

bloom

ISSUE 20 MAY 2014

2015
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breaking
news
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Reach to Recovery International (RRI)

RRI is committed to improving the quality of life for women with breast cancer and their families.

Upcoming Events

Beijing CHINA

18th Reach to Recovery Breast Cancer Support Conference

16 – 19 September 2015

www.reachto_recovery_international.org



Lisbon PORTUGAL

16th World Congress of Psycho Oncology

20 - 24 October 2014

www.ipos-society.org.ipos2014

Tel Aviv ISRAEL

BY2 - 2nd Breast Cancer in Young Women Conference

06 - 07 November 2014

Texas UNITED STATES

8 San Antonio Breast Cancer Symposium

9 - 13 December 2014

www.sabcs.org

Melbourne AUSTRALIA

2014 World Cancer Congress

3 - 6 December 2014

www.worldcancercongress.org

Our mission

Reach to Recovery International is built on a simple yet universal principle: a woman who has lived through breast cancer and gives of her time and experience to help another woman confronting the same experience is a valuable source of support. Reach to Recovery International is committed to working to improve the quality of life for women with breast cancer and their families through a wide range of services offered worldwide.

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Bloom is published by Reach to Recovery International. Contributions to Bloom are welcome, please email info@reachtorecoveryinternational.org. For more information about RRI, go to www.reachtorecoveryinternational.org.



We respectfully acknowledge the Indigenous women of our global community, the traditional custodians of our environment.

Reach to Recovery International is a program of the Union for International Cancer Control and is administered by Cancer Council Queensland.



Message from Cathy Hirsch - President of RRI



Cathy Hirsch

It is with great pleasure that the Board of Management of Reach to Recovery International announces the location of the 18th Reach to Recovery International Breast Cancer Support Conference!

The conference will take place 16-19th September 2015 in Beijing, China. The conference organizer, the Chinese Cancer Rehabilitation Society, is partnering with several other organizations in China to create a comprehensive and exciting agenda, which will be preceded by pre-conference workshops and will end with a broad selection of cultural tours. You can find details regarding registration in this issue of *Bloom* and on the Reach to Recovery International website. Don't miss this opportunity to learn about the latest developments in breast cancer support while experiencing beautiful Beijing and the many wonders of China! I hope to see all of you in September 2015!

The theme for this issue is *Returning to work after breast cancer*.

Each of our lives is a unique and intricate tapestry of our many different roles and responsibilities. We are mothers, daughters, sisters, and wives. We may be athletes or artists, employers or employees. We may be the nurturers of our children, breadwinners for our families, and caregivers for sick or elderly family members or friends. For each of us, the tapestry of roles and responsibilities defines who we are and establishes our place in the world. With a breast cancer diagnosis, the tapestry unravels and, at least for while, we may lose our sense of self.

In this edition of *Bloom*, we examine the impact that breast cancer can have on one important part of many of our lives -- our work. Many of us wrestle with decisions regarding work once we receive a diagnosis and develop a treatment plan. Do we want to continue to work? Can we afford not to work? Will we be physically and mentally capable of working? If we need or want to stop working during treatment, will we be able to return to work later? How will our employers and co-workers react?

Despite the growing number of women in the workforce and increased awareness

about breast cancer, working during breast cancer treatment, or returning to work after treatment, remains a difficult, and sometimes insurmountable, challenge for many women. Cancer Societies, support organizations, and mental health professionals from around the world identify typical problems that may arise and share strategies for patients to resolve work-related issues. In addition, several of our contributors relate their personal work experiences after breast cancer. While many of these are success stories, others starkly illustrate that discrimination against cancer patients in the workplace remains a significant problem for which solutions must be found.

In other matters, RRI's Immediate-Past President, Ann Steyn, reports on the recent formation of a new Reach to Recovery Group in Swaziland. Also from South Africa, we receive a progress report on work being done by the Advocates for Breast Cancer (ABC) to facilitate the establishment of a standardized breast health policy there. The Norwegian Pink Ribbon Campaign generously offers to send a supply of pink ribbon pins, free of charge, to any breast cancer support organization working to raise awareness. From our Global Kitchen, the Patients Friends Society of Jerusalem reveals the secrets for making a perfect Semolina Cake.

Again, I hope to see all of you at the 18th Reach to Recovery International Breast Cancer Support Conference in Beijing. Please refer to information provided in this issue by CCRS and visit www.reachtorecoveryinternational.org for regular conference updates.



18th Reach to Recovery International Breast Cancer Support Conference
16 - 19 September 2015

Email your bloom submissions! Email your *bloom* submissions! The theme of the next edition will be *Reducing risk through lifestyle change and diet*. Submissions close 14 July 2014. Please send submissions in Microsoft Word format with any photos to info@reachtorecoveryinternational.org

Work-related issues still pose major challenges to breast cancer patients



“What am I going to do about work?”

That’s a question that every breast cancer patient who has a job or wants to get one faces at some point in the course of their treatment or survivorship. Information from the Cancer Support Community’s [Cancer Experience Registry](#) provides clear evidence that work-related issues pose a wide range of difficult challenges to women facing breast cancer.

“We’re finding that women have a host of concerns about what will happen to their jobs, or how they will be treated in their workplaces,” says Joanne Buzaglo, PhD, Vice President, Research and Training for the Cancer Support Community. “Many report that they have to give up their careers or stop working because of their disease or side effects of treatment. Others are concerned about the impact of their taking time off or not being able to put as many hours or as much effort into their jobs.”

Hester Hill Schnipper, LICSW, BCD, OSW-C, Chief of Oncology Social Work at Beth Israel Deaconess Medical Center in New York City and a two time breast cancer survivor, agrees that work-related issues remain a complex and often problematic area for women with breast cancer.

“There are so many circumstances that influence the work situation,” she says. “Where are you in the treatment process? What kind of job do you have? What kind of benefits? How supportive are your employer and your co-workers? What physical challenges does your job require? It is very hard to generalize because every woman is going to deal with a unique environment.”

Hill Schnipper notes that some women choose to try to continue working throughout their treatment while others take a leave of absence and then re-enter the work place. In both instances, the woman has to assess what she can handle, physically and emotionally and then align that with the demands of her job. Women who are in high paying, high pressure jobs may find themselves unable to keep pace for a period of months or even longer, while women in lower paying jobs usually are not paid if they don’t work, or lose their jobs if they take time off. Other jobs require strenuous physical activity or extensive travel.

There are also a growing number of women with advanced or metastatic breast cancer who are living with their disease. “These are



the forgotten people,” Hill Schnipper says. “Many of them are doing well, and decide to return to their jobs, or are even hired into new positions. I find that in addition to all the other issues these women are confronting, they often have to think about priorities. How do I want to spend my time? What options do I have? For some, that means continuing to work, but others choose to take a different perspective and move away from the workplace—if they have the financial resources. That’s very personal.”

Hill Schnipper says that neither the increasing number of women in the workforce nor increased awareness of breast cancer has made work life any easier for cancer patients. “If your boss has had a personal experience with cancer, he or she will be much more likely to be supportive, but other factors, such as age or gender, don’t seem to make much difference.”

For women who are returning to work after a leave of absence, Hill Schnipper recommends trying to begin with a part-time schedule. She also suggests doing a trial run— going in for coffee or lunch with your boss or colleagues. People often don’t know what to expect, how a person will look or feel or may be uncomfortable about interacting with them. The more social encounter helps clear those awkward moments out of the way. It is also a good idea to identify one or two good friends or contacts who can help you communicate with the larger group. It is also critical to have the conversations with your employer and boss upfront to establish work

schedules and make sure that everyone’s expectations are aligned.

“This is a tough area,” says Buzaglo. “It requires every woman to have the stamina and the resources to advocate for herself. I think there needs to be much more attention on this critical arena and more support for women who are dealing with the myriad of issues they confront in the workplace.”

The Cancer Support Community (CSC) is an international non-profit dedicated to providing support, education and hope to people affected by cancer. One of the largest employers of psychosocial oncology mental health professionals in the United States, CSC offers a menu of personalized services and education for all people affected by cancer. Its global network brings the highest quality cancer support to the millions of people touched by cancer. These support services are available through a network of professionally-led community-based centers, hospitals, community oncology practices and online, so that no one has to face cancer alone. The Cancer Experience Registry, a program of the Cancer Support Community, is an online initiative designed to learn and raise awareness about the social and emotional impact of cancer.

For more information, please visit www.cancersupportcommunity.org. To join the Cancer Experience Registry, please visit www.cancerexperienceregistry.org.

18th RRI Breast Cancer Support Conference to be held in Beijing, China! 16 - 19 September 2015



RRI President Cathy Hirsh with Chairperson Anli Shi and local organizers - "Together we are stronger!"



The Reach to Recovery International Board of Management is delighted to announce the location for the 18th Reach to Recovery International Breast Cancer Support Conference – Beijing, China!

Save the date and start making plans to attend this very special meeting. The conference will be held from 16-19th September 2015. It will be the first RRI conference to be held in mainland China, and only the second global breast cancer support conference to be held in Asia.

The prevalence of breast cancer in China has significantly increased in recent years and it is now considered the "leading killer" of modern women. With economic development and improvement in the standard of living, the incidence and impact of breast cancer in China is rising fast and is characterized by diagnosis at a younger age than in western countries. Currently there are more than two million breast cancer survivors in China.

The local conference organizer is the Chinese Cancer Rehabilitation Society (CCRS), a cancer survivor non-profit organization affiliated with the Chinese Anti-Cancer Association (CACA), in partnership with the Chinese Breast Cancer Society (CBCS) and TrendsHealth Magazine.

CCRS was founded in 1990. It has grown steadily and now has 93 organizations across China and about 300,000 registered members, of which nearly 70 per cent are breast cancer survivors. Every year, CCRS organizes numerous activities such as: "Health Lecture Halls" on Women's Day; free clinics, popular science articles and lectures on preventive medicine during Anti-Cancer Publicity Week in April; running events and artistic performances in spring and autumn; and visits to hospitals to help survivors build confidence that they can beat cancer.

All this has proven to be very beneficial in helping survivors resume normal lives as quickly as possible after rehabilitation.

CBCS constantly introduces new medical techniques, shares academic knowledge and technological developments, drafts diagnostic guidelines, emphasizes the training of young doctors, improves the quality of health care for cancer patients and establishes free clinics. Along with CCRS, it also publicizes scientific information and information about preventative medicine. These activities have enhanced doctor-patient relationships and improved the effects of treatment.

Since 2003, TrendsHealth Magazine has launched the "Pink Ribbon" campaign every year. Together with survivors and celebrities, TrendsHealth encourages Chinese women to take their breast health seriously. As a co-organizer of the conference, TrendsHealth will raise even more public awareness about breast cancer.

A site visit to Beijing was conducted earlier this month by RRI President Cathy Hirsch, RRI Past President Ranjit Kaur Pritam Singh, and Taiwan Breast Cancer Alliance Secretary General Gloria Lin. RRI representatives met with local organizers and toured the conference venue.

A press conference was held during the site visit, at which the conference organizers formally submitted their bid proposal to the RRI representatives. Numerous government officials were present to show their support, including Ms. Bin Wang, the Deputy Director General of the Bureau for Disease Prevention and Control of the

People's Republic of China's National Health and Family Planning Committee; Ms. Hui Xie, the Director of the Division of Chronic Disease of the Bureau of Disease Prevention and Control of Beijing's Health and Family Planning Committee; and Ms. Peng Yuan, Secretary General of CBCS.

Ms. Anli Shi, Chairman of CCRS announced the upcoming conference and the theme of the conference, which will be "Together we are stronger!" Ms. Shi said, "In the 18th RRI conference, we [will bring] together breast cancer survivors, health care and other professionals, family members, carers and volunteers, staff of NGOs, policy makers, media members and other interested individuals from around the world to share their experience and love." She added, "This conference will definitely arouse a great concern from society in the anti-breast cancer field, strengthen public's respect and courtesy for the breast cancer survivors, and set an important milestone for Chinese cancer rehabilitation career in moving to an international arena and all Chinese women would witness this grand international party."

Approximately 700 delegates are expected to attend the conference, including Chinese breast cancer survivors and survivors of many other nationalities, family members, policy makers, members of the RRI Board of Management, media members, breast cancers specialists and scholars from different countries, as well as members of cancer rehabilitation organizations from around the world.

Do not miss this opportunity to connect with breast cancer survivors from around the world in Beijing! We look forward to seeing you there! For more information, visit www.reachtorecoverinternational.org.

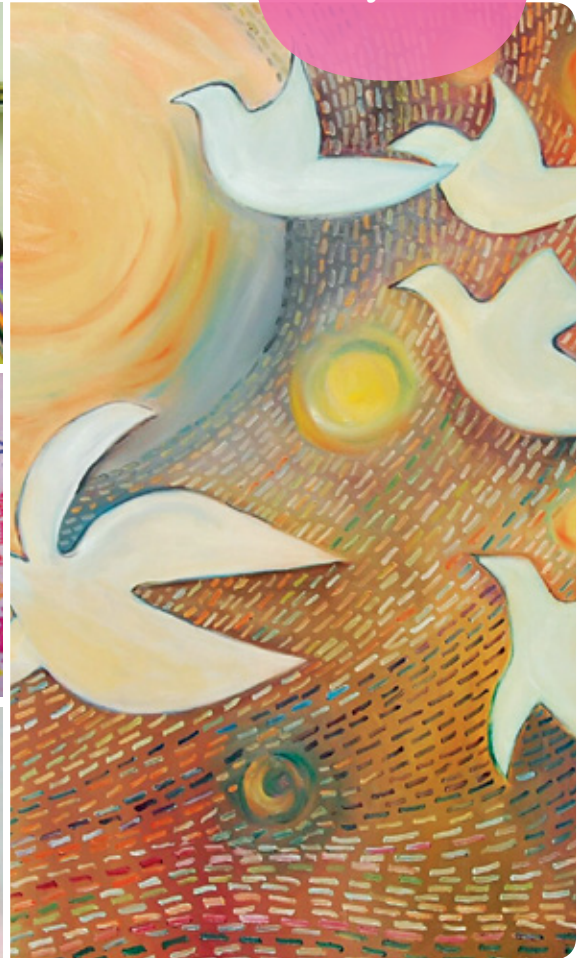
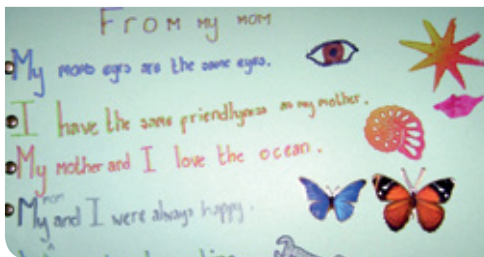
Back to university and work after breast cancer

By Hendriette Wilhelmina du Plessis, Republic of South Africa

a
personal
story



Hendriette
Wilhelmina du Plessis



In 2002, after being re-married for only six months and at the age of 57 years, I heard that I had grade III breast cancer. I had to choose between my life and a breast and chose life in totality.

I decided not to cry or be sad about it and decided to do what the doctors told me regarding treatment.

I immediately had a mastectomy during which the lymphatic glands under my right arm were removed as well. During my chemotherapy treatment, I decided to make the most of the rest of my life. My new husband supported me all the way.

I started off doing a *Foundation Course in Art Therapy* in Johannesburg, South Africa. I had no hair and was wearing a wig. I was still too weak (with the chemotherapy treatment still going on), to drive the 60km for the weekly sessions. Other students gave me a lift. I finished the Art Therapy course successfully.

In 2003, I started on my Master's Degree in Play Therapy (MSD Play Therapy) at the University of Pretoria in South Africa. I decided that the cancer would not prevent

me from being successful.

I decided to work very hard and do the degree in the shortest period permitted. I worked very hard, still wearing my wig for a while.

After two years I got my Master's degree and the graduation ceremony was in May 2006 when I was 61 years old.

I got a job at a welfare agency named FAMSA (Families, South Africa) as play therapist, where I worked with traumatised children up to my 67th year. I felt that I could change the lives of children who experienced hardships like parents committing suicide, shooting accidents in which people died, rapes, etc. The children responded very well and it also changed my life.

These years, both my studying after being diagnosed with cancer and the period of work afterwards, were the best years of my

life. I really felt fulfilled and felt that I grew so much in life and emotionally. I am 69 years old now.

I am retired now but I am still painting as a hobby and giving art classes and lectures. I have a website, www.artpower.co.za.

I can now say, "I always wanted to do it, and I did." It is 12 years on and tests show that I am clean. I am still very happily married. I am not going to stop living before my last breath. I thank cancer for changing my life and made it more purposeful.

Managing work during treatment and recovery

Decisions about how to manage paid work during treatment and recovery can add to the stress of breast cancer.

Dr Carrie Lethborg is the Clinical Leader, Cancer Social Work and Coordinator Psychosocial Cancer Research, at St Vincent's Hospital, Melbourne. Robyn Batson is the Group People & Development Manager at the Sussan Group.

In this article, Carrie and Robyn discuss work-related issues for women affected by breast cancer.

What do women need to consider when making decisions about work?

Carrie: From an emotional wellbeing point of view, it is important to acknowledge the trauma involved with a breast cancer diagnosis. For most women, it is an experience that shakes us up. We need to be gentle with ourselves during and after such a trauma.

If you need to keep working, be aware that you may feel more anxious, tired, forgetful and sensitive to others' comments, and more easily overwhelmed by work, than you did previously.

Some women find that work helps them to keep a sense of control in their lives; for others it is the last thing they feel like doing. Of course, there are times when it is not possible to work because of appointments and side effects of treatment, including fatigue.

What should women tell their employer when they are diagnosed with breast cancer?

Robyn: It may be difficult in the early days to know exactly what sort of flexibility and support you will need. Be upfront about this with your employer, and keep them in the loop.

Sometimes you may need to take unplanned leave. Keep in mind that your employer may also need some time to figure out how to balance your personal needs with the needs of the workplace.

Your employer may not have any experience with breast cancer, so you might be on this journey together. On the other hand, your employer may have worked with women with breast cancer in the past. Your own

needs might be different from those your employer has previously encountered, so it's important to let them know what you need from your own perspective.

What are some strategies for women returning to work following treatment?

Carrie: Talk through your fears or concerns with someone else before returning to work. Consider how you will respond to comments and questions such as 'How are you now?'; 'You look great!'; 'Is the cancer all gone?'; 'We've been really busy without you'.

It is also important to pace yourself, even if you feel pressure from others to 'get back to normal' in terms of what you could manage before your treatment. Energy, concentration and confidence come back in time, but pushing yourself beyond your capacity will only increase anxiety and reduce self-confidence.

What should women do if they encounter difficulties at work?

Robyn: Be open and honest with your manager about what you are and aren't coping with. Think about the type of support you need from your workplace, and what might help. Ask for temporary changes and be realistic about what you are able to commit to within the workplace.

If you manage a woman who is having difficulties, try to approach the job in a different way. Have regular discussions with her about her workload and be willing to negotiate changes and reallocate resources if needed.

Where can women go for help?

Carrie: Cancer social workers, psychologists and breast care nurses, as well as family, friends and other women who have been through similar experiences, are helpful to talk through your feelings about your breast cancer experience and direction for the future.



Breast Cancer Network Australia recently published articles on managing work during treatment and recovery in its free quarterly magazine, The Beacon. The following extracts are reprinted with permission from BCNA.

Overcoming life's challenges

Written by Olga Budnyk, Translated by Tatiana Karimova

Charming smile, mischievous eyes, sparkling wit, overflowing with ideas and an inexhaustible energy apparent in every look and movement. A few minutes after meeting, I feel as if I've always known her. It's impossible to believe she is ill, or even feeling badly.

There are people who are denied the usual amount of time but don't let that deter them from striving for and reaching their goals – people who are not afraid of any difficulties and devote every minute they have to their callings. Larisa Yachchenko, President of Ukraine Donna, is one such person.

Larisa Yashchenko was born in April 1941, during the Second World War, which she miraculously survived. As a baby, she traveled all over the country by train. Childhood was challenging - her father died at the front line of the war and her mother passed shortly thereafter, leaving Lyalya (Larisa's childhood nickname) and her three sisters in the care of their grandmother. "It was awful, even today, [I] cannot stand to think about those times," says Larissa. "Cold, hunger, insecurity and labor - that's what I remember from childhood." Larisa left school at age 13 to work in a factory, pretending to be older than she was so she would be permitted to work. She pursued her education in the evenings, then entered the evening department of the Kiev Technological Institute of Food Industry, eventually becoming an engineer-economist.

With the restoration of the country after the war, life for Larisa began to improve. She found a job she enjoyed in the Ministry of the Food Industry, met and married her husband, and raised a son. Then, in 1994, the floor dropped out. Larisa was diagnosed with breast cancer and underwent a radical mastectomy. Two weeks later, during a post-surgical procedure, a nurse pierced one of Larisa's arteries and a second surgery was required to repair the damage. Finally, she was released from the hospital. In Larisa's words, "actually, I was sent home to die." Her husband was warned that she would not last a month.

Always a fighter, Larisa surprised everyone by not surrendering to the disease. She survived, but her recovery was not easy and she was brought face-to-face with conditions that many breast cancer patients in Ukraine experienced at the time: a lack of financial, social, or psychological support, and a medical community that equated cancer with complications of the flu.

Those experiences led Larisa, in 1997, to form Ukraine Donna, a social organization

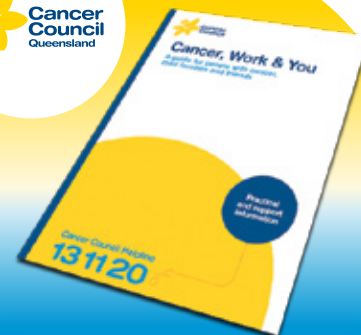
for female breast cancer patients and survivors. The first branch of the organization was operated out of Larisa's home in Kiev. Under Larisa's guidance, the organization grew quickly. There are now 32 branches throughout Ukraine which serve more than 145,000 women. Ukraine Donna's motto is "SUPPORT, HELP, EXPLAIN." Thanks to the organization, breast cancer is now a topic addressed at the highest levels of government. Ukraine Donna conducts trainings, seminars, and conferences, all free of charge, and provides instruction and a forum for monthly breast self-examinations. It also distributes literature on dealing with breast cancer.

The difficulties that Ukraine is currently experiencing translate to problems for Ukraine Donna which, as a charitable organization, is always in need of donations. Larisa remains optimistic and says, "even [though we are] unable to pay utility bills, phone [bills], [for our] website and [for] other essential expenses... we will break ahead[.] [T]he thicker the haze, the lighter the morning. The world is not without good people."

Larisa Yashchenko has more than 10 high state awards, as well as diplomas and many different titles. She is well-known in Ukraine now. "When they say that I made this feat by creating Donna, penniless and without support, I do not agree. This is not a feat; it is my choice to protect those who need support. I think the Lord gave me a chance to live, to help people, to enjoy every new day," Larisa says. She adds that Ukraine Donna still has a lot of work to do. "In Ukraine, there is no law that would protect cancer patients. There is no state rehabilitation program, financial or psychological support for women who have had breast cancer. Preventive measures are also at a very low level. As President of the public organization UKRAINE DONNA, I'm happy that I can support women and bring warmth and heat to their families. Tears of gratitude and joy for a returning to life give me the strength and fill in the content of my life."

Ukrainian civic organization for women with disabilities - "Donna Ukraine"
www.donna.ua/en/home

a personal story



Cancer, Work & You is a practical resource for employees and self-employed people with cancer, and working carers.

It contains information about how cancer can affect your ability to work, tips about working during treatment and recovery, and information about your rights and entitlements. The Key Questions section answers common questions such as should I tell my employer? Should I tell my colleagues? And what should I tell my employer?

The booklet is a useful tool for starting a conversation with your employer about adjusting your duties, work space and hours so you can continue to work during or after treatment. If the cancer diagnosis has made you reconsider your work values and goals, the booklet includes information about finding a new job and dealing with any discrimination you may experience.

If you are working and looking after a family member or friend, the carers section includes information about balancing employment and caring duties.

[Click to download the booklet!](#)

Cancer and work: Factors associated with positive and negative outcomes for return to work



Prof. Dr. Karima Elshamy, DNSc,
Head of Critical Care and Emergency Nursing Department
Faculty of Nursing, Mansoura University, Egypt
AORTIC Vice President of North Africa

Introduction

Cancer is a complex array of illnesses that can bring a potentially overwhelming spectrum of physical, psychological, social, emotional, functional and economic challenges¹. Over the past 20 years, psychosocial oncology programming, services and research have greatly expanded in recognition of these hardships². While it is agreed upon that vocation and employment are distinct and fundamental components of psychosocial wellbeing, the work-related needs of cancer survivors have been insufficiently addressed in the continuum of cancer care³. The advance of successful medical treatment for many of the over 200 types of cancers has resulted in a dramatic increase in both the life span and quality of life of people with cancer. At the same time, the incidence of cancer continues to grow due to early detection. Thus there is a growing population living with cancers who have distinct psychosocial and vocational needs.

Factors associated with positive outcomes for return to work

Work-related factors

Work accommodations stood out among the most influential components of a successful return to work (RTW) experience from the point of view of cancer survivors⁴. Effective accommodations included employer flexibility regarding both work hours and duties; identified support at work; and positive attitude of co-workers. Public sector and larger organizations offered greater assistance in accommodations such as paid time for medical appointments and reduction in hours, resulting in better RTW outcomes⁵. Employees interviewed three years post diagnosis reported that having some discretion regarding work hours and duties facilitated a successful RTW experience⁶. These individuals described their relationships with their employers and/or managers to be supportive and respectful of their changing needs post diagnosis.

It was reported that a good social climate and support at work fostered high commitment and work engagement on the part of employees with cancer. Also, workplace accommodations, such as reducing number of work hours and reducing physical task demands after RTW⁷.

Individual characteristics

Most studies included good social support as a salient factor in successful RTW⁸⁻⁴. Younger men treated for prostate cancer who were better educated and had more prestigious jobs had an easier time returning and readjusting to work⁹, and that higher educational levels, and a high level of commitment to work facilitated the RTW experience¹⁰.

Cancer / Health factors

Numerous cancer-related factors influence the RTW experience. Breast cancer, prostate cancer and testicular cancer are associated with somewhat easier and more positive RTW experiences⁹. Differences in the treatment and severity of disease in these types of cancer also mediate as predictors for RTW outcomes. People who returned to work a longer time after treatment fared better, which depends on the type of cancer and treatment⁴. The need for health insurance was also identified as a strong motivator to RTW¹¹.

Factors associated with negative outcomes for RTW

Work-related factors

Work demands can greatly influence the RTW experience of a cancer survivor. For jobs where heavy lifting and greater physical demands are required, cancer survivors may no longer be able to perform these tasks to the same degree they could pre-diagnosis¹². Physical tasks such as lifting heavy loads and stooping, kneeling or crouching as limitations in their post-cancer employment experience. Cognitive tasks that presented as limiting included: keeping pace with other workers; concentration; data analysis; and ability or pressure to learn new skills or knowledge⁸.

Employees who feel supported and accommodated in the work place fare better overall. Non-supportive work environments are consistently correlated with poor RTW experiences¹³. Survivors' fears regarding negative reactions from co-workers to their return to work may have some foundation. On the other hand, people feel relatively well supported in the workplace post diagnosis⁴.

Individual factors

There are several individual factors negatively associated with RTW for cancer survivors. These include higher age, less education, multiple co morbidities, blue-collar jobs and

lower income¹⁴. A change in attitude to work, i.e. decreased aspirations and increasing age were associated with poor RTW outcomes⁴. Psychological issues like depression and anxiety are, however, highly correlated with problems in employment during or after cancer¹²⁻¹³. It is difficult to separate some of the individual characteristics from cancer-related factors, as the research does not indicate whether these issues predated the diagnosis.

Cancer / Health factors

Some of the most significant impediments to successful RTW for cancer survivors involve disease, treatment, as well as side effects and long-term effects of cancer and its treatment¹⁵⁻¹². Advanced disease stage, disabling cancer and/or treatment, depression, fatigue, and cognitive impairment present as major barriers in the first year post diagnosis but may decrease thereafter. Issues that arise after RTW include greater number of sick days, decreased ability to perform job duties, and lack of energy.

Other factors include psychosocial symptoms such as anxiety, depression, and feeling useless¹². Some of these problems have been linked to a lack of communication with doctors regarding RTW needs including vague medical advice regarding time to RTW⁶. Sometimes these issues are associated with a reduction in hours or change in job due to a premature or unrealistic RTW for an individual struggling with fatigue and /or nausea¹⁶.

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RRI Volunteer Training in Swaziland



For several years now, volunteers from Swaziland wishing to undertake the Reach to Recovery training have had to travel to South Africa to be trained. Since 2012, Lena Preko, the Project Manager of the Swaziland Breast and Cervical Cancer Network (SBCCN), has been anxious to establish a Reach to Recovery group within the SBCCN and, to this end, has been requesting that RFR South Africa conduct training in Mbabane. Her patience was finally rewarded in February this year when Stephné Jacobs was able to present a three-day training workshop for 12 prospective volunteers.

The aims of the workshop were to provide the necessary knowledge and skills for a peer-support service and to create a greater awareness and understanding of relevant breast cancer issues. The South African Training Manual was used, with the topics following closely the guidelines of the RRI training programme. Siswati translators were available and the participants thoroughly enjoyed the workshop, finding it informative and useful. They particularly liked the practical hands-on sessions. As in all Reach to Recovery training workshops, they wished for it to be longer!

The future of the newly formed group looks bright. With the backing of the SBCCN, they have formed a peer-support group, elected a steering committee and planned for a follow up meeting. Referrals of patients come through the bi-weekly breast clinics where the peer-support volunteers are considered a part of the medical team. Their role is to provide the emotional and practical support that the women need. They have the same challenges to meet as do many groups: limited financial capacity, how to provide appropriate culturally sensitive information and also information

for women with little formal education. In a country where there are no chemotherapy or radiotherapy services and only one mammography unit (which is in the private sector), there is a challenge to advocate for better breast cancer service. There is a national fund to cover treatment not available in the country. However, there is often no satisfactory outcome to the application for benefits. Patients often then have to wait long periods to obtain approval for treatment in South Africa

The Swaziland Breast and Cervical Cancer Network (SBCCN) welcomes their newly formed breast cancer support group and hopes its volunteers will assist many women as they struggle to come to terms with a breast cancer diagnosis and the treatment that follows.

In recognition of the completion of this important peer support training, the Swaziland Breast and Cervical Cancer Network has been granted full RRI membership.



Working during breast cancer diagnosis and treatment - pleasure, burden, necessity?



Sara Vieweg Rosen, M.D. is a psychiatrist who sees patients diagnosed with breast cancer at the Greater Baltimore Medical Center Breast Center in Baltimore, Maryland.

Breast cancer diagnosis and treatment is often a challenging time. During this time, work can be experienced as pleasure, necessity and/or a burden. Some women feel that work provides them with pleasure during a time of great difficulty. The consistency of routines, distraction from thoughts of breast cancer, control and competency at work can provide great support during a time of little consistency and control over medical matters. Others feel burdened by work and feel it adds too much stress during an already stressful time. Many women do not have a choice about work; their financial situation requires them to work during this time. Most women feel many different ways about work. Factors such as job security, flexible hours, supportive co-workers and management, disability insurance, medical insurance, and potential income lost during this time play a large role for most women in determining their best plan for work throughout treatment.

If you have been diagnosed with breast cancer, you will need to consider if or when you will tell people at work about your diagnosis. Most women I see tell people at work about their diagnosis and treatment. However, you may want to keep your diagnosis or details of your treatment confidential and you will have to decide how to do that based on what treatments you are having. You may be able to tell people that you are having a “medical procedure” and feel more comfortable with that level of information. There is no right way to deal with having breast cancer and there is no right way to work and/or return to work during this time. However someone decides to work during and/or after intensive

treatment for breast cancer, here are some ideas about treatment and returning to work.

1. Be honest with yourself and others.

Tell your boss that you are not coming back at full speed. Be honest about what you can expect of yourself. If you can talk with someone who has undergone similar treatment, ask them about how they felt a month, six months, a year out of treatment. Incorporate this into your own expectations.

2. Ask for help.

Women are often helpers and becoming the person who asks for help can be difficult. With intensive treatment, you will need help managing medical procedures, family obligations and work, whether it is asking someone to drive you to treatment, setting up a sign-up list for meals for you and/or your family, getting care for a child, or delaying a deadline at work. Remember that people enjoy helping, they just don't often know what to do. Consider how much pleasure you gain when you help someone in your circle and show others how to do the same for you.

3. Think about what you want to say when people ask about what you are going through.

Some women find it helpful to discuss the details of their medical experience; others find it very upsetting to share these details openly. Co-workers, acquaintances, and family members will likely ask at some point about what you are going through. They do not know what you feel comfortable discussing or not discussing. Think about what you are comfortable sharing with

whom, and think about how to tell them. Write down what you want to say to certain people that you think may be difficult to tell. Remind yourself that it is okay to say, “no thank you” and “I would like to answer your question, but, I find that talking about these things at work (or the grocery store or on the phone...) makes my day feel longer and I need all the energy I have to get through this. Thank you for asking. I will let you know when I am more able to tell you about it”. Consider that there are some people you will want to talk with a lot and others you will not. Pay attention to how you feel and be respectful of your own needs.

4. Become comfortable saying no when you don't want to add a responsibility to your list.

Often, people think that when you are done with intensive treatment you are “better” and ready to get back to the way you were before diagnosis. Many women find the end of treatment difficult. They worry about not being seen as often and, with more time on their hands, may begin to worry when before they focused on what needed to be done. Some women have side effects from medications. Many women take more time than they expect to recover and compare themselves to others who they perceive to have gone through diagnosis and treatment with no problems. It takes time to return to an energy level that feels compatible to the work you previously did. And you may make different choices post treatment as you may have gleaned what and who is most essential in your life during treatment.

5. Make time for sleep, healthy activity, nutrition, faith and supportive relationships.

You need to replenish yourself and you will need to prioritize and make time for the people and activities in your life that nourish you.

6. Think about how you will handle days when things do not go as planned.

Consider whom you will call on when you have a bad day, have an adverse reaction to a new treatment or medication, or just do not have the energy to do everything that is expected of you. Think through your options and go over that idea with the people that you think can be the most helpful. This will allow you to better focus on caring for yourself.

A new vision and meaning of work when faced with life's greatest challenge - breast cancer

By Shirley Stitt, M.S., L.C.P.C., Baltimore, Maryland

Image Credit: Robert S. Donovan <https://www.flickr.com/photos/booleansplit/>

We are defined by gender, race, religion, marital status, political affiliation, geography, and careers. Before receiving a diagnosis of breast cancer, one of life's daily activities included working. Working provides a sense of meaning and purpose; however, the work environment can be challenging even if you're doing something you love.

The work environment is hectic, fast paced, demanding, overwhelming when managing crises, and difficult when dealing with other people's attitudes and personalities. Long days and hours are spent at work, with many missed meals, and lots of stress.

Even as we await the results of tests, undergo surgery, treatment and aftercare, a constant thought we have is what about work? The decision to work is a personal choice, however maintaining work gives us a sense of normalcy, routine, and, of course, it's the paycheck we receive that is extremely important. The earned income helps to maintain households, fulfill financial obligations and lifestyles. We can't wait to get back to work!

As a survivor, I certainly understand the relationship between self and work. When I was not working, I didn't feel productive, wasn't contributing to anything, so who was I? I concluded that I was still the same

person, however, I needed to reframe the way I defined work. During the many tests, surgery, visits to the doctors, and treatment, my work was wellness and wholeness. I was working to ensure I was able to experience life, see children and grandchildren grow up, and make meaningful contributions to society. So if you consider this perspective, we never stop working.

Returning to the daily workplace environment is filled with anticipation and hesitation, for we walk right back to an environment that might leave us drained at the end of the day, dealing with issues of body image, self-esteem, and old habits. You will hear stories from well meaning co-workers about other people they know who have dealt with cancer and even died. And of course you wonder what will happen to you.

helpful tips

Consider the following suggestions for when returning to work:

1. **Talk with your employer before you return to discuss shorter work hours, limited days and reassignment of duties.**
2. **Expect to feel drained even though you may not have exerted yourself physically.**
3. **Take breaks as necessary.**
4. **Avoid persons who are ill. Remember, your immune system is still weak.**
5. **Set aside time for exercising, yoga, meditation or quiet reflection.**

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Returning to Work After Cancer Treatment

If you can go back to work shortly after your treatment, you might find that it helps you maintain your sense of who you are and how you fit in. It might help even boost your self-esteem – not to mention your income. Your job may remind you that you have a life apart from cancer – you are a valued employee, a great boss, or a trusted co-worker. You'll also have regular contact with others when you go back to work. Sometimes cancer can make you feel very isolated and lonely, and being around people can be a great comfort.

As you make plans, you may want to talk with your employer about possible options, like flex-time, job sharing, or working from home (telecommuting). Options like these may help ease your mind and body back into the demands of your job.

For some people the transition to working full-time is easy, but for others it takes some adjustment. You may find that you tire easily or have trouble focusing at first. Try to be patient and take care of yourself as you go back to your "normal" life.



Telling co-workers

How open you are with your co-workers about your cancer and health after cancer treatment is a personal decision. In some workplaces, it may not benefit you to share details. For instance, it may not be a good idea to share everything with your colleagues if you work in a highly competitive and fast-paced work environment. You might want to decide who you know best and who will most likely understand your situation, then confide only in those few people. They might be able to help you develop the best plan for telling others and give you ideas on how to transition back to work. Try not to feel pressured to share or explain things. Only you can decide what works best for you and your situation.

You will likely find that your co-workers have many different reactions to you when you go back to work. Those who know what you've been going through may react to your cancer diagnosis and absences with understanding and offers to help. Others may feel uncomfortable around you. Some people may be reminded of a loved one's time with cancer. Many find cancer an unpleasant reminder of their own mortality. They may react awkwardly out of a vague fear or uneasiness, thinking of cancer as some kind of lurking, unknown danger. Some co-workers may resent that they had to take on extra duties because of your absence. Others may ask intrusive questions about your health or why you've been gone. Some might even avoid you.

It helps to think ahead about how you will handle the reactions of other people, and have a plan for what and how much you want to share. It might help you to read our document, [Talking With Friends and Relatives About Your Cancer](#).

Legal protections

You have the same rights as anyone else in the workplace and should be given equal opportunities, regardless of whether you tell people at work about your cancer. Hiring, promotion, and how you are treated in the workplace should depend entirely on your abilities and qualifications. As long as you are able to fulfill your job duties, you can't legally be fired for being sick. You also shouldn't have to accept a position you never would have considered before your illness. Many people with job problems related to cancer are protected by federal laws like the [Rehabilitation Act](#) and the [Americans with Disabilities Act \(ADA\)](#).

Some people also benefit from the [Family and Medical Leave Act \(FMLA\)](#). This law lets many people with serious illnesses take unpaid leave to get medical care or manage their symptoms. This leave can take many forms, such as a part-time schedule for a limited time, or taking off 1 or 2 days a week for a while. This may not be available to you if you have already taken 12 weeks off, or if your company does not have to follow FMLA. Talk to someone in your human resources department or another workplace expert to find out what your options are.

For some people, it may take a time of adjustment and some extra help to get back to their regular work schedule. If you try to go back to a full-time schedule before you're ready, your work may suffer. Talk with your doctor about the kind of work you do and any problems you are having as you decide how to re-enter the workforce. You may need to start with shorter workdays or work fewer days a week until you see how things go. You may find that the way you work has changed, or you need something more to help you do your job.

Reasonable accommodations at work

Employers are not required to lower standards to accommodate an employee, nor must they provide personal-use items like glasses or hearing aids. But an employer must accommodate a qualified applicant or employee with a disability unless the employer can show it would be an undue hardship to do so. Examples of reasonable accommodations include, but are not limited to:

- Providing or modifying equipment or devices
- Restructuring a job
- Offering part-time or modified work schedules
- Reassigning an employee to a vacant position
- Adjusting or modifying tests, training materials, or policies
- Providing readers and/or interpreters
- Making the workplace readily accessible to and usable by people with disabilities

A vocational rehabilitation counselor can help with some of your job-related legal questions, but you may also want to look into laws that affect you and how you deal with any problems that may come up. Some cancer treatment centers offer referrals to vocational rehab counselors, so ask your cancer team's doctor, nurse, or social worker.

To find out more about job accommodations and employment of people with limitations, contact the Job Accommodation Network at 1-800-526-7234 or visit their website, <http://askjan.org>. They can talk with you about the requirements of the ADA or the Rehabilitation Act, whichever applies to your case.

Worries about discrimination

Even though the public's understanding of cancer is getting better, sometimes prejudices and fears are still found in the workplace. Even after your cancer treatment has ended, you may face work and workplace discrimination issues. If your workplace has a union, its officials can be good sources of information about illnesses and the workplace.

Keep notes and records of your contacts with office personnel, including the names of the people with whom you spoke about your illness, the date and place you spoke, and the information you received. It's also a good idea to keep copies of your job performance evaluations and any other written information about your work. These can be very helpful if problems come up later.

If you want to file a discrimination complaint

If you think you have been discriminated against at work on the basis of disability, you can file a complaint with the United States Equal Employment Opportunity Commission (EEOC). You must do this within 180 days of the time you think the discrimination occurred (although some states or local laws allow you to take up to 300 days).

For more specific information about ADA requirements affecting employment, contact the EEOC at 1-800-669-4000 or 1-800-669-6820 (TTY). For general ADA information, answers to specific questions, free ADA materials, or information about filing a complaint, call the ADA Technical Assistance line at 1-800-514-0301 or 1-800-514-0383 (TTY).

Get more help and information

If you would like to read more about asking for help as you go back to work, get our document Americans With Disabilities Act: Information for People Facing Cancer by calling our toll-free number, or read it on our website. If you need extra time off as you go back to work, you may also want to ask for our document Family and Medical Leave Act (FMLA). These documents explain more about federal laws that can help many people with medical problems.

If you collected Social Security disability benefits during cancer treatment and recovery, you might want to try Social Security's Ticket to Work Program. This free program offers support as you try to go back to work, and allows you to continue to receive disability benefits for a trial period while working. You can learn more online at <http://choosework.net/about/index.html>, or call 1-866-968-7842.

Along with the federal laws, some states also have laws about employing people with various illnesses, including cancer. These state laws may help you in other ways. You can find out more from your state's Department of Labor. Contact information is in the blue pages of your local phone book, or visit the US Department of Labor website at www.dol.gov/whd/contacts/state_of.htm to find your state.

For more information, call the American Cancer Society's our toll free number, 1-800-227-2345, or visit www.cancer.org

Visit the American Cancer Society website for other related information related to cancer, including Working during cancer treatment.



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Kamala's Choice – Returning to work after breast cancer

By Rama Sivaram, Breast Cancer Advocate, Health Educator and Counsellor, HEAL Consultancy and Breast Friends, Pune, India

“Everything is over Madam. Me kaay karu shaat naahi (I can't do anything). me dharti var bhoj padli (I am a burden on this earth). I have no job, no income, no support, no education. All I have is a swollen arm that does not move properly, physical and emotional pain and a sense of worthlessness.”

This is the scenario of the poorer women in India who have gone through breast cancer and have developed lymphedema. Hard physical labour such as carrying water, bricks and sand in construction and farm sites, tailoring, sweeping and mopping, making rotis and papads (Indian bread and flat crisps) by the hundreds, is necessary for survival.

Kamala is 31, poor and uneducated. She worked as a domestic help in a rural household and in the little spare time she had, she sewed on a hand machine to eke out a living. After work one day, Kamala sat down at her sewing machine and felt pain and heaviness under her right arm. She ignored it and was aghast to eventually receive a late diagnosis of breast cancer. As a poor, childless, uninsured woman working in the unorganized sector, her husband and his family abandoned her. Her world collapsed. People believed Kamala was divorced due to her infertility. Kamala went to live with her mother and was lucky enough to fit into a clinical trial. She continued to work carrying pots of water on her head, sweeping and washing the cow shed, lifting earth, sand and fodder for the animals. Her employers were kind enough to take her back after her mastectomy. Carrying the burden of poverty, divorce and the double stigma of sterility and breast cancer, she was grateful for any kind of job and acceptance.

With treatment complete, Kamala was given her discharge summary with do's and don'ts and a follow up appointment. She was briefly counseled on self-care, exercises, diet and rest. She was relieved to return to work, however survival anxiety soon surpassed healthy survivorship. Although her employers took her back, she quit within a year due to her inability to perform heavy tasks. She came to us with pain, lymphedema, no job and fear of recurrence.

What could we do for Kamala?

We addressed her immediate problem by **treating** the lymphedema flare up. Her pain and infection were treated. When she

was more comfortable, **we listened** to her 'life story'. Using an eclectic counseling technique, **we facilitated** various ways of looking at things - thought processes and possibilities to deal with her circumstances. At a moment we thought right **we educated** her on the irreversibility of lymphedema and its management. We firmly pointed out the job she was in bad for her lymphedema. **We posited** the flare up episode was a good indicator. **We helped explore options** of what she could do to work.

What options does Kamala have? What she did for herself

With her background Kamala was vulnerable on all fronts - survival, self-worth and self-esteem. She needed a job where she would be useful as well as be kind to her arm. Her options were limited. We could only show the way to Kamala, she had to do her homework and find a job within her capacity. Today, a new Kamala has returned to work after her treatment, knowing her circumstance and her realities. She buys and plucks flowers for the temple and from the temple garden. She weaves garlands for the Gods and is responsible for their disposal. She makes small sachets of traditional turmeric, vermilion and Prasad - offerings. She undertakes making garlands for devotees as offerings or for auspicious occasions. Her clientele is growing. Kamala also makes and sells thecha - chilly preserve - as an additional source of income.

Kamala's quality of life is now adequate. Her income is not much, but the good will has grown and she is a small entrepreneur in her own right. Because of occasional lymphedema flare ups she gets upset, but not depressed. She wants to learn massage therapy - lymphatic manual drainage - and help us out, but she doesn't want to learn or teach bandaging, which she finds too hot and cumbersome for the Indian climate. Kamala is collecting money to buy an electric sewing machine with an electric foot pedal and hopes to sew drain bags, underarm pillows, scarves, and add bra pockets to bras and make paddings for her kind of survivors. There is HOPE in Kamala's eyes.



case study

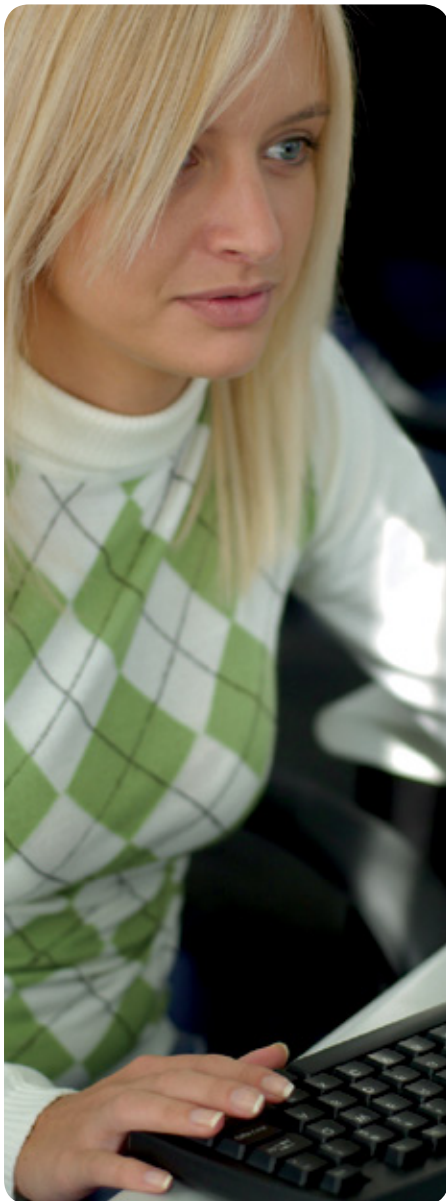


End word: The primary aim of patients, caregivers and health professionals is treatment and cure. However, it is also important to expand patient education and counseling beyond routine information on chemo side-effects, surgical procedures, costs and clinical trials. We need to explore personality type, psycho-social impact, personal circumstances, rehabilitation and occupational aspects and then make an assessment that includes the inevitable ups and downs in a woman's life. The timing to address these issues is critical and must be decided by counselors and educators based on the receptivity status of the woman. Follow up care needs to include mental health and rehab issues keeping in mind behavioral therapies or remedial measures. The adage "forewarned is forearmed" is useful here to deal with potential problems. Part of follow up care requires we give nutrition, physical therapy and grooming education to suit the new normal.

Kamala made a choice. This is the most important outcome of follow up and counseling care. Even with the best of services, we remember the idiom, "you can lead a horse to the water but you can't make it drink." Since Kamala had no insurance, no job in an organized sector, no support, and no education, we did not merely use positive mantras but emphasized positive, action- finding solutions. The instinct and will to survive against odds made Kamala a good learner, able to assess her own capacity and take positive action. She chose to return to work on her own terms.

Getting back to work after cancer

Rebecca V. Nellis, MPP,
Vice President, Programs
and Strategy, Cancer
and Careers



When looking to return to work after a cancer diagnosis or treatment, the first thing to ask yourself is, are you really ready to go back? You'll want to think about physical issues like fatigue or concentration challenges that may be ongoing, your social and emotional needs, and of course, the practical and financial challenges. For example, if you are still in active treatment, do you have a sense of how much longer that will be and how you will balance that with work?

If you are going back to your former job, you should think carefully about if you can integrate flexibility in both tasks and time before approaching your company and asking for it. As with anything when talking to your employer, you should remain proactive and calm, and make sure you're presenting what's needed in a way that will resonate with your employer. It is also important to think about how any ongoing side effects from treatment may impact your return to work, and what strategies you might use to make being back at work easier as a result. For instance, make your work space and schedule as comfortable as possible. Maybe you need a special chair or back rest, access to a printer at your desk, or additional break times.

Being back at work can be overwhelming; going back to the basics can help you manage everything. Some tips include:

- Keep one notebook with all your lists and notes in it so you always know you have it with you.
- Be sure to write everything down so if you're worried that you're having memory issues or concentration problems, it is all there.
- Do one task at a time and prioritize. This way you are breaking things off into smaller, more manageable pieces and you are actually able to get some things done.

One of the biggest concerns that we hear at Cancer and Careers is the fear that when you go back to your old job, you will always be seen as the "cancer person" in the office. This may come out via well-meaning but not helpful comments. It is useful to think about how you will constructively refocus the conversation back to work. We refer to this technique as "the swivel." You can use the swivel to address a comment like, "my uncle had cancer, too," by saying something

that is validating like "thank you for sharing that, I'm sure it must have been challenging" and then swivel away from the cancer topic by bringing in something work-related. For instance "thank you for sharing that, it must have been challenging. Do you have time this week to sit down and talk about our upcoming meeting?" By focusing on work you will help your colleagues see you how you want to be seen.

One of the upsides for those of you who find a new job with a new employer is that you are getting a fresh start. There is no pre-existing idea of who you are or what you should be like and certainly no knowledge of your cancer unless you choose to make it part of your story. What makes a new job hard during or after treatment is that you don't know any of the basics about that place or the way it works. You're going to have to utilize some energy to understand the culture and the expectations of this new environment, and then figure out how you can realistically meet them.

For more information on working during or after cancer treatment, please visit the Cancer and Careers website, www.cancerandcareers.org where you will find articles, interactive tools, videos and more!

Discrimination and stigmatization in the workplace



Kiconco-Turyamurbe Cecilia

a personal story

By Kiconco-Turyamurbe Cecilia

My name is Kiconco-Turyamurbe Cecilia and I am known as Antiguddu. I am 55 years old and am married with two children. By profession, I am a secretary with 33 years of experience. In 2003, I was diagnosed with breast cancer.

At the time of my breast cancer diagnosis, I was serving as a personal assistant in a government institution, where I had worked for 17 years. I had joined the organization as a secretary on merit, after comprehensive interviews. After serving for 10 years as a secretary, management had promoted me to the post of personal assistant, which I held until I was terminated.

When I was told that I had cancer, it was like receiving a death certificate because my relatives, my colleagues and I were so shocked and fearful. Arrangements were quickly made and I received treatment from the government hospital. After treatment I reported to the office, but I was confused when I noticed that my colleagues were trying to avoid me when, in fact, I expected to be embraced!

I was out of the office for a period of two months while receiving treatment (surgery and radiotherapy). After two months I could not wear a bra as the scar was too fresh, but I was strong enough to do my routine work. Three days after returning to work, I was served with a letter redeploying me to the pool office. I questioned my immediate supervisor about the demotion but was told only that it was "management's decision," and that I should take it up with the human resources manager, not him.

By this time, I noticed that friends at the office were actually shying away from me, and one of them confided in me that she feared she might contract the disease! I did not blame her at all. I shared the little information that I had gathered about breast cancer with her and even taught her how to do a breast self-examination.

Although I was demoted to the pool office, I continued to enjoy my benefits as a personal assistant because salary was 'personal to holder' and could not be changed. Even so, I struggled as no assignments were given to me at all. I finally took courage and approached the HR manager about the situation, only to be told that I should not complain because management was doing me a favour by keeping me in the office at all.

At the end of my then-running contract, I was dismissed without grounds or due cause! I was not given any severance pay or other benefits. This caused significant psychological distress and financial hardship as our family struggled to pay for my ongoing treatment and school fees for our children.

Coping with a breast cancer diagnosis and the unexpected discrimination and stigmatization that came along with it was very difficult. With God's help, I found the strength to carry on. Currently I am self-employed, after starting up and manning a Secretarial Bureau of my own! I do thank God for his providence!

RRI conferences foster international friendships

Beulah Jankelowitz, Reach for Recovery South Africa

Being a breast cancer survivor for many years has certainly enriched my life. It is not an enviable disease and when I was diagnosed 26 and a half years ago, I saw it as a definite death sentence.

I initially had a segmental mastectomy and six weeks of daily radiation. I soon resumed my teaching and found being with little children was very healing and helped me forget my problems.

I had a recurrence 17 months later and had a mastectomy and immediate reconstruction. In fact, I celebrated 25 years since my last surgery on February 9th.

Returning to work after my mastectomy was a boost to my self-esteem. In addition to resuming work, I became very involved with

the support group Reach for Recovery and it has been my salvation in many ways. I have met such amazing people and hope that in my small way I was able to make a difference.

I have been fortunate to be able to attend numerous international conferences. Amongst the many countries were Italy, Portugal, Sweden, Australia, Ireland, Taiwan and the most recent being in my own beautiful country - South Africa.

I met Teresa Cuda in Taiwan where she was delegate. She is originally from Argentina but now lives in Australia. In spite of an age difference, we connected well and remained in e-mail and Facebook contact. She attended the Reach to Recovery international conference held in South Africa in 2013, accompanied by one of her lovely daughters.

a personal story



Beulah Jankelowitz

At the end of last year, my husband and I visited Sydney, Australia to see our children who live there. Teresa and her daughters travelled three hours by train in order to meet up with us in Sydney.

She took us to an amazing Chinese garden in the heart of the busy city which was so tranquil and beautiful.

She insisted we dress up in Chinese national dress and we had such a fun day together.

Were it not for the fact that we are both breast cancer survivors who have chosen to live our lives fully and with purpose, our paths were unlikely to have ever crossed. My life would certainly have been poorer for not having met her.

Advocates for breast cancer join hands in South Africa

At the 17th Reach to Recovery International Breast Cancer Support Conference held in Cape Town, South Africa in March 2013, a meeting was held with the Deputy Minister of Health to advocate and lobby for a breast health policy.

For this meeting, the Breast Health Global Initiative's summary tables, from their Guidelines for International Breast Health and Cancer Control Implementation, were provided as an example of what South Africa can consider as a standardised breast health policy.^[1] This document covers all aspects of the cancer continuum and discusses services for basic, limited, enhanced and maximal settings. A firm commitment was made that such a policy would be developed nationally.

One year later, South African breast cancer non-profit organisations have come together as one voice under the banner of the Cancer Alliance to form the Advocates for Breast Cancer (ABC), the purpose being to campaign for a national breast health policy for South Africa. The ABC will develop a three-pronged approach that will include the following:

- Advocating and lobbying with regard to skills training for breast cancer organisations to build the skills capacity of women.
- An extensive communication strategy that will focus on the main issues around breast health to ensure that the voice of women in all communities is heard.
- Building partnerships with the National Department of Health and other departments that focus on women and education to ensure policy development and implementation.

Organisations that came together for this historic event were:

- Reach for Recovery
- Breast Health Foundation
- Pink Drive
- People Living with Cancer (PLWC, incorporating Cancer.vive)
- Amabele-Belles
- Journey of Hope
- Breast Course for Nurses



There is currently no breast healthcare policy in South Africa. In the 2013 – 2019, non-communicable diseases (NCD) Strategic Plan for South Africa, treatment of stage 1 breast cancer is listed as one of the most cost-effective interventions, as the financial cost is low.^[2]

ABC believes that to significantly change breast cancer services for the majority of women in this country, management of this disease must be prioritised by national government. Involved organisations must combine their efforts with healthcare professionals to make it a matter of prime importance.

Breast and cervical cancer are the leading causes of cancer mortality in South African women and in 2000 these cancers accounted for 1.3% of deaths (N=3 157).^[1] If breast cancer is detected early, the patient survival rate is ≥80%. In 2006, the National Cancer Registry (NCR) reported that one in 32 South African women will develop breast cancer in their lifetime.^[4] These are the latest figures.

Of the total number of women diagnosed with breast cancer in 2006 (N=5 869), 3 832 4 (65%) visited private healthcare facilities, which can be attributed to better access to diagnostic resources in this sector. It is widely accepted that there is significant under-reporting of breast cancer in the public sector.

Many factors contribute negatively to the diagnosis of cancer. Examples include the stigma attached to this disease in rural communities, little or no awareness of cancer in general, and co-morbidities, e.g. HIV/AIDS, poverty, lack of equitable services, inability of health professionals to diagnose cancer at an early stage and referral pathways that do not allow for easy access to services.

1. Anderson BO, Yip CH, Smith RA, et al. Guideline implementation for breast healthcare in low-income and middle-income countries: Overview of the Breast Health Global Initiative Global Summit 2007. *Cancer* 2008;113(S8):221-224. <http://dx.doi.org/10.1002/cncr.23844>
2. Strategic Plan for the Prevention and Control and Non-Communicable Diseases 2013 - 2017. DOH, Pretoria, ISBN: RP 06/2013978-0-621-41510-0
3. South African Medical Research Council (MRC). What are the top causes of death in South Africa? <http://www.mrc.ac.za/bod/faqdeath.htm> (March 2014)
4. National Institute of Occupational Health (NIOH). Summary statistics of cancer diagnosed histologically in 2006. All females. http://www.nioh.ac.za/assets/files/NCR_2006_TABLES_FINAL.pdf (March 2014)



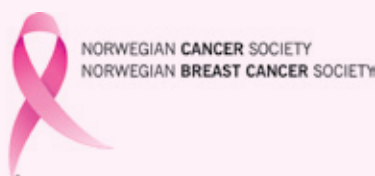
The Norwegian Breast Cancer Society and Cancer Society donate pink ribbon pins

Since the early 1990s, the Pink Ribbon Campaign has been held every October in more than 100 countries. The pink ribbon is the official symbol of International Breast Cancer Awareness month and has become well known throughout the world. In Norway, 90 per cent of the population is aware of what the pink ribbon symbolizes. That awareness has contributed to early detection of breast cancer and has inspired great solidarity among women living with the diagnosis.

The leaders of the Pink Ribbon Campaign in Norway, Anne Lise Ryel and Olaug Mortensen, want to give Pink Ribbon pins to other national breast cancer support groups and organizations that want to spread the ribbon's message to their citizens.

The Pink Ribbon Campaign in Norway knows how important it is to raise awareness about, and draw attention to, breast cancer. It will ship pink ribbon pins, at no charge, to any organization or support group that does not have its own pink ribbon products.

Does your organization or support group want to receive a supply of the original pink ribbon pin to distribute to women in your area? Please email rosa@kreffforeningen.no. Tell us a little about your group or organization and how you will distribute the pin in your country.



Cancer Council Queensland taking on women's cancers

case study

Over 4,000 Queensland women will be diagnosed with women's cancers in 2014. Cancer Council Queensland (CCQ) runs Pink Fundraising activities throughout the year to help take on women's cancers and provide funding for vital research, prevention and free support services. Pink Fundraising has multiple campaigns throughout the year, including a recent campaign, Mum for Life, which ran from 13 April to 13 May 2014. The campaign targeted people aged 16-40 and was timed to coincide with Mother's Day on 11 May 2014.

The concept behind Mum for Life was a vintage eCard that allowed visitors to create a personalised eCard to share on Mother's Day whilst donating on behalf of their mum. A micro-site was designed and developed. The microsite was a fully responsive, mobile and tablet optimised solution that connected with visitors via intuitive design.

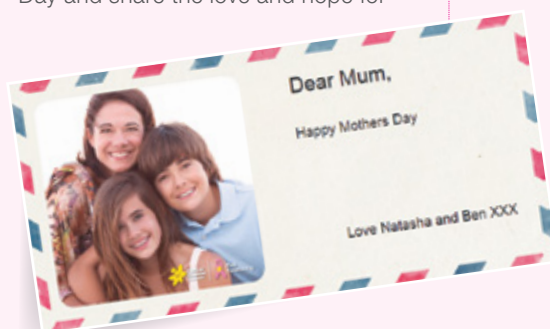
The campaign was supported by radio and online activity to encourage donations and word-of-mouth promotion. Strong digital activity included Yahoo!7 expanding MREC to over-the-page banners, banner advertising, Facebook custom audience targeting and page posts. Digital advertising delivered over 3,380,000 impressions and a click through rate well above the industry average. Fifteen and thirty second radio advertisements complemented digital activity in the weeks leading up to Mother's Day. The clever creative asked the audience to 'give the gift of giving this Mother's Day and share the love and hope for

all women affected by cancer.' The radio advertisement needed to demonstrate an emotional appeal to cut-through the noise, and reached a Queensland audience of over 315,000.

During the campaign, Google analytics and micro-site transactions were continuously monitored. In the fortnight prior to Mother's Day, changes were made to the micro-site to encourage a higher number of transactions and decrease the bounce rate. A working party consisting of digital experts, CCQ Fundraising and Strategic Marketing, brainstormed ideas to streamline the micro-site's process and simplify the user experience. Changes included simplifying the homepage and changing the transaction process to ensure users created their eCard prior to registration and donation. Analytics tracked a 15% drop in the bounce rate once the micro-site changes were implemented.

Mum for Life gathered significant learnings and information that CCQ will use for future campaigns and initiatives moving forward. All donations will help CCQ to take on women's cancers.

To see the campaigns visit www.mumforlife.org.au and Pink Fundraising www.womenscancers.org.au



Making the law work better for people affected by cancer

Professor Jeff Dunn
Chair, RRI Board of Management
Secretary, International Psycho-Oncology Society
Chief Executive Officer, Cancer Council Queensland



Professor Jeff Dunn

Professor Jeff Dunn reports on a new project examining the laws and policies that impact on those diagnosed with cancer, and the key focus area of employment and return to work. The project is called *Making the law work better for people affected by cancer*, and is being conducted by the McCabe Centre for Law and Cancer. Jeff serves as an Advisory Committee Member of the Centre.

In 2012, 1.7 million women were diagnosed with breast cancer, with breast cancer the most frequently diagnosed cancer among women in 140 of 184 countries worldwide. Today, there are estimated to be about 6.3 million women alive who have been diagnosed with breast cancer in the past five years, and breast cancer now represents one in four of all cancers in women.

While breast cancer survival rates vary greatly worldwide, more women are living longer after a breast cancer diagnosis, reflecting improvements in preventive strategies, early detection, screening, and treatment.

With greater numbers of women surviving a breast cancer diagnosis, an increasing need has emerged to better address the myriad of issues women may possibly face when returning to work after their diagnosis.

As an Advisory Committee Member of the McCabe Centre for Law and Cancer, I am pleased to report on one such initiative examining the needs of patients, survivors, and carers when returning to work.

As many readers of Bloom will know, retaining, returning to, or finding new employment can be challenging for all those affected by breast cancer. While some women are able to continue working throughout their treatment, others are required to take leave and then return to work following treatment, which in many cases is lengthy. In all cases, employment challenges will be specific not only to each unique woman, but to her work place and its human relations framework.

Key findings from the project, to date, suggest that current approaches to supporting women working through their cancer diagnosis or returning to work after treatment may not be appropriately sensitive to the needs of cancer patients and survivors, or their carers:

- Understanding the nature of employment problems for people affected by cancer is a challenge.
- Each employer responds differently, where some patients experience discrimination and other patients receive understanding and support.
- Patients experience personal concerns about taking time off, losing opportunities and being unfairly terminated from their role.
- Common concerns experienced by patients included relationship and communication difficulties with employers and workmates, often related to taking time off.
- These concerns were also experienced by some carers.
- Despite these concerns, very few patients or carers take formal action in response to unfair treatment at work.

Learning from these key findings, the project investigators worked with participants to help identify **consumer suggestions** to better support patients and carers. These were:

- Greater flexibility, including flexible hours or the ability to work from home.
- More knowledge, understanding and sympathy among employers and colleagues regarding the effects of a cancer diagnosis and treatment.
- Allowing a phased return to work and full responsibilities—where this is needed and desired—which recognises the gradual recovery process.

These suggestions helped to provide the foundations for two initial **recommendations**:

1. Education programs for employers, people affected by cancer and their colleagues about:
 - The effects of a cancer diagnosis and treatment on an employee;
 - The legal frameworks, rights and responsibilities that apply when an

employee or potential employee is affected by cancer, whether personally or as a carer, and practical solutions to common problems.

2. More research to accurately assess the extent and type of employment problems that people affected by cancer and their carers experience.

Initial findings further suggested that industrial relations frameworks may need to be broadened to ensure patients, survivors, and carers are given sufficient time to lodge formal action when they experience unfair treatment or dismissal.

Reach to Recovery International has an important role to play in encouraging awareness and action on this issue, to support those affected on their journey and to ensure that no woman gets left behind in the workplace.

About the McCabe Centre for Law and Cancer

The McCabe Centre for Law and Cancer is a joint initiative of Cancer Council Victoria and the Union for International Cancer Control. Its mission is to contribute to the effective use of the law for cancer prevention, treatment, supportive care and research.

The McCabe Centre conducts research, policy development, capacity building and advocacy. It employs lawyers, and hosts international interns and fellows, law student interns and pro bono secondees in a multidisciplinary environment that includes expertise across cancer control generally, including epidemiology and behavioural science. It brings together lawyers, legal academics and cancer control experts and advocates. It collaborates with other non-governmental organizations, law schools and legal practitioners, and works, as appropriate, with governments and intergovernmental organizations.

The McCabe Centre is the only centre of its kind in the world. It aims to help build capacity globally in the effective use of law for cancer control, working with member organizations of UICC, the leading global cancer control non-governmental organization, with over 760 member organisations across 155 countries.

<http://www.mccabecentre.org/>

Welcome to **Global Kitchen**, where we feature exotic recipes and home cooking from cultures around the world.



If you have a recipe to share, please email

info@reachtorecoveryinternational.org

Semolina cake (eggless)

Ingredients

- 2 cups semolina
- ½ cup sugar
- 1 cup plain yoghurt, unsweetened
- ¼ cup vegetable oil
- 1 ½ teaspoons baking powder
- ½ cup coconut (optional)
- Almonds or any kind of nuts (optional)
- Syrup
- Tahina paste to grease tray (or cooking oil)

Preparation

- Mix dry ingredients together
- Add oil and plain yoghurt and mix together with your hands
- Pour the mixture in a tray 8" x 12" approx (round or square) greased with tahina or vegetable oil
- Make 'slices' with wet knife and decorate it with almond slice (optional)

- Put in oven for half an hour on 180°C
- Put the hot syrup on the cold cake

SYRUP Ingredients

- 2 cups of sugar
- ¾ cup water
- 1 teaspoon lemon juice

Preparation

- Add sugar, water and lemon juice in a saucepan and simmer till thickened
- Remove from heat and put it over the cold cake (according to taste)

Submitted by Patient's Friends Society-Jerusalem

<https://www.facebook.com/pfsjerusalem.org>

