



"So I bit down on the leather.."

Ending the silence for men whose
partners have breast cancer



NATIONAL
BREAST CANCER FOUNDATION
FUNDING RESEARCH FOR PREVENTION AND CURE

'Peter'

When I heard about it, my wife was at the radiologist. She couldn't get in to see the doctor. She was left standing on the street corner crying. I'm in tears racing over to get to her in the car. I called a friend on my way, who gave me the advice: "Make life as normal as you can because you are going to have to hold it all together". So, I bit down on the leather.

Then I had to go and speak to each of our sons' schools. I found every time I went to tell them, I broke down. Her parents fell into denial and didn't even visit, and I didn't know how to support them. Her sister got really worried about herself. I didn't know how to bring our kids into it. One of our sons, who had always been such a happy kid, stopped smiling and laughing for some years. The woman has been the sun around which everything has revolved, and suddenly you find yourself in that position.

There was no support for the family. There was no advice. She had a lumpectomy, 12 months of normal chemo, then a different, new chemo, then had to wait 12 months to have a mammogram, and they found it again. Then she had a mastectomy, followed by radiotherapy. She chose not to get the rebuild. This all stretched over two years.

When she had the mastectomy, a nursing sister gave me a cassette from the husband of a survivor. It really changed everything. I needed a real man's advice and where the hell was I going to get it? Men don't share this stuff. Well, I got it from this cassette. It answered a question I didn't even know I had – how am I to behave to address not how I am feeling, but how she is feeling? It told me to stay in the practice of intimacy and not fall out of it. It told me to make sure that I touched her chest on both sides as though nothing had changed. The fact that her breast had gone didn't matter to me, what mattered was giving her the response she wanted and needed.

People talk about the woman's journey. There is also a partner's journey, and mine had several different phases. I spent the first two years being very strong, as primary carer. Then I became really angry and went into a very dark place where it all fell apart for me for a few years. I felt like my contract with life was null and void, everything could be taken away from me and there was nothing I could rely upon. Hope was sucked out. I had to travel a lot for work and alone in my hotel room I would call friends up at midnight because I didn't have confidence I would be awake in the morning. I never would have thought that three to five years later, I'd be feeling like that.

Even years later, you're living in agony every time she feels unwell or sore because you know she hasn't told you everything and it could be a recurrence.

If someone had just said to me, this is how it will play out; these are the phases you need to watch out for; here is a roadmap.....that would have made a difference.

Foreword

The National Breast Foundation (NBCF) was founded in 1994 on the belief that research is the most effective way to reduce the impact of breast cancer for all. To that end, to have maximum impact on the disease, NBCF needs to fund the full spectrum of research, including research into the psychosocial issues of breast cancer.

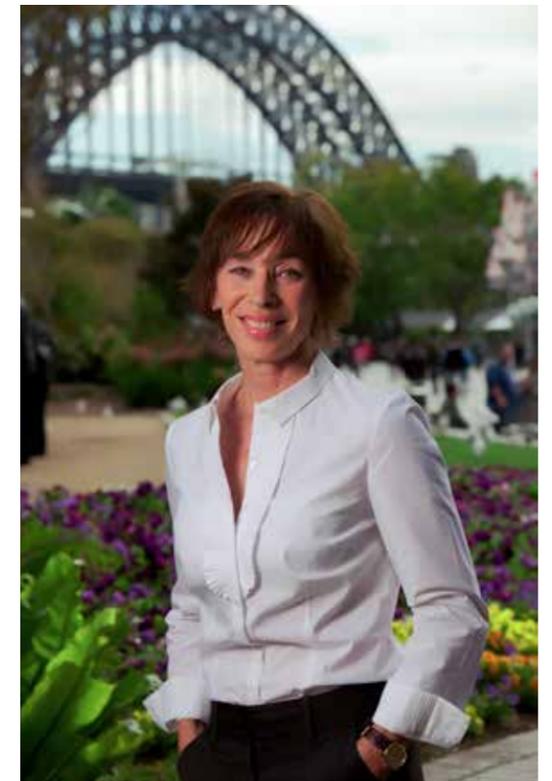
Breast cancer sweeps many people up in its path, not only the woman who has the disease. While we want research to continue to drive towards our goal of zero deaths by 2030, and beyond that prevention and cure, there are a number of silent, invisible casualties of breast cancer whose unmet needs research must now address. Male partners are not the only people who fall into this category and of course not all partners are male. However, many male partners do seem to get hit particularly hard by breast cancer and have little help available to them.

NBCF's objective in publishing this report is to identify and draw attention to their unmet needs to stimulate research into these areas, and encourage men to participate. This is key to also helping the woman affected by breast cancer.

It is a rare privilege to find men who are willing to open up about their experience of breast cancer. This has been one of the impediments to research to date. I have been deeply moved by the raw honesty of the men who have shared their stories with us, and offer them my heartfelt thanks for enabling NBCF to end the silence.



Carole Renouf
Chief Executive Officer
National Breast Cancer Foundation
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Authors:
Carole Renouf
Dr Susan Henshall, Three Stories Consulting

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Introduction

Research into the issues of male partners and breast cancer, and in cancer more generally, has been conducted for over two decades, both nationally and internationally. However, this remains an area of great difficulty and major gaps exist in meeting the specific needs of partners, with effective, proven, quality interventions often not reaching those most in need.

As survival rates continue to drive upwards in Australia, the short- and longer-term pressures of breast cancer on male partners – with flow-on effects for the women affected and also any children in the family unit – urgently need to be understood and alleviated through research.

NBCF began this keystone analysis with a literature review of extant research into the needs of partners in breast cancer. We uncovered a broad base of published papers and reports. Consistent themes emerged as well as some key challenges. NBCF also surveyed existing resources for partners and a selection of these are listed on page 17.

NBCF subsequently developed a simple online survey about the partner experience and then

disseminated this through survivor volunteers with the request to pass it on to partners. Interestingly, while over 400 were sent the survey, only six male partners responded, echoing the degree of difficulty noted in previous work in promoting participation of partners in research.

Outside the survey, NBCF was able to make direct contact with a limited number of male partners who were willing to participate in an in-depth, one to one interview. Their de-identified voices can be heard in these pages. NBCF also sought the perspective of clinicians treating breast cancer patients.

This is by no means a comprehensive review. The numbers of male partners involved in the survey and interviews are far too small to draw any scientifically valid conclusions. Even so, patterns emerge where it has been possible to marry data from the literature review and information from the survey and interviews, and these patterns do provide real insight into the world of male partners and breast cancer.



The concept of a partner's journey

"People talk about the woman's journey. There is also a partner's journey."

From the moment a partner hears a diagnosis of breast cancer, things change forever. Should a man agree to talk about his experience, he can often relate the exact day, time and place when he received his partner's diagnosis - recently, or many years ago.

That partners have their own journey is a concept rarely brought to the fore. This journey occurs both at an individual level and as part of a 'unit of care'. From the day of diagnosis, many men must take on the cancer caregiving role with little or no preparation and without questioning whether they have enough knowledge, resources or skills to manage this responsibility (Manne S., Ostroff, Sherman, et al, 2003; Pistrang & Barker, 1995; Northouse, Williams, Given, & McCorkle, 2012). There is now a well-established body of work demonstrating the enormous impact that caregiving can have on both physical and mental health and well-being. Therefore, understanding the partner's journey and providing them with

evidence-based information and tools needs to become part of a coordinated approach to breast cancer care (Northouse, Katapodi, Song, et al, 2010). Understandably, it is a hard call to ask busy clinicians to deal with two 'journeys', not just one – but this is ultimately what may be required to yield the best possible outcomes for the patient.

Based on anecdotal evidence, the partner's journey has different phases (similar to, but not the same as, the woman's) and can be of much longer duration than previously contemplated. NBCF's interviews demonstrate that in some cases, the journey continues even over a decade after diagnosis. It is marked by changes in sexuality and intimacy; the ongoing fear of recurrence; and far-reaching repercussions on both the man and the relationship as a whole.

The partner's journey is inextricably linked to the woman's and there is a reciprocal influence in terms of the attitudes, values and behaviours each brings to the experience. Features of the partner's journey are highlighted in this report.

Partner/carer distress

"I became really angry and went into a very dark place where it all fell apart for me for a few years. My contract with life felt null and void."

Many partners suffer emotional distress and a minority can experience severe depression (Northouse L. L., 1989; Northouse L. L., 1994; Nakaya, Saito-Nakaya, Bidstrup, et al, 2010; Wagner, Bigatti, & Storniolo, 2006). Feelings of distress may not only be confined to the early phase of breast cancer. Research studies have demonstrated emotional distress can persist up to 18 months after diagnosis (Northouse L. L., 1989), although anecdotal evidence suggests that the time frame is much longer, with men consistently anxious about their partners and fearful of recurrence many years later. Levels of

distress may also increase if the patient progresses to advanced, life-limiting disease (Grunfield, Coyle, Whelan, et al, 2004). While many men want to focus their attention on their partners and 'hold it all together', leaving their own mental health needs unattended can be detrimental. The decision to seek help may prove to be mutually beneficial to both breast cancer patients and their partners. Research confirms that distress between partners and patients can be interlinked, with partner anxiety affecting patient anxiety in couples dealing with breast cancer (Hodges, Humphris, & Macfarlane, 2005; Hagedoorn, Sanderman, Bolks, et al, 2008; Segrin, Badger, Dorros, et al, 2007).

Examining beyond distress alone, researchers have looked more broadly at Quality of Life (QoL) of

partners of women in treatment for breast cancer, covering emotional, physical, spiritual, social and economic well-being (Wagner, Bigatti, & Storniolo, 2006). Partners experience lower psychological well-being and greater fatigue that impacts on their other roles and activities.

As male partners are forced to move into the carer role, first they must confront their own values and feelings about this change. One clinician said, "Their world where their dinners get made falls apart. I have observed the shift in role can make them angry and resentful". Secondly, the multitude of tasks with which they often are unfamiliar - learning about breast cancer, undertaking household duties, caring for the children, managing the financial costs of treatment - all contribute to an increased burden of care (Stenberg, Ruland, & Miaskowski, 2010).

Men and coping

"You want to grab the sword and charge off and say, 'I'm going to fix this for you'. I didn't know how to fix it, and that's what I was good at. I just didn't know how to deal with it, how to comfort her, how to engage."

There is a robust evidence base to show that men and women respond differently to taking on the role of a cancer carer. In a study of cancer caregivers in NSW that sought to determine the links between gender differences and distress, men rated highly in some aspects of 'self-silencing'. This is a measure of the tendency to engage in compulsive caretaking, pleasing the other and inhibiting self-expression. Men saw this as a normal aspect of stoical masculine behaviour, reporting pride and pleasure as a result (Perz, Ussher, Butow, & Wain, 2011), and regarded expressions of needs or feelings as signs of weakness, and maintaining a positive front as a way of coping (Ussher & Perz, 2010).

Interestingly, a partner's coping style can have unintentional negative effects on both partner and patient distress. When researchers looked at 'protective buffering', a coping strategy used to protect from upset and burden by concealing worries and yielding to avoid disagreement, they found this approach is more often used by partners experiencing higher levels of distress

"I just didn't know as a carer what I should or shouldn't be doing. It's like becoming a parent for the first time."

While there are many reports documenting partner distress, it's important to note that not all partners are affected. An analysis of 46 studies assessing distress, including 15 studies of couples dealing with breast cancer, concluded individual levels of distress were determined more by gender than by role. Women consistently reported more distress, regardless of role (Hagedoorn, Sanderman, Bolks, et al, 2008). Some studies have concluded that in ~42% cases, women with breast cancer reported their cancer experience brought them closer to their partner, and only a small proportion (6%) reported they were more distant (Dorval, Guay, Mondor, et al, 2005).

(Hinnen, Hagedoorn, Sanderman, et al, 2007). In a parallel study, increases in 'protective buffering' were associated with increases in patient distress in couples rating their relationship as highly satisfactory (Manne, Norton, Winkel, et al, 2007).

The desire to be stoic, conceal worries, and take action or 'fix things' rather than express feelings were common threads linking the men interviewed. From the woman's perspective, a survey of 64 women with breast cancer carried out by Breast Cancer Network Australia (BCNA) reported that women said, 'It was very helpful when their partners listened to them, took an interest in research about breast cancer, supported them emotionally and didn't try and 'fix' things' (Breast Cancer Network Australia, 2008).

A recurrent theme in virtually every interview was that men are reluctant to share deep feelings or cannot find other men to share these with. They may well not talk to their partner. They typically will not talk to each other, even though some state what they need the most is a strong male voice of experience that can offer them direction. They do not tend to seek professional help from a GP or psychologist. There can be awkwardness around the need to find a professional who is not also treating their partner.

'Richard'

My wife's breast cancer diagnosis was 10 years ago, but to this day I've never even got to see her oncologist, I was not invited to attend any consultations, I went with her to some things but communication was always addressed exclusively to her. I had no input to any decisions. I was just told this is what's happening. It makes you feel very helpless.

It would have been good to have someone tell me what I was going to have to expect, or how I was to manage it. I am the sort of person that if you just point me to a resource, I'll use it, but there was nothing. It wasn't about struggling to become a carer. The two of you are in a caring relationship, sometimes you are cared for and sometimes you are the carer - I accept that. I just didn't know as a carer what I should or shouldn't be doing. It's like becoming a parent for the first time. Without this guidance I just spent all day in the hospital, sleeping in the chair by the bed, working remotely. I was fortunate enough to be my own boss at that time so I didn't have to worry.

The task was to face her mortality. In those days, there was no prognosis. She decided to stop work altogether because she didn't know how long she had left. She has lived every day since then as though it might be her last.

The relationship changes, physically, emotionally, in every way. We had no family support. People at work knew but I didn't feel the need to talk to somebody there. To this day, I don't have a male friend with whom I could have had that conversation. Blokes are just hopeless at that sort of thing. Fortunately I had my own GP (male), completely separate from her GP, and I talked to him, which helped. I still do.

I don't even know what cocktail of medications she has to take, but they affect her. She has absolutely no sex drive. You get used to the change in intimacy but it remains hard, even 10 years later. You don't want to run off and sit in bars, although some men do and some men also leave their wives. I tend to suffer from depression, but interestingly I did not have it during my wife's breast cancer, because I felt useful. Gradually, this lack of intimacy becomes the new normal. And it was important to know from my GP that it is normal.

The three words that sum up what was missing for me are information, communication and inclusion.

Partners and social support networks

"To this day, I don't have a male friend with whom I could have had that conversation. Blokes are just hopeless at that sort of thing."

The importance of partners maintaining social support networks is clear. Low social support has been shown to be detrimental in partners of women with breast cancer and is associated with ineffective coping and depression (Bigatti, Wagner, Lydon-Lam, et al, 2011). The broader cancer literature also indicates that family caregivers with more limited social networks are more likely to feel burdened (Stenberg, Ruland, & Miaskowski, 2010); and restrictions in social activities due to caregiving may lead to social isolation. Some researchers have called for interventions that address both coping and social support simultaneously.

"Fortunately we had a lot of support. Grandparents stepped in and a huge group of friends helped with all of the practicalities."

Providing the right type and level of support to the male partner, as well as the patient, can prove quite challenging, based on anecdotal evidence. Support can come from family (his, hers or both); friends; work colleagues; or the local community in general. However, men report that it can be either a positive or a negative experience for them, depending on their journey.

"Her mum came to stay, followed by her best friend, followed by her sister. That really got to me and put the pressure on. What I wanted to do was offer strong emotional support, and I was relegated to functional things like paying the bills."

Male partners interviewed reported a range of responses by parents and siblings to the need for support.

"Family were hopeless and unable or unwilling to be part of it. They were scared, ill-informed, switched off."

However, partners were often deeply grateful for the practical support provided by work colleagues or the school community – meals, shopping, transport – which is perhaps less likely to cause them to feel threatened in their new role or challenge them emotionally. In the BCNA survey, women reported when their partners were stressed this affected their ability to provide support. Their partners found the most support from family and friends, followed by printed information, then their breast care nurse (Breast Cancer Network Australia, 2008).

"Very few of my mates could even scratch the surface with any level of understanding. It's almost like they don't give a toss, they don't understand what to do and how to do it, so they almost avoid you. I felt isolated because my friends would do anything rather than listen."



Partner inclusion

"I was not invited to attend any consultations, I went with her to some things but communication was always addressed exclusively to her. I had no input to any decisions. I was just told this is what's happening."

In a systematic review of the issues and burdens experienced by cancer caregivers covering 164 studies, information was found to be one of the most important support needs (Stenberg, Ruland, & Miaskowski, 2010). Carers felt responsible for gathering information, and described becoming researchers. Carers reported a need for more information about diagnosis, treatments, and management of symptoms, side effects, and physical care, particularly regarding home care after discharge. Often carers described not knowing what their information needs were until a crisis occurred, and feeling frustrated and helpless when information was not provided by clinicians.

"We entered the whole thing as a partnership and we got through it as a partnership. It's a two-person task just to handle the information given."

In interviews, some partners believed there is an important role for them to play during visits to health practitioners. There is an enormous amount of information to be absorbed about breast cancer

severity, prognosis, the range of treatment options and upsides and downsides. In a filmed interview with a partner whose wife had secondary breast cancer for eight years, he noted that they would go along to her appointments together, often hearing different things and comparing notes afterwards (Walking Beside Her: A Partner's Journey with Secondary Breast Cancer, Advanced Breast Cancer Group).

Some women may choose not to include their partners. A clinician reported, "The breast cancer diagnosis comes to define some women, and partners can find this alienating". Clinicians may also influence inclusion of partners. In the BCNA survey, 69% said that their partner was encouraged by their doctor to be involved with their treatment, while 17% indicated that their partner was not encouraged (Breast Cancer Network Australia, 2008). Researchers have commented on the need to provide education and training to health professionals to recognise patients and their family caregivers as a 'unit of care', with legitimate needs for help (Northouse, Katapodi, Song, et al, 2010).

"I think you have to force your way into these circumstances as the partner. I have got involved because she wanted me to, and I have seen the benefit of that."

Communication and changing relationships

"Frankly, it has been horrible. Gnawing levels of stress creeping up on you over a period of several years now. It has changed our relationship forever. It has changed me forever. And rarely in the shiny, positive way wed all want these stories to end."

Most couples would recognise that communication about cancer-related issues and concerns is important. In reality, ineffective communication can be a source of contention. Couples may not always share the view that talking is important (Manne S. L., Ostroff, Norton, et al, 2006). Studies have evaluated the role of cancer-related communication patterns in the distress and marital

satisfaction of patients and their partners. The results showed that mutual constructive communication was associated with lower distress and higher relationship satisfaction. 'Demand-withdraw communication', where one partner puts pressure on to talk about cancer-related issues while the other withdraws, was associated with greater distress and lower marital satisfaction.

"The subsequent five years have not been easy for both of us. She's angry. There's been quite a few times when I've thought do I really want to stay in this relationship? But you hang in."

Sexuality, intimacy and body image

"I don't even know what cocktail of medications she has to take, but they affect her. She has absolutely no sex drive. You get used to the change in intimacy but it remains hard, even 10 years later. You don't want to run off and sit in bars."

Sexual well-being is a key aspect of quality of life, and for many, one of the longest lasting, and most devastating consequences of breast cancer. The experiences of partners are often neglected in research on sexuality and intimacy post-cancer, although there is growing acknowledgement of their unmet needs in this area. Reported disruptions include decreases in their own sex drive; fear of initiating sex with their partner; difficulty regaining a level of 'normality' within the sexual relationship; and feeling unwanted and unattractive because of cessation of sex. In a survey conducted by Ussher et al. (Ussher, Perz, & Gilbert, 2012), of 1348 participants who were asked whether their partner had experienced any negative consequences because of their breast cancer, the most frequent responses included fear of hurting her during sex (52%), lack of interest in sex (37%), difficulties in communication (34%), tiredness (28%), and change in role (seeing me as a patient) (20%).



Intimacy in general and sexual intimacy in particular, is often altered for a long time, if not forever. Existing research notes decreases in the frequency of participant talking with their partners about changes in sexual intimacy following a diagnosis of breast cancer. Relationship difficulty or breakdown was reported in approximately 10% of cases. This was due to factors such as partner rejection or absence of support, exacerbation of existing relationship difficulties and also changing relationships from being a partner to a carer. A clinician who treats breast cancer but other cancers as well observed, "With male partners, the sexuality and body image aspects of breast cancer can become over-emphasised. There is an expectation that she should look like she used to. There is a lack of tolerance for long-term issues with pain from surgery and radiation". The effects of treatment such as surgery and chemotherapy can be as hard for the partner to deal with as they can be for the woman.

"You sit on the sidelines and you see your partner wither away...her hair falls out...her fingernails and toenails fall out...it was hard work but you count it down and you get through it."

Some of the partners interviewed articulated the challenge of renegotiating intimacy. One partner was given an audiocassette recorded by another man, which 'rescued' him.

"It told me to stay in the practice of intimacy and not fall out of it. It told me to make sure that I touched her chest on both sides as though nothing had changed."

Renegotiating sex and intimacy has not previously been on the research agenda, and studies have focused on sexual changes and difficulties. Interestingly, findings from a recent study demonstrate that coital sex is not always imperative and can be optional or negotiable, without loss of pleasure or satisfaction with renegotiation of sex or intimacy reported by 70% of participants (Ussher, Perz, Gilbert, et al, 2012).

'Ben'

She was 35 when she received her diagnosis and our little boy was 11 months old. I went with her for the mammogram and what I didn't appreciate at the time was the long face the stenographer pulled when he came out. It scared the bejesus out of us. Two days later I got a call from my partner in tears and I rushed out of the office five seconds later. It's petrifying when you hear your partner in that state. We walked up to the GP, who appeared not used to giving this type of result. In the end I had to say, "Just tell me – has she been diagnosed with breast cancer, yes or no?" When we left the GP gave her a hug and wished her good luck. I just felt angry: I needed leadership, direction, support and advice, not a hug and good luck.

The specialist was brilliant. He said, "This is what's going to happen. You're going to stop breastfeeding this afternoon. I am going to send you for another scan". Suddenly I had what I needed. Without it, your mind is just in this tailspin. You're the partner, you've got to be strong but to be strong you need strong direction and advice.

I was scared because I didn't know what it would be like after your partner has major surgery. I was stupid enough to look up pictures of mastectomies on the internet and that didn't help.

My boss and colleagues at work really helped. My boss said take the time you need and come back when you are ready, and when I told him I was ready, he said take another week. They even turned off my access to the server so I couldn't receive emails. One of the ladies in my team cooked a week's worth of food, another sent a packet of magazines every day, they sent bowls of fruit.

Once we got home, her mum came to stay for a couple of weeks, followed by her best friend, followed by her sister. So we had people there for about a month. That really got to me and put the pressure on. What I wanted to do was offer strong emotional support, and I was relegated to functional things like paying the bills.

My partner started seeing a clinical psychologist. She offered a non-judgemental point of view. I started going to see her as well and that gave me an outlet. I didn't talk to any friends about it.

To see the physical effects of chemo was really tough. You sit on the sidelines and you see your partner wither away....her hair falls out...her fingernails and toenails fall out...it was hard work but you count it down and you get through it. To make matters worse, all the advice she was getting was for women twice her age.

My role now has become to offer unquestioning respect and support for anything she feels she needs to do. Our lifestyle is now completely organic. Our food bills have rocketed. Our medical expenses are huge. I thank God we are in a position to afford to do all this.

I think you have to force your way into these circumstances as the partner. I have got involved because she wanted me to, and I have seen the benefit of that. You want to be strong but you don't know what strong is, and it changes over time. My main need was to have clarity about my role – you have to define what you do and what everyone else does, and be absolutely focused.

Concerns about employment and finances

"I'd like to be able to go to all the treatments scheduled without the fear of losing my job."

There are very real concerns for both the patient and the partner going through breast cancer around employment and finances. There is a substantial financial burden associated with cancer caring both in out-of-pocket expenditures and in lost income and benefits (Northouse, Williams, Given, & McCorkle, 2012; Girgis, Lambert, Johnson, et al, 2012). In a double-income household, the financial impacts of being reduced to one income and of initial and then longer-term treatments

are significant, particularly where young children are also part of the family. Caregiving may also reduce a person's chance of being employed, and many caregivers are unable to work, need to take leave without pay (e.g. as a result of inadequate carer's leave), have fewer work hours, are in lower paid jobs, or work from home to manage the caregiver demands (Girgis, Lambert, Johnson, et al, 2012).

"Our lifestyle is now completely organic. Our food bills have rocketed. Our medical expenses are huge. I thank God we are in a position to afford to do all this."

Partners of women with advanced breast cancer

"Living with the constant threat of discovering the next metastasis and knowing that may spell the end changes your perspective. At first it sucks all of the joy out of your life, you then slowly realise the importance of enjoying each episode for what it is. Others don't seem to understand. This has quite an isolating effect on our entire family."

NBCF has heard consistently from women with secondary breast cancer that they feel invisible and unacknowledged for a number of reasons. By their very nature, they cannot participate in the euphoria of 'pink hopefulness' the breast cancer movement has generated in the developed world. They report finding it a challenge to keep friends close, as they can be seen as a walking reminder of mortality which others can find too hard to deal with.

For male partners, the diagnosis of secondary breast cancer also marks a different stage in the partner journey. In addition to the challenges

facing all partners in this situation, these men are facing the full impact of breast cancer as a life-threatening disease – coming to terms with a terminal diagnosis, implementing palliative care plans in hospital or at home, and working through feelings of grief and loss.

The research base on interventions to assist this group of men is limited. In a recent study of 29 clinical trials of interventions offered to family caregivers of cancer patients, only one study looked exclusively at women with advanced breast cancer and their carers, of whom 62% were spouses (Northouse, Katapodi, Song, et al, 2010). In this study, carers participating in family interventions aimed at improving psychosocial and QoL outcomes reported less negative views of breast cancer in the short-term (Northouse, Kershaw, Mood, & Schafenacker, 2005). This was most likely due the opportunity to discuss concerns about the illness and the opportunity to obtain information and to learn new ways to manage issues.

The gap in resources: reaching men in need of support

"It would have been good to have someone tell me what I was going to have to expect, or how I was to manage it. I am the sort of person that if you just point me to a resource, I'll use it, but there was nothing."

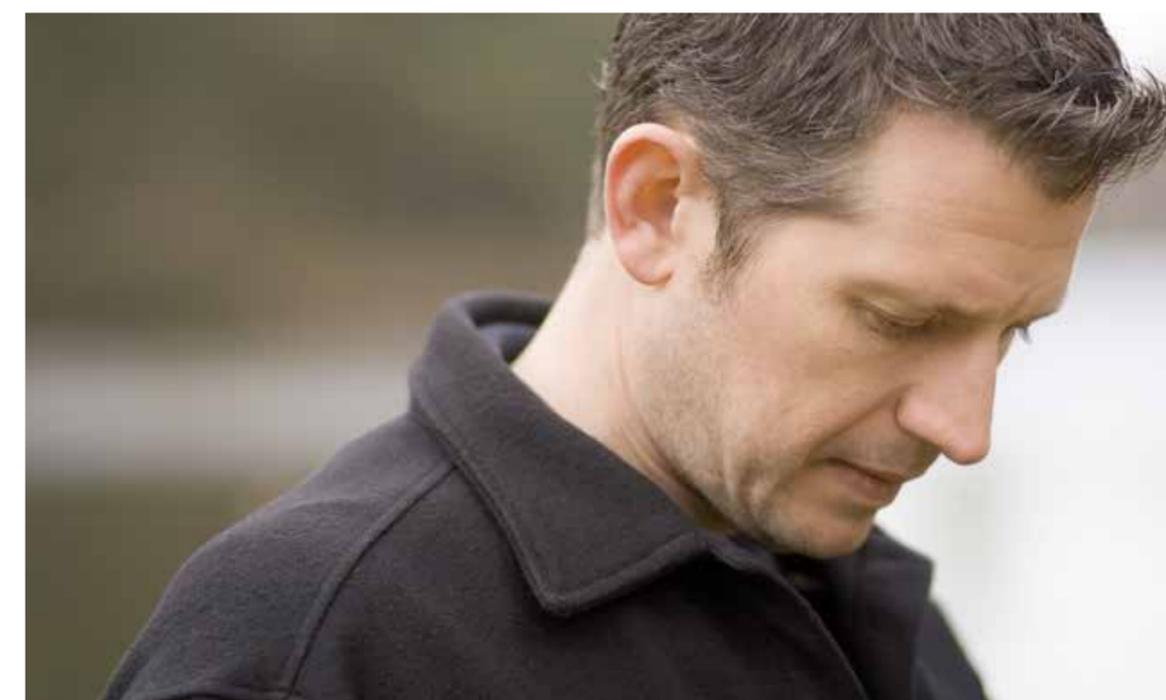
While the voices of only a handful of men are represented in this report, they bring an essential human face to the perceived challenges and unmet needs of men who are carers and partners of women with breast cancer. It was alarming to hear that their experience was largely that they had to find their own way. The main plea of this group of men was for direction so they can set realistic expectations, have a 'roadmap' of what lies ahead, and have clarity about their role.

The literature base supports the conclusion that cancer caregivers receive little preparation, information or support to carry out their vital role (Northouse, Katapodi, Song, et al, 2010). Looking at both the research and anecdotal data raises the question of what can be done to bridge the gap between the evidence that shows partners' need

for support and the lack of resources available to them in practice? Is it that the research and evidence base is insufficient or that evidence-based solutions are seldom implemented in practice? The answer is that both areas require further attention.

The recommendations for research action at the end of this report represent gaps in the evidence base relating to breast cancer carers. Most particularly, there are specific challenges with engagement and recruitment of male partners, highlighted by NBCF's experience. Addressing the fundamental issue of reaching a diverse and large number of men and engaging them in research from planning to implementation is key to assisting those men most in need and seeking support.

"When you are dealing with the health system they say to your wife, "You go to this group and do that". They say to your kids, "Here you are, read this, talk to that person". And the only thing they have to say to you is, "Go your hardest, mate."



'Mick'

It was six years ago that I got home, went upstairs to change and as I passed my wife in the kitchen she said, "I have breast cancer". I really didn't take it in and after a few minutes came downstairs and said, "It won't be that, we'll get this sorted". I was thrown into denial.

When the specialist confirmed the diagnosis, I went through a very 'Oh woe is me' selfish phase, where I was pissed off about how this was affecting my life. I just thought 'What about me?' I had plans, an overseas trip, was busy buying businesses. I feel really sad about that now. I compartmentalised and put my wife into a box over there. Eventually my daughter sat me down and said, "Get over it, Dad, you're just being a dickhead", and that was what I needed. Thankfully our adult kids stepped in and they were much better at it than I was.

I was running around in circles, totally lost. You want to grab the sword and charge off and say, "I'm going to fix this for you". I didn't know how to fix it, and that's what I was good at – fixing things. I just didn't know how to deal with it, how to comfort her, how to engage. I'm not very good at dealing with even mundane sickness, let alone life-threatening. I just had no coverage for the emotional side. That caused her to feel anxiety and to feel low. How can you engage in an intimate way in those circumstances....how do you cuddle...?

She had a partial mastectomy, followed by chemo, radio and drugs. I was in and out and round about. She'd be up in bed and I'd be downstairs. It was very awkward. We are both quite silent types and breast cancer really stuffs it up.

The subsequent five years have not been easy for both of us. She's angry. There's been quite a few times when I've thought do I really want to stay in this relationship? But you hang in. And I think we are coming out the other end of that now.

I would have loved a hotline I could ring up at the time. Someone I could go and talk to and share the emotion and say, "I just don't know how to handle this". I tried talking to a professional for a while but it didn't help. I got quite depressed at one point and moved out of home for a few weeks.

I would advise other men in this situation to get involved; find some time; try like crazy to talk through the emotional bits and be prepared to open up.



Eight recommendations for research action

There is a strong case for increasing resources dedicated to research on partners, particularly in the absence of clear guidelines for providing support and information, both at an individual level and as a couple or unit of care.

- 1 There is a need for further research into breast cancer as a relational experience (a so-called 'we disease'), including the ways in which partner support or absence thereof affects women, and how partners are affected by breast cancer (Hubbard, Menzies, Flynn, et al, 2012) (Kayser, Watson, & Andrade, 2007).
- 2 At an individual level, some reports have shown that there are strong predictors of a partner's role adjustment problems and levels of emotional distress. These include the partner's own baseline level of role problems and distress and relationship strength prior to cancer (Northouse, Templin, & Mood, 2001). These areas require further investigation.
- 3 There is a need for further investment in longitudinal studies as the vast majority of published studies take place at a single point in time and fail to take into account the varying needs of partners through different stages of their breast cancer journey. Evidence shows that the unmet needs of cancer caregivers change over time (Girgis A., Lambert, McElduff, et al, 2012), and continue for many years after diagnosis.
- 4 Research into the needs of partners of women with advanced breast cancer, and how to best assist them, is important. Concerns have been raised regarding the disproportionate attention paid to women and partners experiencing localised breast cancer. We have limited understanding of how to best intervene in cases of metastatic disease. This is a time when the evidence suggests partners are most likely to be experiencing distress and are at risk of significant anxiety and depression (Hagedoorn, Sanderman, Bolks, et al, 2008). There is also evidence that suggests that men's distress continues after their partner dies, and there is a need for further research and support for men at this stage.

5 Practical barriers to research need to be overcome. The challenges of recruiting and retaining patients and partners are significant. Participation rates of less than 50% for couples' research in breast cancer are not uncommon and are often much lower. A consequence is that it is often very difficult for researchers to interpret findings with only small numbers. Understanding the barriers to partners participating in research is key to developing effective, sustainable interventions. This may include assessing methods of recruitment with some researchers having noted that the dependence on cancer survivors to recruit partners may be a potential barrier to the partner enrolment rate. 'Gatekeeping' may cause biases towards couples with good communication and high levels of marital satisfaction (Adams, Boulton, Rose, et al, 2012).

6 The most appropriate methods of delivery of interventions need to be explored. Some researchers have called for better utilisation of technological innovation and communications to reach large numbers of partners with quality, tailored content; and to offer in-built flexibility so partners choose how, what and when they want to access information (Girgis A., Lambert, Johnson, & et al, 2012) (Zulman, Schafenacker, & Barr, 2012). In a recent analysis of clinical trials of interventions, most were delivered in face-to-face sessions (69%), fewer were delivered by telephone (20%) or in a group format (11%), and none were delivered via the internet (Northouse, Mood, Schafenacker, et al, 2013). Male partners are already struggling to juggle work and caring commitments, and reporting losing work hours or using special leave or holidays to fulfill their caregiving responsibilities (Grunfield, Coyle, Whelan, et al, 2004). Therefore, exploring the use of technological innovations in communications and the modes of delivery preferred most by partners and couples warrants research (Regan, Lambert, Girgis, et al, 2012). In addition, assessing the affordability of solutions should be given more consideration.

7 Implementation of evidence-based interventions into clinical practice itself requires research. Researchers acknowledge even when interventions are supported by evidence, they are seldom implemented in a coordinated manner or subject to robust evaluation and monitoring. Collaborating with clinicians to develop and participate in interventions, taking on the lessons learned in accelerating research findings into practice in others areas of breast cancer research, may facilitate integration of evidence-based resources into clinical care for evaluation in practice settings.

8 Researchers are also becoming increasingly aware of underrepresentation of couples and individuals of different socioeconomic status and ethnic and cultural backgrounds, acknowledging that tailored approaches and specific efforts to recruit these groups are required. In a recent analysis of 29 clinical trials, only 16% of the participants were self-identified as members of a minority group (Northouse, Katapodi, Song, et al, 2010).

NBCF wishes to actively encourage researchers to pursue these much-needed directions.

'Aaron'

It's now five years since her diagnosis. It was a great shock. You think that when you are sick, you'll feel sick, but she felt great, she was running, doing yoga. Luckily the breast cancer was at a very early stage and the specialist, to whom we went together, was excellent. Then came waiting for the tests....surgery....and after a few months, further surgery as she decided to have a mastectomy.

We entered the whole thing as a partnership and we got through it as a partnership. That's what she wanted and needed, a partner and a good communicator. When you are seeing all these practitioners and having to make decisions, you are in a surreal state and there's a lot to take in. It's a two person task just to handle the information given, even though she was experienced in navigating her way around the health system. We remember commenting on how difficult it would be if you didn't have a partner at all, or didn't have a partner who was inclusive or willing to be included.

The challenge we had early on was that you want to get your life back and get back to normal. You hope it's all over but you've still got this thing in the background. As a partner that's the contribution you can make, helping to balance all that. It's a very complicated period.

Resources for partners

Advanced Breast Cancer Group

<http://www.advancedbreastcancergroup.org/partners-dvd/>

A DVD resource for partners and carers, "Walking Beside Her: A Partner's Journey with Secondary Breast Cancer" is based on the experience of Peter and Fran, who had secondary breast cancer for eight years. Fran was a member of the Advanced Breast Cancer Group, and Peter was a member of the Partners' Group. In this DVD, Peter talks about their journey together.

American Cancer Society

<http://www.cancer.org/treatment/caregivers/copingasacaregiver/index>

The American Cancer Society provides on-line resources for caregivers to assist with coping strategies. This includes a caregiver self-assessment questionnaire to help assess a partner's level of distress.

Breast Cancer Network of Australia (BCNA) – Partner Support

<http://www.bcna.org.au/group/22285>

BCNA has established an on-line community for partners to share their experiences of breast cancer:

- Partner support for men 'For the boys'
- Partner support for same sex couples

Cancer Australia: Audio CD resources and podcasts

<http://canceraustralia.gov.au/affected-cancer/cancer-types/breast-cancer/awareness/awareness-campaigns/boys-do-cry>

When the woman you love has early breast cancer, and *When the woman you love has secondary breast cancer* feature personal stories, insight and wisdom from women diagnosed with breast cancer and the men who supported them. They also feature advice and practical tips from leading Australian clinical and psychosocial experts

Cancer Councils in each state and territory of Australia

- Cancer Helpline – call 13 11 20

Cancer Council Helpline is a free, confidential telephone information and support service run by Cancer Councils in each state and territory of Australia. Anyone can call the Cancer Council Helpline - cancer patients, people living with cancer, their families, carers and friends, teachers, students and healthcare professionals. Trained staff are available to answer questions about cancer and offer emotional or practical support.

- Cancer Connections for Partners, Family and Friends

<http://www.cancerconnections.com.au/carers>

A place for partners, family members and friends of people with cancer to connect, chat and access resources specifically for carers.

National Cancer Institute, USA

A series of booklets around caring.

<http://www.cancer.gov/cancertopics/coping/when-someone-you-love-is-treated>

Susan G. Komen for the Cure® Co-survivor program

<http://www5.komen.org/BreastCancer/FriendsampFamily.html>

Susan G. Komen describes co-survivors as family members, spouses or partners, friends, health care providers or colleagues - anyone who is there to lend support from breast cancer diagnosis through treatment and beyond. Fact sheets, videos, publications and other on-line resources are available on supporting carers of women with breast cancer.

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'Gary'

I had just got home after interstate travel and she offered me a red wine. I didn't want one. She said, "I think you should." I took one look at her and said, "Please tell me you've had an affair". She said, "Promise me you won't go into control and fix it mode, because you can't fix what I'm about to tell you". I promised, and I was able to keep my promise. We hugged and stayed on the front balcony holding each other till 4 am. Only that one time has she ever said anything about dying, "Promise me you'll get on with your life". She just needed me to listen and to hear it.

I went to every appointment irrespective of what it was. She was happy for me to do whatever I needed to do. She was fearless, and it gave me unbelievable strength. As we are older parents of young children I said, "Let me try to look after the children". So I did the age-appropriate books and pictures –we had one child under five and another under one. Until then, the four year old was the most balanced kid in the world. After the age-appropriate materials, he wet the bed every day for six weeks.

Family were hopeless and unable or unwilling to be part of it. They were scared, ill-informed, switched off. Very few of my mates could even scratch the surface with any level of understanding about what we were going through. It's almost like they don't give a toss, they don't understand what to do and how to do it, so they almost avoid you. I felt isolated because my friends would do anything rather than listen, and that's what I needed.

Today, two and a half years after my wife's diagnosis, acquaintances direct men who are in this situation to me. I believe we really need a phone buddy service where the partner can talk to someone who's been there. Unlike me, a lot of men aren't talking to their partners. I've had three examples recently of men who've been shell-shocked and then just disintegrated. They won't even go to chemo with their wives, they won't acknowledge it's happening.

You are treading on glass a lot of the time and second guessing. But there is no right or wrong thing to do. She told me later, "I knew there would never be a time when I'd turn around and you wouldn't be there for me". I guess that means I mostly managed to do things right for her.

When you are dealing with the health system they say to your wife, "You go to this group and do that". They say to your kids, "Here you are, read this, talk to that person". And the only thing they have to say to you is, "Go your hardest, mate".

Twelve months ago we lost a friend to breast cancer. Today we are burying another one. My wife goes very quiet at times like this. But we're pretty damn positive.

Sometimes you're who you think you are, and sometimes you're the real thing. And I think it's only those who are the real thing that can come out of this solid.

FOR FURTHER INFORMATION CONTACT

National Breast Cancer Foundation
Level 9, 50 Pitt St Sydney NSW 2000
GPO Box 4126 Sydney NSW 2001
Ph: (02) 8089 4800
Email: info@nbcf.org.au

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Level 9, 50 Pitt St Sydney NSW 2000

GPO Box 4126 Sydney NSW 2001

ABN 37 144 841 707

www.nbcf.org.au