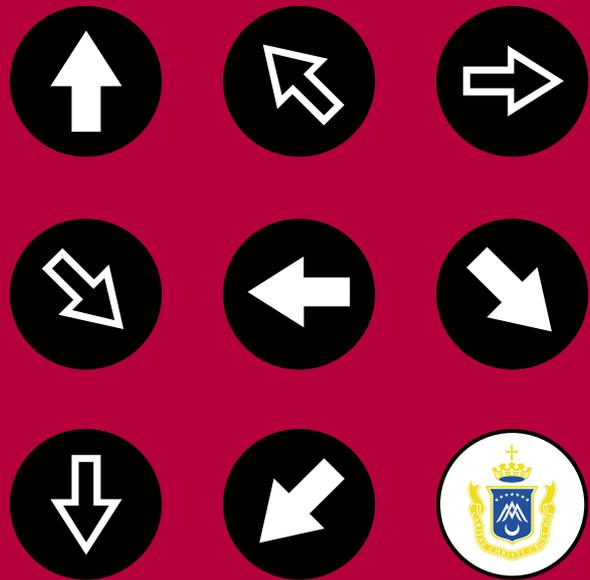


Now What?

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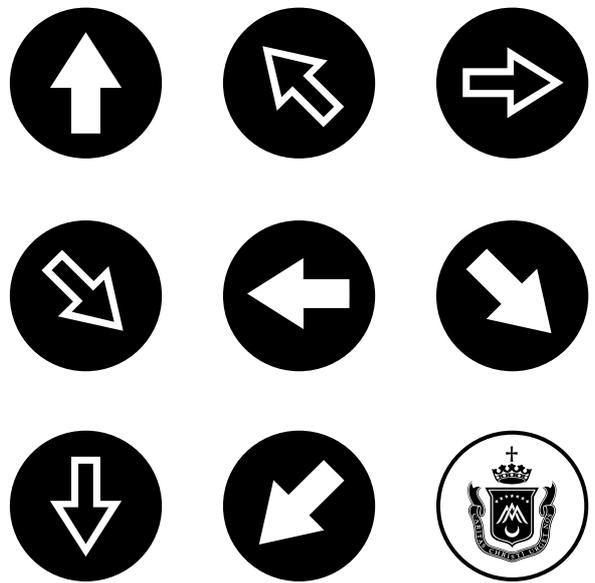


When treatment ends:

A publication for women who have completed treatment for early stage breast cancer, and their partners.

How are you supposed to feel now?

Now **What?**



When treatment ends:

A publication for women who have completed treatment for early stage breast cancer, and their partners.

How are you supposed to feel now?



Often it's only when we look back at an experience that we can make sense of it. Much of the information in this booklet comes from interviews with women who have completed treatment for breast cancer. It also includes interviews with their partners. We hope that their experiences help you to make sense of what you have been through and may still be going through. We also hope this helps you in your planning for this next phase in your life.

As someone who has been through (or supported someone through) the experience of cancer treatment, you will know that cancer is not just a disease but an experience that impacts on the entire life of the cancer patient and those close to them.

Common metaphors used by patients and carers to describe their experience of early stage breast cancer, include the notion of, 'going through' a battle, or 'weathering a storm'.

You are now on the other side of 'the storm' that was anti-cancer treatment and this may be the best time to review your experience. Such a review can be an important part of moving on.

This booklet will consider some common experiences involved with the diagnosis and treatment stages of breast cancer. It will then address the experience of treatment completion and make some suggestions for coping with this stage.

It is intended to include the experiences of women who have had breast cancer as well as their partners. We believe that the adjustment, when treatment ends, can be challenging in different ways for both groups of people. We also believe that it is helpful to understand each other's experiences.

The **Diagnosis and Treatment** Phases

"...you're in go forward mode, ... I didn't stop to think about what was really happening to me..." (Mary)

"...I think those around her go through as much as she does..." (Dean, partner)

Regardless of what phrases you would use to describe the experience you have been through, most would agree that the first hurdle to get through was the shock of the diagnosis. Before they knew it, they then had to face the challenge of treatment.

THE DIAGNOSIS PHASE FOR WOMEN

Annie, described her diagnosis as, *"...one of those moments that will live on in life."*

A diagnosis of breast cancer for most women represents an incredible shock - a moment frozen in time that provokes fear, dread and devastation. For some it is only in retrospect that they are able to think about the meaning of their diagnosis, because the shock of the diagnosis meant that this period was a blur. They describe feeling overwhelmed at a time when major decisions had to be made.

The shock of the diagnosis also continues to some extent throughout treatment.

"I suppose the chemotherapy was such a big thing. The surgery, they sort of whipped me in and did the surgery. I'm sure I was still in shock all the way through" (Barbara).

In many ways, the coping mechanisms used by women during this time involves concentrating on 'getting through', of not thinking too much about anything other than survival. Many deal with the uncertainty of this time by focusing on each day as it comes and anticipating the relief of treatment completion.

"...at that point in time you're in go forward mode, well I didn't stop to think about what was really happening to me... for each of the steps that I took, I based it on one more brick wall to climb. And so when I got to the end of the treatment I had climbed all the brick walls that I had to climb" (Annie).

Many women talk about their experience of breast cancer as having a big impact on their family and friends. And in turn, their family and friends had a big impact on the way they coped with breast cancer. They felt protective of family and friends as well as finding support from these people. Though some women talk about instances where members of their social network brought about stress, many described them as 'stress buffers'.

"This experience has given me confidence because I didn't know people liked me so much" (Claire).

For those women in relationships, partners in particular are commonly noted as the most significant support person throughout the experience of breast cancer.

THE DIAGNOSIS PHASE FOR PARTNERS

"...I think those around her go through as much as she does, obviously in different ways than what she has gone through, but it is extraordinarily traumatic on everybody near her" (Craig).

Partners of women with breast cancer have been found to experience as much distress as their loved ones following their diagnosis and treatment. However, soon after the shock of the diagnosis, partners often look to what they can do to take control of the situation. This is an understandable response when faced with the uncertainty of cancer in a loved one.

"...after we went to the doctor it was a shock to both of us, but it took us a very short time to realise the situation and that we had to act as quickly as we could to get a solution for the problem" (Gordon).

This often means that partners put their own needs and concerns aside and focus on being the carer or protector.

"... my needs or feelings were irrelevant compared to what she was going through, and therefore the issue for me was more the support and care of her. It's as simple as that" (Damien).

However, during this stage, knowing what to do for the best was often the hardest part.

"I wanted to help as much as I could but I didn't know how...I think the initial shock took a while for me to get over, but then how to help her was something that I didn't know how to do. I didn't know whether to be very sympathetic or to assist, overdoing that line. You just try to work it out the best you could. It wasn't easy..." (Harry).



THE TREATMENT PHASE FOR WOMEN

Beginning treatment is often extremely confronting, and brings out the fear that surrounds a cancer diagnosis. The physical impact of treatment often becomes a focus at this time. For some, the constancy of the nausea, pain and tiredness is overwhelming and can impact on all other aspects of the woman's life.

The psychological or emotional impact of treatment, in many ways relates to how destructive it can feel to one's body when a variety of side-effects are experienced. One also has to manage the fear of the unknown about what is going to happen next, throughout treatment.

"I think whenever you face your own vulnerability, it has to change you really, you sort of get pulled up short. I think I always knew that I would die one day, but you don't sort of have to face that. The experience of cancer means you are faced with death, you are actually getting older... Who knows why someone gets cancer, but for me, the meaning of illness is suddenly you're not in control" (Barbara).

As noted earlier, the uncertainty of this time is often managed by simultaneously focusing on one day at a time, while also looking towards treatment completion.

THE TREATMENT PHASE FOR PARTNERS

In many ways, partners tend to manage this difficult time through trial and error; they find that they have to learn very fast how to play the role of carer. Providing practical assistance, such as increased help around the home, is a common form of support mentioned by partners.

Some find that they throw themselves into work during this time - to take their minds off what is happening.

However, many partners admit that this experience makes them think about their own mortality, family, and future in general.

Craig felt that this experience encouraged him to put his whole life "back into a daily perspective, rather than the big picture".

Damien used the analogy of running a marathon to explain what it was like to support someone through treatment.

"I think it has been difficult - no not difficult, it's been draining. I think because it has been quite a long period of time. I've just become more tired over the last 6 to 8 months, from the emotional trauma of finding out and then the contracted treatment period. It's quite physically draining ... Anybody that has trained in marathons knows what sustained periods of effort are all about."



While some partners find that their relationship with their spouse becomes closer during this experience, many state that this is quite a lonely time where they are needing to give out much more support than they receive.

Many partners find themselves taking on the majority of the emotional support in the relationship in addition to the roles of protector, advocate, carer and lover.

It is understandable then, that as the end of treatment approaches, many partners feel quite depleted and look forward to life getting back to normal. This expectation however, often leads to disappointment when partners find that the end of treatment seldom means the end of the breast cancer experience.

Treatment **Completion**

“Now it’s becoming real” (Annie).

“It isn’t over” (Craig).

THE TREATMENT COMPLETION PHASE FOR WOMEN

It may not be until treatment is over that a woman with breast cancer is able to begin to fully comprehend the experience they have been through, including their fears and hopes for the future. When treatment ends it is a time for recovery. Many feel that they have not fully recovered until some time after the final chemotherapy or radiotherapy treatment.

Many women say that this can be a lonely time because they feel that their family, friends, workmates and even partners expect them to be ‘back to normal’ or how they were before their diagnosis. It is important to remember that treatment is, for many, a very traumatic, often life changing time and that anyone who has been through such a time can benefit from time in recovery.

“Being operated on and going through treatment was a period when I didn’t really have time to think that I had cancer. Even though I had down days and up days, looking back I think it was a bit unreal, whereas only now that treatment is finished it is becoming real” (Annie).

The goal of ‘getting on with living’ is also influenced greatly by the issue of uncertainty about the future. Many women feel worried about the possibility of recurrence once treatment ends and visits to the outpatient clinic become fewer. Uncertainty is a tough thing to deal with, most of us like to believe that we have some control over the future.

“Once treatment was over, the support network starts to wind down fairly quickly. You’re no longer going to the hospital, so you haven’t got people checking how you are all the time. And the appointments wind down fairly quickly too...once physically I started to heal. I suppose that’s it, I’m now just on my own.... cast adrift” (Annie).

THE TREATMENT COMPLETION PHASE FOR PARTNERS

For many partners, there is an expectation that once treatment is over life will soon get back to normal. At this point, similarly to the women who have completed treatment, there is often a mixture of feelings that can occur. Many say they are exhausted from the long haul since diagnosis.

Though partners mention some relief that treatment is over, many note a common concern that the uncertainty about the future is not over.

“When she completed treatment, I thought it was all over, like everything else that’s happened so far, every stage has been a bigger surprise than the one before...I just realised that some of her problems really are only just starting. It isn’t over” (Craig).

Partners also talk about some of the positive ways this experience has impacted on their lives. How they are making the most of living in the wake of coming close to losing their loved one.

“We go out to have meals a little more often than we have in the past, rather than putting away money for the future. We try and increase that quality of life and enjoyment now with one eye on the future, but at least a little bit more aware of the importance of the moment” (Brian).

The **Recovery Stage**



When treatment for breast cancer is over, there are reasons why a woman may feel relief, as well as increased anxiety. As this booklet has described, the experience of diagnosis and treatment can be challenging for both the woman who has had breast cancer, and her partner. It is understandable that after treatment is over there is a recovery period necessary before many feel they can begin to move on. There are some strategies that both the woman who has completed treatment and her partner can use to manage the stress of this time.

STEPS TO RECOVERY

1. Share your feelings about the diagnosis and treatment with each other.

This may seem a strange suggestion because you may feel that you have just shared the whole time since diagnosis with your partner. The fact is that we are often not able to articulate how an experience is affecting us when we are going through it. You may benefit from hearing what that time was like for them.

For example, if both you and your partner are feeling differently about treatment ending, this may be because the experience you went through was different. Now might be the best time to look back over the experience and share your feelings. Then look forward together!

2. Goal Setting.

The woman who has come through an experience like breast cancer and the partner who has supported her may find that this time can lead to them wanting to make changes in their lives. They reassess priorities and work on achieving goals they have put off in the past. Others want to find some normality again, some of what their life was like before breast cancer. There are no right or wrong ways to look to the future.

What is clear is that it might take you some time before you are able to find the energy to move ahead, and it is important to take small steps first and continue to be gentle with yourself during your recovery. You may want to build on some of the relationships you have in your life, or you may decide not to put so much energy into them. You might want a holiday, to start a new hobby, to follow an interest you've always had.

Find some time to sit down and think through some of these things. Write down some thoughts about what and who is important in your life. When you have some clear directions you might want to share them with those close to you and develop a plan.

3. Learning to Live with Uncertainty.

Many of us believe that we know what is going to happen tomorrow. We think that we have control over our lives. However most people who have been through what you have, know better. Understanding the reality that none of us have certainty in our futures can be very anxiety provoking. It can prevent us from living in the present for fear of the future. People who have experienced cancer need to master the unenviable task of living with uncertainty.

This means many things such as, learning to manage clinic visits, learning to deal with minor 'new' illnesses without panicking that it is a recurrence, learning to read new information about cancer in the newspaper without getting upset every time. These tasks may be difficult ones to master but success does come with time and some effort.

The anxiety you feel will come and go. It is important to learn how to deal with each concern as it arises so that you can conquer these stressful times. Here are some tips that might help.

If you find that you are feeling particularly worried about something you've read or your physical condition, ask yourself, what it is that has made you worried and then take an honest look at whether it is really worth worrying about?

For example, you may see a television report about a different sort of cancer to yours, and find yourself getting anxious. It is important to remind yourself of the fact that this does not relate to your own situation, that there are over 300 different types of cancer and just because you've had breast cancer doesn't mean this information necessarily relates any more to you than someone who has

never had a cancer diagnosis. Or, you may get a cold in the winter time and worry that you are going to get very sick. In this case it might help to remind yourself that we all get colds, and this does not necessarily mean anything worse will happen to you.

If the issue you are worried about is causing concern, ask yourself if you need to do anything about it, and if you need to find out any more information about it.

One antidote for worry is action. Rather than sitting with your fear it is often better to do something about it. Make an appointment with your doctor and check out what is going on with your body. The fact is that even if you were found to have a cancer related illness of some sort, there is always something that can be done to tackle each problem. Worrying about it without doing something about it will not make it any better. It may be that getting some more information may be enough to settle your fears. Information often helps us to gain control.



There are times, however, when we need to learn how to put negative thoughts aside because they relate to 'maybes' in the future, that we have no control over. The best way to deal with these times is to learn how to divert our attention from these thoughts and get on with something else. Often, with time, these thoughts become less and less frequent.

4. Learn some stress management strategies

Learning how to relax and deal with anxiety is a good thing for all of us to do. There are relaxation classes available in your community or relaxation tapes and videos you can purchase or hire. The Cancer Council of Victoria (formally ACCV) has a good publication called, 'How Can I Relax?' It is also important to get some exercise, good nutrition and adequate sleep (Anti Cancer Council of Victoria has some helpful publications to do with these topics). These points may sound simple but many of us do not adhere to them.

5. Talk to others in your situation

Talking to other cancer survivors or partners who have supported someone through cancer, can be invaluable.

It can be very helpful to talk to someone who really understands your experience and who has ideas about what worked for them. You can either ask at your treatment centre to be put in touch with someone or you could join a support group in your local community.

The social worker at your treatment centre can put you in touch with a local support group, or you can call the Cancer Helpline in Victoria on **131120**.

If you feel that more individualised support would help you, it may be beneficial to talk to a professional counsellor. Again, the social worker at your treatment centre can give you a referral, or you can contact your local Community Health Centre or Cancer Helpline for counsellors in your community.

Final Points in Summary

Treatment completion after breast cancer can be cause for celebration, but it can also generate new anxieties for women and their partners.

It is normal to feel:

happy,
afraid,
angry,
in limbo,
unsure,
fragile,
resentful,
confused,
excited,
disappointed,
worried,
proud,

and many other emotions, as you face life after breast cancer.

Reflections

The following words are from letters from women who have completed treatment from breast cancer.



Reflecting on the events of the past nine months, I feel as though I've been unwillingly co-opted into a tragi-comedy-farce, with no script and no provisions, apart from my own inner resources and a dogged determination to see it through and ultimately, to find meaning in it all.

Recently it occurred to me that I am content! I am OK again! I am learning to successfully ride the emotional roller-coaster, cherish myself when I'm down and rejoice in the exhilaration of the ride back 'up'. I am like a precocious child; the stages of my recovery do not maintain a well ordered pace, but are skittish, unbalanced and out of kilter with each other. For now, I am comfortable with this erratic process of healing - but eventually I hope to achieve a nicely balanced rhythm with time for both 'doing' and 'being'. I must. But where to next? Who knows?

At the end of the day, I carry the same hopes and dreams as always, albeit intensified. I have been given no false assurances, no empty words, just honesty and a desire to trust in the future. This is enough. I know now, that each day has the answers I look for, each day with its mundane

rhythms and 'ordinariness' supplies me with the courage I need to put one foot in front of the other and...get on with living!

The phrase 'getting back to normal' I have heard many times. There will be no normality for me. This experience has changed my life. The letter 'C' is not for cancer but for change, so how can I be 'back to normal'? I would love to be but I see things differently now, my life has taken on a different perspective.

I am presently at the 'limbo stage'. People ask me what am I going to do now that the treatment is over. Am I going back to what I was doing six months ago? Probably not. Is my life to be shortened or lengthened through this experience? I don't know. What I do know is that I intend to enjoy each and every day.

“You can only go halfway into the darkest forest; then you are coming out the other side.”

Chinese Proverb

This booklet was written by Carrie Lethborg, Oncology Social Worker,
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UNDER THE CARE OF THE SISTERS OF CHARITY