and may cause stresses in your relationship. If you feel that you need support yourself in order to deal with some of the emotions or thoughts that you have, ask the health professionals involved in the care of your partner or family member. You can also call the NSW Cancer Helpline (Ph: 131 120). Other sources of support are listed in the contacts section of this web site.

Tips for partners, family and friends

Do.....

1. Do respect my decisions and choices
2. Do make specific offers of help (say what you will do)
3. Do listen to me
4. Do offer to come to appointments and treatments
5. Do recognize that I may not want to talk about it, ask
6. Do acknowledge and recognize how hard I am trying
7. Do make me feel special
8. Do appreciate that sometimes I need time out.

Try not to....

1. Try not to say, "are you OK" all the time
2. Try not to forget me - cancer is what I have, not who I am
3. Try not to forget I still might want cuddles
4. Try not to put everything down to the cancer
5. Try not to think there is a 'right' way to react
6. Try not to say "I know how you feel", you don't
7. Try not to tell me 'cancer horror' stories
8. Try not to tell me about all the new 'wonder' treatments
9. Try not to think I will ever forget what has happened to me
10. Try not to expect me to know how you are feeling
11. Try not to get angry or huffy if I say I don't want to talk today
12. Try not to tell me what to do.

These tips were contributed by members of the Westmead Gynaecological Cancer Support Group. Information about this, and other sources of support, can be found in the contact section.