

# bloom

Issue

**15**

February  
2013

## Reach to Recovery International - RRI

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



# Message from Ann Steyn

President of Reach to Recovery

**The theme for this issue is Survivorship Care Planning and we received many submissions from you which highlights the importance of this topic in breast cancer care.**

As the submission from the HEAL Consultancy, India (page 12) says "...today when we talk of cancer we immediately associate it with survivorship". Breast cancer today does not necessarily mean an immediate death sentence; so how we live our days is important. Their article looks at meeting the challenges after breast cancer and details the objective and the contents of their survivorship care planning. It is an interesting read for groups looking at survivorship care planning.

From the Israel Cancer Association we have information on 2 of their programmes based on a Healthy Lifestyle that they offer to help survivors. (page 3) Indonesian Cancer Foundation is concerned about the correct information on breast cancer being available and they have apps for mobile phones that enables people to ask questions and interact with doctors! They believe it to be a first! (page 9).

There is an interesting read from the Sunrise group in Palestine (page 4) They are concerned about poor patient -doctor communication and held a workshop that brought together health professionals and survivors. Using communications and role play between health professional and patient was an important part of the workshop. Perhaps more of us

should think about involving our medical profession in discussions with survivors.

Also included is a worthwhile article from **LIVESTRONG** which deals with the challenges and opportunities that survivorship care planning presents (page 8). The article reflects the latest research and makes essential reading for groups wishing to improve health care for cancer survivors. As the article points out cancer survivors are a complex population and so there is not a comprehensive one-size-fits-all model of survivorship care that can be implemented.

As always we are delighted to read about volunteer driven organizations that offer care and support to patients. Reach for Recovery Ghana, and Donna Ukraine were both started by survivors and today are offering programmes of support, care and advocacy for breast cancer patients. Read about their activities on (pages 6 and 11).

I hope you will find this bumper issue one of interest. Please let us know your feelings on Bloom. We rely heavily on your input so that we can offer the articles that you would like to inform, stimulate and challenge you!

The 17th RRI Conference in Cape Town South Africa is just around the corner. I believe it will be a conference worth attending, with delegates at the moment representing over 40 countries –a record for RRI Conferences. If you haven't already registered please do before it is too late! [www.reachtorecovery2013.org](http://www.reachtorecovery2013.org)

Email [annsteyn@reachtorecoveryinternational.org](mailto:annsteyn@reachtorecoveryinternational.org)



Ann Steyn

## New RRI Membership

**RRI's new membership guidelines have just been released! Existing and new members must reapply now using our easy online form.**

[Click here to apply!](#)

I greatly look forward to giving you a warm South African welcome!  
Wamkelekile e Afrika!

See you in Cape Town March 19th-22nd 2013.

[www.reachtorecovery2013.org](http://www.reachtorecovery2013.org)

**Warm Reach to Recovery greeting to you all!**

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### Email your submissions!

The theme of the next edition will be 'E-health and digital support: is this the future?'. Submissions close April 17, 2013. Please send submissions in Microsoft Word format with any photos to [info@reachtorecoveryinternational.org](mailto:info@reachtorecoveryinternational.org)



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For more information about RRI, go to [www.reachtorecoveryinternational.org](http://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 administrated by Cancer Council Queensland.



# ICA Steps to a **Healthy Life Project**



**The Israel Cancer Association (ICA) acts to promote the rehabilitation and quality of life of breast cancer patients through various projects.**

**One of these projects is "Steps towards a Healthy Life", which aims to engage breast cancer patients in experiencing the healthy advantages of physical activity. The program encourages women to build time in their schedule for planned, structured physical activity and make it part of their daily routine.**

The program also offers consultation and professional guidance to breast cancer patients who wish to join. The program includes a group training session delivered by psycho-oncologists, where each participant gets an explanatory booklet as well as a tension elastic to use at home.

Prof. Naama Constantini, a sports medicine specialist, provides professional guidance and a source of knowledge and updates, responding to questions, and offering ongoing professional advice and involvement.

ICA Rehabilitation and Welfare Department Director, Social Worker Orit Shapira, leads the program in conjunction with Livia Kislev, ICA Head Nurse. Physiotherapists from various hospitals who are selected to operate the national project undergo intense annual training at Beit Mati ICA Headquarters in Givatayim.

Today the project runs in 17 oncology centers throughout Israel, with the aim of incorporating all medical centers in Israel into this program and expanding it to pediatric departments and community health centers.

## **Workshops – "Survivors towards a Healthy Life"**

The aim of this workshop is to help breast cancer survivors cope with life after treatment, to enhance their quality of life, to provide them with tips on how to lead a healthy life, and to encourage them to return to their normal personal routine and active community life.

The participants take part in a series of professionally moderated meetings which discuss various topics: returning to one's normal life and family routine; sexuality; health challenges after treatment and coping with long-term side effects; engaging in physical activity tailored specifically to the needs of breast cancer survivors; developing a customized nutrition plan during and after the disease, complementary medicine for breast cancer patients and survivors. Participation in these workshops is free of charge. This year saw "Survivors towards a Healthy Life" seminars in major cities and various oncology centers.

*Article submitted by Nira Tammuz, Head of Information Center, Israel Cancer Association*

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**'Yad Lehachlama' (Reach to Recovery)  
- Israel Cancer Association**

# A Palestinian perspective: The importance of positive communication in supportive care

By Carol El Jabari, MPH BSc RN

**‘I travel for three or four hours to be told my doctor can’t see me today.’**

**‘I got to the hospital and the doctor had to see about 40 patients so he only had two minutes for me.’**

**‘When I asked the doctor a question, he replied ‘are you the doctor or am I?’**

**These are the common types of challenges experienced by members in our Palestinian breast cancer support group (Sunrise) during their follow up care.**

Treatment in the governmental sector has its problems, but at Patient’s Friends Society-Jerusalem (PFS) we try to work with patients, survivors and health professionals to make the cancer journey smoother.

It has long been recognized that difficulties in the effective delivery of health care can arise from problems in communication between patient and provider rather than from any failing in the technical aspects of medical care. Improvements in provider-patient communication can have beneficial effects on health outcomes.\*

PFS provides counselling, information and advice, with survivors available to provide support. As the support group membership has increased, so too has our awareness of the challenges faced by many women, revealing many areas for improvement of supportive care and post-treatment follow up.

The patients and their families face many barriers, such as access difficulties to their clinician or the treatment facility due to political conflict and a depressed socio-economic climate.



These problems all contribute to their frustrations. In an effort to try and alleviate some of the problems patients face, we asked an expert to hold a workshop on empowering patients and survivors to learn about their ‘Right to Health’ (definition, approach, determinants) and ‘Communication with health providers’.

Dr. Tasneem Atatrah, MD MPH Advocacy and Health Promotion Officer at the World Health Organization (WHO) in Jerusalem conducted the first of what will be a workshop series in December 2012, bringing together cancer patients, survivors and health professionals.

A significant component of the workshop, hosted by Hebron University, involved communications and active role plays, an experience that participants enjoyed and found to be informative and helpful!

The women left motivated and the health professionals were very appreciative of this initiative. They were inspired by the strength and courage of the women.

Traditionally, communication in medical school curricula was incorporated informally as part of rounds and faculty feedback, with little emphasis or structured education about communications per se. This teaching method left gaps, but today communication skills training is gaining more attention in medical schools.

Health professionals have an important role to play in ensuring patients are satisfied and reassured.

**We play an important part in encouraging them to maintain good and effective communications and as much as possible try to inspire kind words and actions during clinical consultations.**

Good communications means our patients and their loved ones can better understand and appreciate the work we do and the role each of us has to perform.

\*Patient-doctor communication; Teutsch, C. Medical Clinics of North America, [2003, 87(5):1115-1145]

# Pink Ribbon Pakistan: Enabling better survivorship care through early awareness and screening



**“I would’ve never opted for a mammogram test. Thanks to Pink Ribbon team, I was diagnosed and treated well in time”**  
*Mrs. Aisha Khan*

**Aisha Khan is a working woman and Pink Ribbon Survivor who never thought that breast cancer would affect her life too. Her breast cancer was diagnosed when she used the free screening service provided by Pink Ribbon Campaign.**

Today she has become an influential voice raising awareness of early detection in Pakistan, showcasing survivorship to other women.

Pakistan faces a significant risk of breast cancer among women. It is estimated that lack of awareness alone contributes to the death of 40,000 Pakistani women each year from breast cancer.

The objective of our program is to highlight the importance of awareness and encourage survivorship care to improve survival outcomes and raise quality of life for women affected by the disease.

The Pink Ribbon Survivorship care program includes survivors, medical experts, social-workers, and online medical experts who provide support and holistic breast cancer survivorship

care for patients and loved ones, offering them the opportunity to share their experience and embrace support.

Awareness programs and events are run by Pink Ribbon throughout the year and have proved an effective way of engaging with women to improve the uptake of screening.

Pink Ribbon acts a bridge between the community and medical facilities and urges women to seek medical advice and screening for early diagnosis, and quality clinical care and supportive care during and beyond treatment.

The program has helped to shift community perceptions, successfully educating women to take preventive health measures. Since the campaign began, there has been a 30% increase in attendance at Breast Clinics, enabled by a high level of support from

many volunteers who help us to reach out to significant numbers of women through grassroots engagement.

The Pink Ribbon campaign also holds awareness events for the broader community, engaging them in our cause to advocate for cancer awareness, to highlight the importance of early detection and to promote ongoing funding and investment in all aspects of fighting the disease.

We are confident that increasing awareness will continue to improve rates of early detection to promote better survival outcomes. The key to our supportive care capacity is to work with the community, whereby everyday women become our eloquent ambassadors, promoting access to Pink Ribbon and raising understanding of how important it is to be PINK!



# Happy 10th Birthday Reach for Recovery Ghana!



**Reach for Recovery Ghana celebrates its 10th anniversary this year. The following report gives Bloom readers an overview of RFR Ghana's major achievements, core activities and current need for the group's services.**

**During the past 10 years, RFR Ghana has been a source of relief and support to many women and their families afflicted by breast cancer!**

RFR Ghana's service achievements:

Providing hands-on, one-on-one education and support to women who have been diagnosed with breast cancer, using the services of trained breast cancer survivors and dedicated health personnel;

Providing a forum for survivors to share with one another and to talk about the latest in research and treatment practices, self-care, and the importance of maintaining good health; and

Creating a greater public awareness of breast and other cancers; thereby, serving as advocates for early detection, treatment, and ongoing healthy lifestyle practices.

Visiting breast cancer patients in the hospitals, where we provide "Goody Bags" after surgery. These bags consist of a temporal prosthesis, a pillow, a squeezing ball, a 32-page mastectomy patient's guide and a post-surgery exercise sheet.

Counselling women concerned about breast health through our participation in health fairs, our sponsorship of health screening programs, and through individual and family counselling services in our offices.

Helping women who have been treated for breast cancer and cannot afford the huge medical bills of their treatment. As much as we could afford, we have covered the medical expenses of many women who would not otherwise be able to afford care.

Sponsoring monthly meetings where survivors – new and experienced – come together to support one another and share ideas. These meetings help women, who may otherwise feel isolated, express their concerns about life after breast cancer and to learn about healthy lifestyle that will prolong their lives and minimize risk for recurrence. It is also the place where women share information with one another about post-cancer treatment and other resources for survivors.

Educating the general public about cancer prevention strategies and treatment options. We had several

public outreach programs including organizing free breast screenings in schools and churches within Accra and surrounding villages. Our recent major screening has been to screen 30000 people in the Western, Central and Volta regions of Ghana. From July 2011 to March 2012 the group was able to successfully screen 22205 people with 365 referrals with sponsorship from 'Susan G. Komen for the Cure'. Our screening activities have also been held strategically at places that have a lot of influence with the public, including the Parliament House and the US Embassy in Ghana during their health fairs. The recent event was on 18th October, 2012. The group also held a number of awareness programs on radio and TV to sensitize the general public about Breast and Cervical Cancer. These efforts are responsible for over 50,000 people screened and over 1000 referrals to the hospitals for further investigations within the past decade.

Holding regular full-day conferences co-sponsored with local and international organizations where attendees hear from renowned experts (from Ghana and abroad) in breast cancer diagnosis, treatment, management, and survivorship. In 2012, it was organized for health professionals from the southern part of Ghana where the group had organized breast screening programs. Educating health professionals in Ghana was necessary because research has

shown that some health professionals in the country delay diagnosis and mismanage breast cancer at the initial stages which contributes to increased incidence of advanced breast cancer in Ghana and the women affected die after a few years post-mastectomy. Thus, 'Breast Cancer Information Day' for medical personnel particularly doctors and nurses are being organized annually with experienced and expert facilitators. The 2012 program was very successful with participants (about 150 health professionals) taking away some valuable information on breast cancer to enhance their various fields of practice in the prevention and management of breast cancer. The organization hopes to raise enough funds to continue with this project and other on-going projects.

### Our Plans for 2013

Our focus in 2013 is educating and offering free breast screening in colleges and tertiary institutions and nearby towns and villages in the Eastern region of Ghana. Our objective is to train the students who will be future advocates in

their homes, and workplaces especially those who will enter the teaching field and impact the communities in which they will live and work. The focus on youth is important because the incidence of breast cancer has been found to increase among the youth in the country.

### Our Needs

We seek additional funding to expand our outreach activities from your organization in the following ways:

- To conduct more work in the rural villages by acquiring funding to purchase a vehicle, ideally a pick-up truck to transport staff and equipment to screening locations.
- To expand our ability to give out more 'Goody Bags' to patients and to cover medical expenses for patients who cannot afford treatment since all aspects of breast cancer treatment is not covered by the national health insurance scheme in Ghana.
- To expand our capacity for collaborating with other NGOs working on other forms of cancers to

consolidate our activities and increase impact on the Ghanaian populace. We have begun to serve as a resource for other NGOs, particularly in the area of cervical cancer. Our ability to expand in this area is limited by our current staffing situation.

- To increase staff to improve our administrative structure so that the RFR Ghana's office can remain open for longer periods during the day to welcome and attend to visitors who have the need to access our resources. Currently, our offices are locked when our staff go out visiting patients and/or undertaking other outreach work.

The strong commitment and dynamism of the group's members makes it possible for us to achieve our targets. We are proud that Bloom readers will celebrate our milestone around the world and support our success story!

Thank you!

Gladys Boateng  
Director  
Reach for Recovery Ghana



# Survivorship Care Planning: Challenges and Opportunities

L I V E S T R O N G<sup>®</sup>



By Naveen Rao, MHS,  
LIVESTRONG Foundation.

**There are 14 million post-treatment cancer survivors living in America today, a number that is expected to surpass 18 million by the end of the decade. Unfortunately, many of these individuals may not receive the necessary health care they need. As a landmark Institute of Medicine (IOM) report detailed in 2006, these individuals are often “lost in transition” between different parts of the health care system. Bridging this gap requires a way to address the complex litany of side effects, toxicities and long-term symptoms that can accompany or follow a course of cancer treatment. Moreover, there is a dire need for enhanced communication and information-sharing between primary care physicians, oncologists, and patients. Survivorship care plans are a pivotal part of establishing this continuum.**

Recommended as part of the IOM report, survivorship care plans are comprehensive, customized documents that typically contain a medical treatment summary (surgical, treatment, therapeutic and medication history), directions for ongoing care, as well as possible side effects, late effects, or other complications for patients and health care teams to consider. They can be used both by patients themselves as a roadmap for their follow-up care

appointments, as well as by medical oncologists and primary care physicians as a resource at the point of care.

While there is a need for more comprehensive research into the effectiveness and long-term outcomes associated with delivery of survivorship care plans, support is growing. The American College of Surgeons Commission on Cancer (CoC) is a national medical association that accredits treatment facilities that care for a combined 71 percent of American cancer patients. The CoC built on the IOM's recommendation by implementing a set of standards for providing patient-centered care: By 2015, accredited cancer treatment facilities must provide survivorship care plans to all patients undergoing treatment. The LIVESTRONG Foundation convened 150 of the nation's cancer experts, community leaders, survivors, and patient advocates to establish consensus on identifying these and other essential elements of survivorship care. Recently, the American Society of Clinical Oncology (ASCO) included care plans as part of a comprehensive set of research-based recommendations for high quality survivorship care.

## Challenges Remain

While support for and research into survivorship care planning grows, considerable challenges remain.

Cancer survivors are a medically complex, heterogeneous patient population, with increased risks for comorbidities and side effects. As a result there is not a comprehensive one-size-fits-all model of survivorship care that can simply be implemented in all treatment facilities. Moreover, because care plans are unique, customized with each patient's information, they are labor-intensive to create. While much of the data that makes up these documents are found in electronic medical record (EMR) systems, hospital or state-level tumor registries or elsewhere, they are rarely available in a location and format that is easily shareable with primary care clinicians and/or understandable to patients.

Technological barriers have also impeded progress to date. Electronic medical record vendors have not prioritized the development of post-treatment modules or applications, such as integration of survivorship care plans or treatment summary documents within their systems. A lack of interoperability across disparate vendors and institutions has also proven challenging to information flow between oncologists and primary care physicians.

Aside from such workflow challenges, broader awareness about cancer survivorship has yet to take root. Policymakers and public sector officials still do not include survivorship issues in the broader



conversation about health reform, access to care, chronic disease management, quality improvement, and coverage expansion. For example, reimbursement for survivorship programs remains a significant barrier to the widespread adoption of care plans and other tools or programs. The time required to complete a survivorship care plan or treatment summary is not typically reimbursed by public or private health plans. Completion of a plan does not count against any existing quality improvement program metrics or incentive programs for physicians.

### The Path Forward

Addressing these myriad challenges will require both specific action and general education. Programmatically, the field of survivorship will require collaboration, funding, more standards development, dedicated pilot sites, expansion into different cancer types, and ongoing effectiveness research. One example of such a collaborative research effort is a feasibility study on automating survivorship care plans through EMR

and registry data, conducted by the **LIVESTRONG** Foundation, the American Cancer Society and the CoC.

More awareness is also needed at all levels. For patients, this means access to navigation services, self-advocacy skills training, and education on issues from late effects to recurrence, nutrition counseling, or general health promotion. For clinicians, it can mean providing information on medication and treatment-related effects, promoting general information and awareness of survivorship, or undergoing specific training for pain management, palliative care, rehabilitation, psychosocial treatment or other specialized services.

With combined efforts and dedicated leadership from all fronts, reforms to the health care delivery and payment systems, technological innovation, and the voices of thousands of cancer patients, survivors, and other advocates demanding better health care, the opportunity to bridge the gap in

survivorship care has never been greater.

<sup>i</sup> Siegel R., DeSantis C., Virgo K., et al: *Cancer treatment and survivorship statistics, 2012. CA Cancer J Clin* 62:220-241, 2012

<sup>ii</sup> Hewitt M, Greenfield S. Stovall E (eds): *From Cancer Patient to Cancer Survivor: Lost in Transition.* Washington, DC, National Academies Press, 2006.

<sup>iii</sup> Rechis R, Beckjord EE, Arvey SR, et al: *The Essential Elements of Survivorship Care: A LIVESTRONG Brief.* Austin, TX. LIVESTRONG Foundation, December 2011. <http://livestrong.org/pdfs/3-0/EssentialElementsBrief>

<sup>iv</sup> McCabe, M.S., Bhatia, S., Oeffinger K.C., Reaman, G.H., Tyne, C., Wollins, D.S. Hudson, M.M. *American Society of Clinical Oncology Statement: Achieving High-Quality Cancer Survivorship Care. Journal of Clinical Oncology, 2013.*

<sup>v</sup> Digiulio, S., *The Survivorship Care Gap: What Works, What Doesn't. Oncology Times Vol.34 No 17., 2012.*

<sup>vi</sup> Rechis, R., Arvey, S.R., Beckjord E.B., *Perspectives of a lifelong cancer survivor – improving survivorship care. Nature Reviews Clinical Oncology, 2012.*

## Indonesian innovation embraces technology as a support tool!

**The Indonesian Cancer Foundation (ICF) was founded in 1977. The ICF is a non governmental organization which is developed rapidly since it was chaired by a civilian, Mrs Umar Wirahadikusuma, who was a breast cancer survivor married to the vice President of Indonesia at that time.**

The ICF's programs are mainly aimed at social activities to help cancer patient access social services.

Our strategies engage members who are enthusiastic about participating in fundraising, so that we can carry out activities for prevention and early detection. This work includes community cancer education, awareness seminars, screening clinics, and accommodation for cancer patients from regional areas of Indonesia who undergo radiation or chemotherapy treatment in Jakarta. We also fund provision of chemotherapy medicines for financially disadvantaged cancer patients and make affordable chemotherapy available for patients who can not afford to buy the medicine from the pharmacist.

The support groups of ICF consist of InOA which helps cancer patients with ostomae, while our Cervical Cancer Support Group and Reach to Recovery Support Group are helping and supporting patients of Cervical Cancer and Breast Cancer with moral support and providing assistance in hospitals and also free hospice home care services, so that caregivers of cancer patients know how to provide appropriate care.

The role of ICF as partner of the Government focuses on cancer education, encouraging healthy life style, motivating people to participate in regular screening, funding treatment when necessary.

One recent innovation, in collaboration with Phillips, has been the establishment of a mobile phone application for Breast Cancer Information that can be downloaded to certain cellphones and smartphones.

The application, or 'app', is called "Spot It Yourself" and can be downloaded in iTunes or via [bit.ly/spotityouself](http://bit.ly/spotityouself).

It is the first Indonesian mobile app to enable people to interactively ask ICF doctors questions through email, twitter and text message.



Indonesian people are crazy about mobile phone technology, so we hope to report soon on the success of "Spot It Yourself" in improving routine self-checks, regular screening and early detection!



17th REACH TO RECOVERY INTERNATIONAL  
BREAST CANCER SUPPORT CONFERENCE  
20 – 22 MARCH 2013  
CAPE TOWN  
SOUTH AFRICA

The 17th Reach to Recovery International Conference is to be held in Cape Town, South Africa from March 20 to 22 in 2013!

The theme of this year's conference is 'Together We Reach' and we'll be looking at breast cancer from the perspectives of the patient (both the newly diagnosed and those with metastatic spread), the survivor, the partner, the family, the community, the breast cancer activist and the health professional.

For those attending the conference, we look forward to welcoming you to Cape Town. If you are unable to attend, there are still a number of ways for you to be involved:

Follow us online, join our conversations, engage with our delegates in Cape Town!



Key Dates

Pre-conference workshops

18 & 19 March 2013

17th RRI Conference

20-22 March 2013

Click here to follow the conference blog

LIVE from Cape Town!

Visit the RRI website

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# Survivorship Care: A Ukrainian perspective

**The Ukrainian organization, Donna, was founded in 1997, at a time when women in the Ukraine seldom spoke of breast cancer and Ukrainian women affected by the disease did not have their supportive care needs recognized or managed.**

Larisa Yashchenko (above) created the Organization after her personal experience with breast cancer, an experience she found tremendously challenging. After radical surgeries and several complications, she found herself alone in hospital with many questions but no-one who could provide experience and support based on an understanding of her diagnosis.

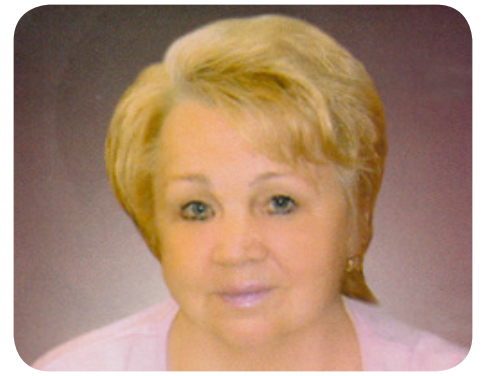
And so began her two-year journey to find other women who were affected by disease. She found many women in need of greater support. Step by step, a group formed, and they decided to create an organization, Donna Ukraine, in order to advocate publicly on breast cancer.

Donna Ukraine's work originally focused on the psychological support of women after surgery, although the group quickly identified a need to expand their reach.

After officially registering as an organization in 1999, Donna Ukraine became a full member organization of both RRI and the UICC in 2000, and many more women continued to join the movement to call for improvement of breast cancer services and support in the Ukraine.

Donna Ukraine is currently working to advance breast cancer clinical and support services in the Ukraine, with health services at a less advanced stage in development compared to high and middle income countries.

The organization has benefited from UICC support and affiliation with RRI, attending UICC World Congress events in Portugal, the United States, and Sweden.



Today Donna Ukraine has 27 branches and unites 135,000 Ukrainian women who have been affected by the disease. All of them help to offer support to women during treatment and beyond, as well as those who are newly diagnosed.

Importantly, the organization has been publicly active in raising awareness of breast cancer, encouraging women to make informed decisions about treatment options and supportive care.

For more information about Donna Ukraine, and to view their video 'Breast Cancer in the Ukraine' go to their new website at [www.donna.ua](http://www.donna.ua).

# Survivorship care planning in India



by Ramaiah Vinay Kumar and Suman Bhasker.

**Breast cancer is second most common malignancy in Indian population and top the list in urban population-based cancer registry.**

Like many economically emerging nations, cancer in India go under- or un-reported in India and has not generated the popular response from both policy-makers and the general public including the patient groups.

India is also facing dual problem of lack of access of newly diagnosed breast cancer patients to cancer centers on the one hand and the inability to ensure that the cancer survivors are compliant to follow-up schema and schedule on the other.

In the study published by Das B.P., 51%, 8% and 5% of all treated cancer patients completed six months, three years and five years of follow-up respectively. Poor survival of cancer, lack of access to follow-up care, bankruptcy due to the cost of treatment, exorbitant medical fees, poverty, low literacy level, inherent fear of untrained non-oncology specialist to provide follow-up care of survivors, failure of oncologist to understand the potential role of non-oncology specialists and nurses in follow-up of survivors at the community level, not appreciating the need and importance of follow-up may be few of reasons for these low follow-up rates.

Practically no time and resource is at disposal for educating the patients about the follow-up care and schedule. More often than not, traditional medicine practitioners are more appealing to the cancer survivors than the oncologist and the cancer centers.

Most of the time, cured symptom-free patients do not present to clinics until the recurrent disease is at its advance stage. Recalcitrant treatment side-effects and the resultant lack of physicians' satisfaction, shortage of resources, inability of patients to pay for various screening tests, low follow-up rates appears to be some of the factors responsible for neglecting the survivor care planning aspect of management of cancer patients.

Introduction, effective implementation of Survivor Care Planning may need vertical rather than the horizontal approach. Currently, the issues of cancer survivors are not in the priority of the National Cancer Control Programme (NCCP).

In our opinion, repeatedly highlighting the cancer survivorship care planning, conducting plenary and educational sessions and policy-makers' round table on the topic under the auspice of international organizations and professional bodies like World Health Organization, Union for International Cancer Control, American Society of Clinical Oncology, European Society Therapeutic Radiology and Oncology may help the survivorship care planning find priority place in NCCPs.

Without the commitment of international, regional and national policy-makers, cancer survivorship care planning will be another sporadic cancer patients' management programme.

*This article was submitted jointly on behalf of Dr.Ramaiah Vinay Kumar, Assistant Professor of Radiotherapy, Kidwai Memorial Institute of Oncology, Bangalore and Dr.Suman Bhasker, Additional professor of Radiotherapy, All India Institute of Medical Sciences, New Delhi.*

# Survivorship Care Planning

Finding ways to live, love and learn yourself after cancer



**When doctors and caregivers are confronted with a hidden answer in a whispered patient question, “Will I die?” or “I’ll be dying won’t I?” it reveals the patient’s greatest fear. This was an understandable cancer scenario in the late 20th century, but today when we talk of cancer, we immediately associate it with survivorship. No other disease has the concept of survivorship more ingrained in its treatment than cancer has. Because of all the myths and the stigma attached to cancer, the concept of survivorship plays a very important role. It emphasizes that being psychologically satisfied and mentally in charge can improve quality of life and positively influence survival outcomes.**

Cancer treatment has both immediate and long term effects. We are survivors not just on the day our treatment ends and we think we are cancer free, but our survivorship begins from diagnosis, the moment we dare to take on both the disease and its treatment. And when we have journeyed through treatment, we also journey through painful, uncharted physical, emotional, spiritual, cognitive, logistic terrains that can affect and interfere in our daily functioning for the rest of our lives.

‘A survivor is defined as a person who endures, who carries on and one who

stays alive, grappling to learn to accept the new self and take charge of a new normal.’

Most of the survivors we counsel and meet in our support groups ask us, how we survive, they ask: ‘What is it we should know and do to live on?’

This basic question captures in a nutshell survivor goals - the need to live healthy and with quality of life. Breast cancer has its own unique clinical, personal and social meaning for different women. It evokes a response and coping mechanisms that are similar or different depending on the stage of disease, type of breast cancer, age, parity, education, socio-economic and cultural factors.

As such, cancer care that advocates the continuum of care from prevention to palliation is incomplete when it fails to fully address survivorship issues. It is evident that every woman touched by breast cancer needs to be enabled to plan ahead on survivorship issues. But, the question that faces us so starkly is who is responsible for survivorship care planning and what issues would comprise survivorship care, what facilities are readily accessible, available and affordable and what cultural sensitivities need to be considered.

The approach taken by one group in India provides a potential model. HEAL Consultancy and Breast Friends

Support Group had an opportunity to work together for the First Breast Cancer Survivors’ Conference in India. Their first concern was survivorship, that is, meeting the challenges women face after breast cancer. Most breast health initiatives show a concern for improving or optimizing healthcare delivery in low-resource and middle-resource countries (LMCs) through the trajectory of the disease to completion of treatment, but leave survivorship out of bounds even though it requires lesser resource allocation for optimal or maximal health outcomes.

Maybe it is for the best that as survivors we make our own consensus plan for wellness and survivorship care. We also realized that if we need to succeed with ourselves, our support groups, patients and survivors, we need to set achievable goals that are suited to the person, personality, circumstance and background.

**The Objectives of Survivorship Care Planning (SCP):** The aim of SCP is to promote optimal health in its six known dimensions of physical, emotional, intellectual, social, spiritual and occupational - each enabling a woman to be rounded, complete and achieve competent physical, psychological, and social functioning after cancer. A very important closet issue that needs to be incorporated into SCP is sexuality and the sexual self. Within the ambit

of such care every institution and state must combine the clinical, psychosocial aspects and logistical support to address side effects of long term treatment, emotional responses, cognitive process and behaviours.

**A Joint Responsibility - The Patient and the Health Care Team:**

It is best to begin SCP when diagnosed. Issues related to treatment and its side effects and outcomes/solutions are best customized to the patient's needs and treatment protocol. The patient must exercise her right to information on any aspect of her treatment and work along with the medical team as and when the need arises. Providing a simply worded, non-threatening overview factsheet during treatment planning is a preamble to what may likely happen. Specific factsheets are handy as and when needed. The presence of a caregiver needs to be mandatory to help support and caregive. But, the patient-centered approach is the emphasis. This puts the onus of self care and responsibility on the patient herself and affirms her potential competency to achieve the three overarching A factors: Acceptance, Awareness and Action, making surviving breast cancer easier and strengthening her survivorship.

The onus of facilitating the SCP rests with the institutions/hospitals and affiliated NGOs and consulting agencies providing both integrated care or a speciality service. Utilizing, optimizing and advocating the availability and accessibility to such a plan rests with the patient and the support group.

**Implementing the survivorship care plan must begin at the time of a confirmed diagnosis.**

**Issues comprising Survivorship Care Planning:**

During the course of the disease, treatment and post treatment issues that concern women are about further hospital visits or follow up care; recurrence; dealing with long term effects - menopause, lymphedema, fertility, sexuality and bone health; diet, nutrition, fitness and exercise; breast reconstruction and prosthesis; hormonal therapy, complementary therapies; support groups and genetic counseling.

**How prepared are the providing institutions to meet these needs?**

Almost all hospitals and health care providers are equipped to deal with protocols leading to a clinical cure or disease remission. Not one in India has an integrated survivorship plan care; a patient receives some amount of piecemeal care and is lost in transition into survivorship. A classic example would be the potential threat of lymphedema and axillary dissection, which we are not prepared for. So,

how could a woman include it in her survivorship plan until she comes with a 2nd stage irreversible condition? Fertility issues and hormonal therapies are common. Survivorship care planning can be likened to a healing balm upon the salt on our physical, emotional and other wounds.

**Content of Survivorship Care Planning:**

Like the standard operating procedures in organizations, the content of survivorship care planning is to be made known. It must reflect what the content is, why it is a priority, who it concerns, what can be done about it and what services are available for it, where to seek such care and costs. A routine example would be dealing with hair loss, for which every hospital that provides oncology services must be connected to services dealing with hair loss solutions. Survivorship care planning should ensure the patient is provided with details and telephone numbers of a simple hair spa professional who has a selection of wigs or scarves or head gears, or should be available at the hospital on select days and timing or on appointment.



A directory of resources should be available with the patient to minimize the gap between anxiety, self- motivation/self-help and potential solution.

**Specific Contents of Survivorship Care Planning**

**Follow Ups:** Follow up means timing follow-ups to keep track of the three Rs - Recovery, Remission and Response

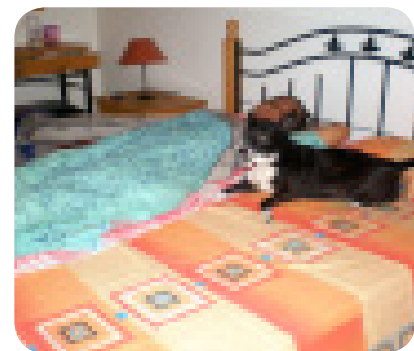
to medication and side effects. Follow screening protocols as recommended.

**Recurrence:** Knowing what recurrence is clinically. Know the difference between recurrence and disease progression. Knowing the risk of recurrence. Recognizing recurrence and seeking appropriate care.

**Hormonal Therapies:** Knowing what different hormonal therapies mean, such as differences between hormonal therapies and hormone replacement therapy (HRT). And side effects and dealing with side effects, such as menopause, fertility issues, fertility preservation, bone loss, medication etc.



**Bone Health:** Knowing what bone health means, the link between breast cancer and bone health, osteopenia and osteoporosis, oral or dental health, risk factors, symptoms, diagnostics and diagnosis - prevention and treatment (clinical management and self management) medications, lifestyle changes etc.



**Lymphedema:** Every oncology department must make it mandatory to have a lymphedema clinic, just like there are stoma clinics. Preoperative and post operative care and prevention risk factors, stages, treatment interventions, simple lymphatic drainage and care instructions, and complete management, under a priority survivorship care plan.



**Sexuality Issues:** Female cancers can have profound affects on body image, sexuality and intimacy, sometimes creating barriers to sexual expression. It's important to know the effects of treatment protocols, perceptions of disease and self, observe any cognitive changes and adjustments, and engagement in interpersonal communication. A priority aim of the SCP is to create understanding and awareness, so that any issues are recognized and managed appropriately. Listing the barriers allows a woman to know what she is and experiencing why she feels what she feels.

These could be treatment barriers like pain, fatigue, loss of sensation, vaginal dryness, dysparunia, fungal and yeast infections and menopausal symptoms. Disease perception and self perception and associated myths can cause misunderstanding and confusion; hence, SCP needs to include dealing with these aspects. Communication barriers can sometimes even become overwhelming. As Simon and Garfunkel once put it, 'silence like the cancer grows'. It is essential to integrate couple therapy in SCP.



**Breast Reconstruction and Prosthesis:** SCP for breast reconstruction and prosthesis must begin prior to surgical intervention. A woman must know what choices she has, what she can afford and what she is likely to be most comfortable with.

During the myriad experiences she faces during the treatment journey it is important that she understand that she is much more than her breasts and with a little help and motivation she can choose what she feels is best for her.

A 'cafeteria' approach works best, where a provider-facilitator outlines the range of options for different types of reconstructive surgery, external and internal prosthesis or implants and tissue expansion, advantages, disadvantages, medium, materials, costs, wear and tear, care etc.

**Diet and Nutrition:** Prevention of recurrence and achieving optimal health is the wish of every survivor. The focus shifts from recovery to recurrence prevention, rebuilding muscle and bone strength, improving immunity, optimal health and well being. SCP of loco-regional guidelines for healthy eating, regulating diet, BMI (body mass index) and BMR (basal metabolic rate), FAQs, simple portion calculations, natural food versus supplements etc. is helpful for many women who are confused about what to eat and what not

**Exercise and Fitness and Complementary Therapies** need to be incorporated into the specific content of SCP to minimize anxiety, stress levels and encourage detox of both physical and emotional excess.



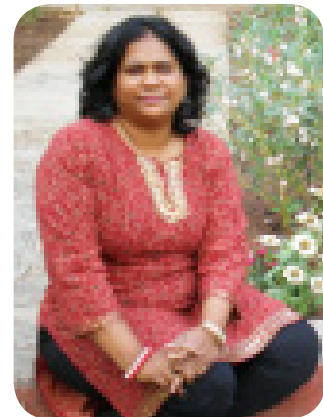
**Support Groups:** Support groups are a window of opportunities for women. The spirit of SCP is enhanced in the support groups it endorses. Referring or sending a woman to a support group gives her the opportunity to explore all those things associated with her survivorship. HEAL Consultancy in collaboration with Breast Friends Support Group, Pune – India explores all possibilities in SCP.

HEAL is an acronym for Health, Education, Awareness and Living essential components for healthy survivorship and quality of life. The founders of Breast Friends, Dr. Shona Nag, Medical Oncologist and Dr. Anupama Mane, Breast Oncoplastic Surgeon contribute their clinical expertise and enthusiasm in making survivorship a much better journey.

***Our aim is to help women find ways to live, love and learn after breast cancer. And planning survivorship care shows we care.***



**Dr. Rama Sivaram**  
Survivor Breast Cancer Advocate  
Health Educator and Counselor



**Rebecca de Souza,**  
Cl. Psychologist and Psycho oncologist



**HEAL CONSULTANCY  
PROFESSIONALS IN HEALTH CARE  
AND EDUCATION, PUNE-INDIA**

# Global Kitchen

This edition we bring you a dish from India, designed to share and show you care!



## Kheer

Kheer is a rice pudding and traditional South Asian sweet dish. It is made by boiling rice or broken wheat with milk and sugar, and flavoured with cardamom, raisins, saffron, cashew nuts, pistachios or almonds. It is typically served during a meal or also consumed alone as a dessert.

### Ingredients

- 75g uncooked white rice
- 2 litres semi-skimmed milk
- 300g caster sugar
- 4 pods cardamom
- 1/2 teaspoon rose water
- 1 tablespoon finely chopped almonds

Preparation time: 1 hour

Cooking time: 1 hour 10 mins

### Method

1. Place the rice in a small bowl and cover with water. Soak for one hour.
  2. Drain the rice and place it in a large, heavy pan with the milk over low heat. Cook, covered 50 minutes, stirring occasionally, until tender. Stir in sugar and cardamom and cook 20 minutes more.
  3. Remove from heat and stir in the rose water. Serve topped with almonds.
- Serves six



If you have a recipe to share, please email [info@reachtorecoveryinternational.org](mailto:info@reachtorecoveryinternational.org)



# Join Reach to Recovery International!



**The Reach to Recovery International (RRI) Network** seeks to improve the quality of life for women with breast cancer and their families by nurturing volunteer peer support and promoting other services to meet their needs, such as advocacy and consumer involvement in research. RRI is a program of the Union for International Cancer Control (UICC) and is administrated by Cancer Council Queensland.

Reach to Recovery International membership is open to organisations and groups that offer support to breast cancer survivors through peer support, advocacy and consumer involvement in research, and to individuals interested in the activities of RRI. Membership is free of charge.

To join, simply visit the RRI website and complete the membership application!

[www.reachtorecoveryinternational.org](http://www.reachtorecoveryinternational.org)

### Benefits for Member Organisations include:

- Inclusion in the RRI global network
- Use of RRI Member logo on request
- Inclusion of Member organisation name, logo and link on RRI's website
- A certificate recognising the organisation's commitment to RRI's Guiding Principles and Membership Code of Conduct
- Letter of support for special occasions from the RRI President
- Quarterly Bloom e-newsletter and other RRI news

Note: RRI Membership guidelines have recently been updated. All previous RRI member organisations need to reapply to ensure their membership is valid. EXE002\_0313

# Reach to Recovery International Governance Structure

## Board of Management

Chair: Jeff Dunn, [Cancer Council Queensland](#)  
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Stella Kyrikides, [Europa Donna Cyprus](#)  
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**Stephanie Newell**  
Advocate, Breast Cancer Network Australia

## EVENTS

**CAPE TOWN, SOUTH AFRICA March 2013:**  
**The 17th RRI Breast Cancer Support Conference**  
**March 20 - 22, 2013**  
Go to <http://www.reachtorecovery2013.org>

**GLASGOW, SCOTLAND March 2014:**  
**9th European Breast Cancer Conference (EBCC-9)**  
**March 19 - 21, 2014**  
Go to [www.ecco-org.eu/Conferences/Conferences/EBCC9.aspx](http://www.ecco-org.eu/Conferences/Conferences/EBCC9.aspx)

## 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.

To contact RRI please email [info@reachtorecoveryinternational.org](mailto:info@reachtorecoveryinternational.org) or visit the website. The material published in Bloom does not necessarily express the views of RRI but is provided for the information of readers.

