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Reach to Recovery International (RRI)

RRI is committed to improving the quality of life of individuals affected by breast cancer and their families.



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Reach to Recovery International, Inc. is a global non-profit organisation based in Baltimore, Maryland, USA.

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Our mission

Reach to Recovery International's mission is to:

- Unite organisations throughout the world which support individuals affected by breast cancer, including their families, in order to share ideas and best practices;
- Disseminate valuable information to support individuals affected by breast cancer throughout the world via bi-annual conferences, our website, our e-newsletter, and other forms of worldwide communications; and
- Assist our Member Organisations in achieving their goals of:
 - Improving the quality of life of individuals affected by breast cancer,
 - Providing psychosocial support to individuals affected by breast cancer, either through group meetings or activities or one-on-one peer support provided by carefully trained survivor volunteers,
 - Advocating on behalf of individuals affected by breast cancer,
 - Providing patient navigation to individuals affected by breast cancer.

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What would you like to read about in the next edition of *bloom*?

Email your theme suggestions to information@reachtorecoveryinternational.org. A theme will be chosen by August 2021. Regardless of whether your suggested theme is chosen this time, it will remain under consideration for future editions.



SUBMIT YOUR ARTICLE



Bloom is published by Reach to Recovery International, Inc. For more information about RRI, go to www.reachtorecoveryinternational.org.

Bloom is introducing a new column!

Do you know a breast cancer survivor who provides outstanding peer support for an organisation in your community? Starting with our next edition in December 2020, we will be featuring a deserving peer-support volunteer in each edition of *Bloom*. These features will also be posted permanently on www.reachtorecoveryinternational.org. Send your nomination along with a 200–400 word article about the volunteer to info@reachtorecoveryinternational.org. Please also include a high-resolution photo of your nominee. It's a great way to say thanks for a job well done, and to raise awareness about your organisation!

Upcoming events:

5th Annual Southeast Asia Breast Cancer Symposium

31 July 2021 – 1 August 2021 (Virtual Meeting)

<https://seabcs2021.com/en>

8th Global Chinese Breast Cancer Organisation Alliance Conference

8 – 10 October 2021 / Hong Kong

www.8thgcbcoachk.com

Advanced Breast Cancer Sixth International Consensus Conference

4 – 6 November 2021 (Virtual Conference)

<http://www.abc-lisbon.org>

World Cancer Day 2022

4 February 2022

<https://www.worldcancerday.org>

20th Reach to Recovery International Breast Cancer Support Conference

22 – 25 September 2022 / Guadalajara, Mexico

website pending

2021.10.08 (Wed) – 10 (Fri)

GCBCOA CONFERENCE
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Message from Cathy Hirsch - President of RRI



Cathy Hirsch

Over the past 15 months, we have seen dramatic changes in nearly every aspect of our lives. We have altered the ways we work, eat, exercise, shop, and socialize. Although some parts of the world are slowly opening back up as vaccines become available, others are seeing spikes in COVID-19 and are tightening restrictions. The impact the pandemic has had on breast cancer care is profound.

In this edition -

In this edition of bloom, we focus on “*Changing roles and responsibilities in breast cancer care: patients, caregivers, and health care providers.*” Two of our Medical Contributors, psychologist Maggie Watson and breast surgeon Cheng-Har Yip, discuss the impact from the perspective of health care providers. We hear from colleagues in India, Malaysia, Palestine, and South Africa about creative ways breast cancer organizations in their countries are adapting so that they can continue supporting patients and their families throughout this very difficult time. We also have a report on efforts underway in Europe to ensure that all breast cancer surgeries are performed by certified breast surgeons.

On a lighter note, for those of you in the northern hemisphere, we share some healthy summer recipes from the US. Enjoy!

We finally have some happy news to report! The Local Organizing Committee in Guadalajara, Mexico is confident that it will safely be able to host the 20th Reach to Recovery International Breast Cancer Support Conference in September of next year. The new Conference dates are

22 – 25 September 2022. Save the dates, and look for the Conference website to go live in September 2021.

Reach to Recovery International is delighted to welcome its new team of Regional Representatives. The following individuals have graciously agreed to help RRI realize its mission of ensuring that quality peer-support and peer-navigation volunteer training is available in all parts of the world:

Sofia Abreu, Portugal
Bertha Aguilar, Mexico
Carol El-Jabari, Palestine
Joanna Grecos, Greece
Stephné Jacobs, South Africa
Ebela Mbanugo, Nigeria
Catherine Ngaracu, Kenya
Faresi Takawira, Zimbabwe
Ellen Utne, Norway
Leonie Young, Australia

“ THE NEW CONFERENCE DATES ARE 22 – 25 SEPTEMBER 2022. SAVE THE DATES, AND LOOK FOR THE CONFERENCE WEBSITE TO GO LIVE IN SEPTEMBER 2021. ”

“ REACH TO RECOVERY INTERNATIONAL IS COMMITTED TO IMPROVING THE QUALITY OF LIFE OF INDIVIDUALS AFFECTED BY BREAST CANCER AND THEIR FAMILIES THROUGH A WIDE RANGE OF SERVICES OFFERED WORLDWIDE. ”

The changing roles and responsibilities in breast cancer care: A health care provider's perspective



Dr Maggie Watson

Dr Maggie Watson, Clinical Psychologist
England

Affiliations:

Institute of Cancer Research, UK

University College London, UK

Health and Life Sciences, De Montfort University, Leicester, UK

Research and Innovation, University of Southern Queensland, Australia

International Psycho-Oncology Society, President Emeritus

In May 2020¹ the WHO conducted a global survey of the impact of COVID-19 on Non-Communicable Diseases (NCD's) including cancer. They found that the more severe the transmission phase of the pandemic the more services were disrupted. Between 41% - 54% of cancer services were disrupted depending on the level of COVID-19 country-wide transmission, and 77% of countries reported some disruptions. Rehabilitation services were the most commonly disrupted.

The WHO *Build Back Better* initiative included forward planning for how to resume services that promote health and well-being. How this is implemented by governments is likely to differ during the continuing impact of a global pandemic and be affected by access to resources that will vary between high- and low-middle-income countries. Pre-existing disparities seem likely to remain including, as has become more obvious over the past months, the inequity of access to COVID vaccines. A global policy may change this, providing there is the goodwill between nations to share resources. Will this lesson be retained?

One resulting change in cancer care, as a result of the pandemic, is that Telemedicine became widely deployed, replacing in-person consultations. In a Special Open Access Issue of the *Psycho-oncology* journal in September 2020, many health professionals involved in supporting cancer patients in terms of the emotional impact of dealing with cancer described how they had to consider new options for provision of care. The use of eHealth

technology was rapidly deployed to ensure psychological support remained available to those with needs. Several issues have arisen and been thrown into high profile as a result.

First, cost is likely to be a factor. The assumption is that telemedicine is cheaper to implement. However, in the area of psychosocial care and support in cancer this is by no means proven. It may simply push costs from one sector, e.g hospital-based psycho-oncology services, to another, e.g., community-based general practitioners or social services. It may even prove more expensive if complicated technology structures are required alongside the professionals offering care. Extra "stuff" to do the job that is normally done in the office or consultation room seems likely: more computers, smart phones, advanced software, and upskilling and retraining in use of computer-delivery.

Second, it's assumed that eHealth methods of care delivery may be as good, or better, than regular in-person/ face-to-face care. There isn't yet sufficient evidence to support either of these

assumptions regarding costs and quality; more cost-effectiveness and care quality data still need to be collected.

For Psycho-oncologists, there were a number of issues to be tackled given the type of services they provide. They had to understand the double whammy of the pandemic on the mental health of people with cancer. Initially, some cancer patients were afraid to attend hospital to receive treatments and/or psychological support. Many patients were also "shielding" and so had reduced social contacts and high fears regarding COVID-19 infection.

Psycho-oncologists described, in the Special Issue of the journal *Psycho-oncology*, how they tried to continue with support for patients and their family caregivers. Family caregivers and partners of cancer patients often found themselves with substantially increased care responsibilities and more worries about the health of their loved ones. They often had to reduce their own social contacts to protect the person with cancer, thereby impacting negatively their own mental health at a time when they had to cope

no matter what. It became clearer that a family approach to psychological care was needed. It was always recognized but now came to the forefront and psycho-oncologists had to re-organize aspects of care to meet the changed needed.

Over recent months many psycho-oncologists have written about their experiences. In general, there is a concern that the model of in-person care they used to give has become eroded and the new tele-medicine approach may be less satisfactory both for them and their patients. In one study² the authors stated that “ Video-consults feel distant; patients and therapists miss the non-verbal contact. Also, non-verbal contact during face-to-face sessions helps clients to express what is most difficult for them”. So a sense of losing a vital channel of

communication was voiced. The feeling echoed was of “...not being able to put a hand on someone’s shoulder to give some consolation or encourage someone, is difficult.” Another feeling expressed was that the prolonged elimination of face-to-face contact was difficult. With psycho-oncology professionals finding that important elements of care felt better being provided with the person in front of you. A more humane and normal element of human socialisation.

We are all social creatures and, although eHealth methods may be retained for the sake of expediency and possible reductions in cost of care, a return to seeing others is predominantly what many wanted. This applies to us as health care providers as much as to patients and their families.

For the future some aspects of care may be more expedient to provide “online” but I, for one, hope that we can once again be in the physical presence of those we are caring for, and caring about. As the WHO has stated in the past “There can be no physical health without mental health”. That is important to remember, and means being able to meet face to face with others as an important dimension of good mental health.

REFERENCES:

1. Rapid Assessment of Service Delivery for Noncommunicable Disease (NCD) During the COVID-19 Pandemic. WHO NCD Department, 2020.
2. van der Lee M.L., Schellekens M.P.J. (2020) Psycho-oncological care via video-consults during COVID-19. *Psycho-oncology*, 29, pp1421-1423

Recommendations for breast cancer management during the COVID-19 pandemic



Cheng-Har Yip

Cheng-Har Yip, MD, *Consultant Breast Surgeon, Ramsay Sime Darby Health Care, Selangor*
Professor Emeritus, University of Malaya, Kuala Lumpur
Malaysia

The COVID-19 pandemic, or Coronavirus pandemic, is an ongoing global pandemic of a viral infection known as Coronavirus-19. The virus was first identified in December 2019 in Wuhan, China, and rapidly spread to all parts of the world. The World Health Organisation (WHO) declared a pandemic on 11 March 2020. As of 18 May 2021, more than 164 million cases were reported worldwide with more than 3.4 million deaths. The USA recorded the highest number of cases and deaths, with nearly 34 million cases and more than 600 thousand deaths.

Although most people infected with the COVID-19 virus are asymptomatic or experience mild to moderate respiratory symptoms, older people—especially those with underlying medical problems such as cardiovascular disease, diabetes, and renal disease—are more likely to develop a serious illness leading to death.

The pandemic resulted in significant social and economic disruption as countries moved to impose lockdowns on all social and economic activity in an effort to control the infection, leading to increased poverty, loss of jobs and global recession. In addition, the pandemic had a major impact on the capacity of health care systems to continue the delivery of essential health services. I know an eminent breast surgeon in India, who is now in charge of a high dependency ward for COVID patients. He had to be retrained to take care of patients with respiratory problems. I have a friend who is an oncologist in New York who had to work in a COVID ward at the height of the pandemic there. Such deployments of health professional are inevitable in situations where there are not enough respiratory physicians, anaesthetists, and infectious disease specialists to cope with the large numbers of COVID-19 patients.

Because health care resources have to be diverted to the management of COVID-19 patients, other diseases such as cancer have to be side-lined, resulting in delays in identifying new cancers and

delivery of treatment and, if unmitigated, can lead to increased cancer morbidity and mortality for many years to come. In addition, cancer patients are at risk of contracting the viral infection because of the immunosuppression associated with the treatment they are receiving such as chemotherapy.

Because breast cancer is the most common cancer in most parts of the world, specific guidelines on the management of breast cancer were developed by some cancer organisations such as the British Association of Surgical Oncology and the American Society of Breast Surgeons. There may be some differences in the recommendations from different groups, but generally the principles are the same, *i.e.*, to minimize risk of transmission of infection, minimize any delay in treatment, and reduce unnecessary procedures and hospital visits. Some of the recommendations in some areas are:

1. Screening mammography should be suspended during the pandemic.
2. Triage all referrals so that only patients with a higher index of suspicion of cancer are seen in the clinics. Appointments for patients on routine follow-up should be deferred unless any suspicious new symptoms develop. Teleconsultation services should be developed and utilised for such cases.
3. If operating time and space is limited

(surgery requires anaesthetists who have to be deployed to manage ventilated COVID patients in intensive care units, and there are reports of operating theatres being converted to intensive care units), surgical priority is given to women with the more aggressive cancers, such as triple negative breast cancers, followed by HER2 positive breast cancers, then premenopausal ER positive breast cancers. Postmenopausal women with ER positive breast cancers can be started on hormonal therapy first pending surgery.

4. Neoadjuvant chemotherapy (that is, chemotherapy before surgery) is currently recommended for women with triple-negative or HER2-overexpressing breast cancer, even if operable, as such types respond very well to chemotherapy. However because of the fear of immunosuppression from chemotherapy, it is suggested that primary or neoadjuvant chemotherapy be used only for women with inoperable or metastatic breast cancer, and surgery upfront is recommended for women with operable breast cancer, whatever the subtype. However in the height of the pandemic in many countries, elective operations were cancelled and only emergency surgery was allowed. Cancer surgery was unfortunately considered non-emergency. If surgery is not available, then chemotherapy may be the only option for women, unless they have ER positive

breast cancer, where neoadjuvant hormone therapy can be used.

5. Immediate breast reconstruction, which can take up more precious operating time, should be discouraged, and delayed reconstruction can be offered at a later date.
6. If adjuvant chemotherapy is needed, there is a suggestion that less toxic regimes should be considered, to reduce the risk of neutropenic sepsis and hospital admissions.
7. Radiotherapy requires multiple visits to the hospital, and hence shorter radiation regimes can be considered, including intraoperative radiotherapy.
8. There should be no surgery for benign breast disease or risk reducing surgery for mutation carriers.
9. Multidisciplinary meetings should be done remotely

The Covid pandemic has changed how we practice medicine. Health care professionals and patients hide under face masks and face shields. We cannot

see each other's facial expressions, and can only communicate with our eyes. The pandemic is still very much in a flux – it comes in waves, and a lockdown is imposed when there is a spike of cases, and once cases come down, lockdown is eased, and then cases spike again, leading to lockdown again. In Malaysia, we have had 3 lockdowns over a period of one year. Although it is hoped that vaccination will bring the situation back to normal, the roll-outs, especially in the low- and middle-income countries, have been lacking, with less than 5% of the population being vaccinated in some countries. Because of the lockdown, women with breast symptoms have problems accessing breast services and, even if access is available, they are scared to go to the hospital. In Malaysia during the lockdown, inter-district and interstate travel is banned and women with breast cancer have difficulties going to breast clinics and cancer centres, which may be in another district or state. They are required to apply for a police permit just to seek medical care which is only available in another district or state. With suspension of screening services and delays in accessing

breast services, there may be a shift from early to late stage of disease, and hence an increased mortality from breast cancer may be seen several years later.

With vaccination programmes being rolled out as quickly as possible, the numbers of new cases and deaths in high-income countries are dropping, and health care services for cancer patients are likely to return to normalcy. However in countries like India and Malaysia, where the numbers of cases and deaths are increasing, it is likely that cancer services will be severely restricted.

The message to all women is that if you feel that you may have breast cancer, do not delay seeing a health professional. Health care services are available, even though there may be barriers to access. At this time, breast cancer support groups will be a good resource to navigate patients to the nearest available health care service.



Editor's note: In Europe, unlike in some parts of the world, breast cancer surgery and related reconstructive surgery has continued throughout the pandemic, albeit at a limited capacity. Many breast cancer patients in Europe have chosen to delay reconstructive surgery until they feel they can undergo it safely, without the risk of exposure to COVID-19. As our colleague Shirley Bianca writes, work has continued throughout the pandemic to ensure that, once these patients are ready, they can be guaranteed their surgery will be performed by a certified breast surgeon.

Breast cancer surgery should be a job for certified specialists – an appeal

Cancer World®



The 2020 launch of the BRESO certification scheme marked an important step in ensuring no one with breast cancer is operated on by a surgeon who is not up to the job. As a survivor and advocate, Shirley Bianca led calls for such a European certification scheme over many years. She's now asking for help to ensure it gets urgently implemented in every place where breast surgery is done.

Many women, knowing they need surgery for breast cancer, are afraid of looking disfigured after their operation. The question, on day one, is how and where to find a specialist breast surgeon. Personal recommendations cannot always be relied on. Often, we end up in the hands of surgeons who lack the knowledge and expertise needed to care for patients with breast cancer.

The 2020 launch of the [BRESO curriculum](#) – a certified specialist training course for breast cancer surgery – marked an important milestone in progress towards

improving the quality of care for people with breast cancer. I feel it was also a bit of a personal achievement, as this is something [I had been campaigning for](#) over many years.

I'm now calling on surgeons, patient advocates and policy makers to take action to help us urgently reach the next milestone – the point at which every breast cancer patient can have confidence that their surgeon is capable of maximising their chance to achieve the best possible outcome.

I was lucky – a highly qualified oncoplastic breast surgeon performed my surgery and removed the triple-negative tumour in 2000, and again in 2005 and 2018. Grateful to be alive, I decided to volunteer and support his patient organisation.

My involvement with the breast cancer patient community started with art. Though I had never painted before, after my second surgery I created a painted story of my survival, called [Message of Hope](#). By disseminating this video worldwide on [YouTube](#) and cancer websites I have been able to encourage cancer patients over

many years, as well as inspiring them to unlock their own creative potential, which can heal both soul and body.

International cancer organisations in Europe invited me to show [this video](#) and the 22 paintings at their conferences. I began to give speeches about, “Cancer and Art walking hand in hand,” and truly enjoyed my unexpected success.

Through this work, I became aware of the many mutilations and unnecessary mastectomies performed by surgeons without specialist training; all this caused literally a deep shock to me. I began to reflect, and I tried to figure out how I could make a difference. So I started to raise this issue in speeches, pointing out the urgent need for a European breast surgeon certification.

In 2016 I held an exhibition at the European Parliament in Brussels. At the opening I emphasised in my speech that there was an urgent need for a formal European Breast Surgeon Certification, as well as for standardisation of training and academic education across Europe, because it takes a specialist to deliver a positive impact on survival and quality of life of the patient.

I was grateful that Cancer World published my Call-to-Action, brightened up with my painting “The Expert Eye”. This was the beginning of my dream to push the issue with passion and perseverance, realising that this would not be an easy task.

The first important step for accredited specialist breast surgical care came when the European Society of Surgical Oncology

([ESSO](#)) and the European Society of Breast Cancer Specialists ([EUSOMA](#)) set up a working group in 2017. This was a forceful initiative that I took part in as a patient advocate.

Organisations involved in training, certification and trials then came on board in 2019 to create the Breast Surgical Oncology Certification Group (BRESO), with a mission “to develop the highest standards of breast surgical oncology in a multidisciplinary setting, for the benefit of breast cancer patients who should receive the best available care across Europe, no matter which country they live in.” They collaborated to develop the Breast Surgery Theoretical and Practical Knowledge Curriculum, which was launched online in 2020.

BRESO is recognised by [UEMS](#), the European Standards in Medical Training, as providing a Europe-wide accreditation of specialist breast cancer surgeons. It offers two pathways to certification: a Prospective Certification, open to surgeons within five years of completing their surgical training, and a Retrospective Certification, open to surgeons with more than five years’ experience working at consultant/attending level.

In my opinion, this breast surgery certification initiative marks a milestone in breast cancer history. But it will only protect patients from substandard surgery if it is put into practice at every centre where breast cancer is treated.

We can all do our bit to ensure that happens.

As a general rule, each candidate who qualifies for the certificate will be added to the list of [BRESO certified surgeons](#), which will be publicly available.

Certified breast units – and indeed all centres where breast cancer surgery is performed – should insist on BRESO certification for any surgeon involved in this work.

Patients should have the right to access treatment by BRESO certified surgeons at certified breast units, and should have the right to the information they need about the benefits of specialist treatment and how to access it.

Policy makers at regional, national and European level should recognise breast cancer surgery as a surgical oncology subspecialty and include mandatory BRESO certification for all surgeons who operate on breast cancer patients, as a key element in their cancer policies.

Did I believe in this success and progress of the project as I began my pioneer work? No, I am truly overwhelmed and deeply grateful for the hard work done by all the BRESO Group Members during the past years.

During my long journey with chemo and radiation therapy, I learnt not only to fight, but also to stand up and raise my voice to end the inequalities in treatment received by breast cancer patients. The more people who join this fight, the faster we will get there.

Satori by sun and candlelight: Changing roles and responsibilities in breast cancer care for patients, caregivers, and health care providers



Rama Sivaram

Rama Sivaram, Consultant, KEM Hospital Research Centre, Pune; Faculty, Sanjeevani Life beyond Cancer

Background

Ruby Ahluwalia, a stage 3 breast cancer survivor, says, "I saw people sitting on the floor of the hospital with no hope in their eyes . . . Those eyes would haunt me."

3 years after her own treatment, Ruby conceived Sanjeevani Life Beyond Cancer (SLBC) in collaboration with Tata Memorial Cancer Hospital, Mumbai. Her first program was called Can-Sahyogi (cancer companion/helper) and involved hand holding, supporting and working with underprivileged cancer patients in the hospital outpatient department. There was no looking back. Today, there are 17 centers across 15 cities in India, all managed by SLBC-trained caregivers. Caregivers undergo the caregiver's course called Can-Saarthi (cancer-charioteers, who drive patient care), a skill-development program with the objective of raising the bar for cancer care in India and providing employment to cancer survivors and their relatives with rigorous training in cancer caregiving.

The need for awareness programs to rebuild the quality of life, health and immunity of cancer patients called for a supportive holistic healing initiative and so SLBC created Satori (awakening to the self) along with Can-Chetna and Can-Varta (meaning cancer-consciousness and cancer-talk). The program model equips patients and survivors with skills to strengthen immunity by working on factors like diet, pranayama (breathing techniques), yoga, tapping, sound and music healing, counseling and rewriting constructive scripts for enhanced living. The initiative addresses both body and health-related physical issues and their primary mental constructs, which play a vital role in wellness.

In the wake of the COVID-19 pandemic, there are distress calls from patients who have very little or no recourse for treatment due to multiple factors. The founder, Ruby, asked me online, "What can we do, that extra something special for patients with

recurrence, denied care due to this pandemic, how can we lift them from feeling left out?"

Satori 2 for patients *with recurrence* was then born.

The cries lost in the pandemic 2020-2021

"My cancer has come back. I am told there is no more treatment, so I need not come back, maybe try something called palliation." Many voices, many women, some lucky to get and complete treatment and others lost in the pandemic. Voices of women with recurrence began surfacing and something had to be done. While all activities of SLBC continued online, in hospitals and at the 17 centres, it was not prepared for patients with recurrence who could not reach cancer care centres due to lockdowns, fear, risks of COVID-19 and co-morbidities, shortfall in cancer services and logistic issues. Team Sanjeevani recognized that optimism, optimal treatment and emerging supportive care for a first diagnosis does not always hold true for a recurrence because how the disease takes its course and affects the patient can only be surmised.

What could we do for patients devastated by a second diagnosis or recurrence? As patient needs grow and change, caregiving too must adapt accordingly. The tools and roles of caregiving cannot be static nor can they always be evidence based; as long as they intend promotive, relative well-being and quality of life, they should be available to patients. COVID-19 in every neighbourhood and almost every home, along with nationwide sporadic lockdowns, have brought life to a standstill and impacted cancer care across India. The need to prepare, plan and execute that extra special supportive care is a clarion call.

Need for Satori 2 for patients with recurrence

Satori 1, the original holistic healing package, is complete in itself to optimize quality of life for those in active treatment and post treatment-survivors, helping them adopt

and adapt to a new normal by rebuilding their health and immunity. However, it does not suffice for patients with recurrence and needs to be more robust. Recurrence brings dramatic changes in the patients and their caregivers; their needs become more specific, personal, clinical, physical, emotional and spiritual. The levels of each component differ from patient to patient, sex-gender, age, type of and stage of disease, clinical treatment available and a prognosis of long or short survival outcomes.

From bits and pieces of conversations, the angst of these women highlights two major themes: one when they did not think about and address their needs before cancer and then when cancer opened them to themselves and they take an active stance to address those needs. So, we hear stories of how cancer changed them. Yet, when some women make changes and come to terms with their new normal, carefully rebuilding their lives and gaining control, they are suddenly undermined by recurrence. Recurrence switches on an avalanche of feelings, implying threat, life limitations, a sense of que sera sera, fear of pain and death, and a sense of betrayal of some x factor. Change again is a challenge when hope, belief and relief are displaced. In the existing models of patient care, the focus for patients with recurrence is medical management. Goals of care are active treatment, passive treatment or palliation. Addressing physical, psychological, existential, social, spiritual, etc components only happen within institutional setting and in clinical context. In the cultural context of India, a hospital is for cure; so, palliation, recurrence and the dreaded cancer together mean no cure, painful death, losses and a hopeless situation. The added burden of the pandemic and resulting isolation continues to cast doom and fatality on lives, livelihoods, and mental health.

Self-care model of chronic illness

Self-Care is the practice of taking an active role or action to preserve or improve one's own health, protecting own well-being and happiness, in particular during periods of stress.

– Oxford Languages

Satori 2 draws on and has adapted from the Middle-Range Theory of Self-Care of Chronic Illness in cardiac patients. It is stated that, “self-care influences both clinical and person-centered outcomes in patients with chronic conditions. Those who engage more effectively in self-care have better quality of life, lower hospitalization rates and less mortality than those who report poor self-care.” So, women who reach out to us are being taught to take care of self and maintain quality of life through a set of health promoting practices to manage illness, cancer recurrence in our case.

Since every cancer is different and breast cancer has its own types, subtypes and treatment approaches, our program is unique and different in that it serves the group as well as the individual, it is designed to address both common and individual needs with respect to both complementary or alternate therapies and medical information-based guidance. It is in response to the dearth of medical information and management of conditions otherwise requiring hospital or home care services. Goals of care in Satori 2 are the new introduction of a medical information module, where women learn self-care skills based on their current health condition and stay engaged in their own self-care. The main two objectives are wellness or complementary therapies and the medical information module.

Wellness or complementary therapies

On a common faculty consensus, the number of participants is limited to between 10-15 so that women get more time to share, talk and learn. On demand are restorative and healing therapies, like specialized medical yogasana (physical postures and stretches), pranayama, and yoganidra (a powerful meditation technique involving a self-body scan, visualization and breath awareness); tapping-emotional freedom technique (tapping specific points on the head, face and torso in a particular sequence). It combines a little of psychology where the person identifies and focusses on an issue, gauges their feelings using a scale of 1-10, creates their own reminder phrase which acknowledges the problem and acknowledges self-acceptance in spite of and along with it. This is followed by a specific sequence of tapping and

feelings are again gauged on a scale of 1-10. Counselling therapies are facilitated for emotional well-being and healthy coping skills. Dietary and nutrition intervention addresses specific and special needs for improved immunity and optimal well being during and after treatment.



Ruby Ahluwalia, founder of Sanjeevani Life Beyond Cancer, and Rama Sivaram

The medical information module

Complementary therapies play a significant role in connecting women to themselves by helping them recognize their needs and deficits and overcome them through acceptance, commitment and adherence. It is a promise they make to themselves. This is making the self-care model a do-able intervention model. The term medical information in this context implies that, with the consent of the women, we have access to their medical file and history and current treatments and treatment protocol. Based on this, we educate them on their disease, side effects and their management, how to practice self-care and when to seek medical care. A very important and often unaddressed aspect that the module focusses on is a close watch on alternative medicine or therapies, drop-out patients and status of diagnostic and laboratory parameters and panels. This is done as the management aspect of self-care after self-maintenance and monitoring of symptoms when women follow naturopathy, ayurveda and other Oriental systems of medicine, where some macro and micro nutrients are eliminated from the diet and some medication could contain lead and mercury with potential toxic effects. Classic examples include protein free diets and edema, saltless diets and altered mood changes, lack of adequate calcium in vegetarianism and banned dairy products combined with aromatase inhibitors like Letrozole, Femara and skeletal metastasis, further exacerbating increased risk of osteoporosis and fractures. Medicines containing heavy metals and dietary do's and don'ts may cause further damage to organ systems or biochemical parameters. One-to-one and group discussions enable the team to connect

with one another. The medical information module immediately asks the women to get their blood panels and diagnostics and to connect with the nutritionist, psychologist and professional caregiver. Be it a clinical or mental health issue the faculty meets online periodically and discusses cases. This is done specifically because the goals of the program are improving and maintaining well-being, monitoring symptoms and seeking management indicators that can be self-managed or need medical /clinical oncologist management. Because they are still living and may continue to live with their disease for a long time, and because they are following different therapies, it is important to be updated and make choices.

An initial activity clock (clocking their daily routine) to assess how much time, care, sleep, rest, exercise they give to themselves is organized for self-assessment. This is to enable them to stay in control of their life and illness. Intended outcomes are adherence, personal responsibility, overall well-being and quality of life, minimizing symptoms and pain, minimizing emergency hospitalization, recognizing when some laboratory procedures and a doctor's attention is necessary and cannot be ignored, whatever choice of treatment one may choose. Women are educated on the three components of self-care so that they can put it to best practice. These are:

Self-care maintenance: Health promoting practices/behaviors like nutritionist-guided eating, managing timing for each activity like sleep, physical exercise and activity, taking medications and committing and adhering to treatment.

Self-care monitoring: Mindful awareness, self vigilance and surveillance, paying attention to symptoms and changes in the body and mind. Tracking physical and mental status in order to respond/act on them.

Self-care management: Responding to a symptom, event or any other change in the body and mind with appropriate and acceptable medication which has been prescribed or alternate approaches for relief from any distressing symptoms. Evaluating physical, cognitive, emotional change, signs and symptoms, progressive pain, change in activities, diet and environment, etc. are part of the discipline in self-care. This means taking action by seeking information and online or telephonic medical consultations when needed in the form of medication or advice.

Satori 2 has emerged as a program for patients with recurrence of any cancers. This article highlights women with breast cancer and ovarian cancer recurrence. Dealing with recurrence in halted services and lockdown,

the vaccine not recommended for women undergoing treatment, less than 45 years of age, and stamped with co-morbidities, it is a trying circumstance. Women wear their Big C like the scarlet letter; they blame themselves and feel guilty, betrayed, anxious and angry. Satori 2 continually works on busting these gender-driven myths, misguided information and beliefs, and over-worked mental processes, which are fed by the self-scripted, depressing thoughts and increase a vicious cycle of body-mind reactions and responses. As caregivers, we are trying to adapt and go beyond hand-holding into training patients in self-care skills and putting them in control. We teach them that the choices they make can be kindnesses to themselves, and it works. We clarify at the outset that they are major partners and contributors in Satori 2

because they will teach us what is useful and what we need to change or add. So, we seek out every opinion and response, putting aside all platitudes. The response is gratifying. It is truly motivating that the women are overwhelmed with a sense of gratitude for being listened to and heard with empathy. They express motivation to recharge themselves and take control. Acceptance and understanding their circumstances, acting on them and feeling more positive, physically and mentally, is because of the positive actions they are taking and the skills they are learning and putting into practice. Satori 2 is confident that in this journey through cancer there is an oasis — a safe place to grieve, heal and move on in their passage to recovery or another space.

I would like to end with a voice which is bubbling with the joy of self-discovery, *“I learnt to live for the first time in 56 years for myself after Satori 1 and 2. I am alive and I am aware that I am here and now with or without breast cancer.”*

I would like to thank Ruby Ahluwalia, the Founder of SLBC, and the very young and dynamic team of administrators and interns: Priyasha, Ghousia, Abida, Arpita, Mouli and Roopika for collating all patient data and keeping in constant touch with every patient, following up, building bridges and keeping us connected.

<https://www.sanjeevani-lifebeyondcancer.com/>

To explain the title of the article – Satori by sun and candlelight – “Satori” is a Japanese Zen Buddhists tradition that means the path to self-awakening or understanding the nature of self. “By sun and candlelight” is borrowed from *How do I love thee?, Sonnets from the Portuguese, No. 43* by Elizabeth Barrett Browning.



REFERENCES:

- Integrating Symptoms into the Middle-Range Theory of Self-Care of Chronic Illness. Barbara Riegel, Christopher S. Lee, Tiny Jaarsma, Anna Stromberg *ANS. Advances in nursing science* · November 2018, <https://www.researchgate.net/publication/329094704>
- Self-care: Who cares? Anna Stromberg Barbara Riegel Tiny Jaarsma; *European Journal of Cardiovascular Nursing* · June 2012; <https://www.researchgate.net/publication/225094743>
- Heart failure self-care, factors influencing self-care and the relationship with health-related quality of life: A cross-sectional observational study-Binu Koirala, Cheryl R. Dennison Himmelfarb, et al. <https://doi.org/10.1016/j.heliyon.2020.e03412>
- Factors Related to Self-Care in Heart Failure Patients According to the Middle-Range Theory of Self-Care of Chronic Illness: A Literature Update Tiny Jaarsma^{1,2} & Jan Cameron^{3,4} & Barbara Riegel^{2,5} & Anna Stromberg^{6,7} *Curr Heart Fail Rep* (2017) 14:71–77 DOI 10.1007/s11897-017-0324-1
- Correlates of fear of cancer recurrence in women with ductal carcinoma in situ and early invasive breast cancer. *Breast Cancer Res Treat.* 2011 November; Ying Liu, Maria Pérez, et al 130(1): 165–173. doi:10.1007/s10549-011-1551-x.
- Diagnosis of second breast cancer events after initial diagnosis of early-stage breast cancer. Diana S. M. Buist, Linn A. Abraham, et al *Breast Cancer Res Treat.* 2010 December; 124(3): 863–873. doi:10.1007/s10549-010-1106-6.
- Quality of Life Intervention for Breast Cancer Survivors: Application of Social Cognitive Theory. Kristi Dove Graves-Ph.D. dissertation, 2001
- Translating Psychosocial Care: Guidelines into Action Suzanne K Steginga,^{1,3} Sandy D Hutchison,^{1,2} Jane Turner² and Jeff Dunn, *Cancer Forum* Volume 30 Number 1 March 2006
- When cancer Returns- National Cancer Institute (NIH)

Coping with the pandemic at Prashanti Cancer Care Mission

Laleh Busheri, CEO, Prashanti Cancer Care Mission

Pune, India



Laleh Busheri

Prashanti Cancer Care Mission (PCCM), a cancer-focused NGO in Pune established in 1996, went on in 2008 to establish India's first stand-alone breast cancer unit called Orchids Breast Health Clinic, a dedicated Centre of Affordable Excellence in Breast Health. This state-of-the-art breast unit has unmatched diagnostic tools such as Contrast Enhanced Digital Mammography with 3-D Tomosynthesis, 3-D Ultrasound, Vacuum Assisted Biopsy (VAB) for removal of fibroids and cysts, and Mammotome Biopsy. It also houses a 10-bed day care for chemotherapy and an in-house oncopharmacy. In addition, Orchids Clinic has been a pioneer in the establishment of a Breast Oncoplasty unit, the first of its kind in Asia, which offers multiple options in breast conservation surgery to avoid mastectomy (*i.e.*, total removal of the breast). This Centre also has in-house radiodiagnosis, precision biopsy, surgery consultancy, chemotherapy and genetics departments which serve the needs of many cancer patients from Pune and surrounding areas. With these comprehensive facilities and services, PCCM has been able to provide concessional and free cancer treatment and support to thousands of patients and their families in the past decade.

The unprecedented global COVID-19 pandemic has affected virtually every country in the world including India. Given the rising number of COVID-19 positive cases in March and April of 2020, Pune was declared as a "red zone" for disease containment. As a result, all hospitals and clinics in Pune were on high vigil.

The COVID-19 crisis presented huge challenges in cancer management not only to the Oncology fraternity but also to the cancer patients and their families. Cancer patients are among those at high risk of serious illness from an infection because their immune systems are often weakened by cancer and its treatments. Given the high risk of COVID-19 infections, cancer patients had to be handled more diligently by achieving a pragmatic balance between cancer treatment schedules and mitigating COVID-19 risk.

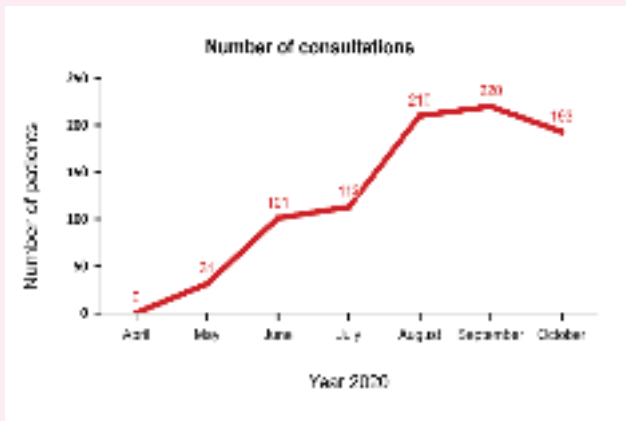
Based on the national and international guidelines and in the medical interest of cancer patients undergoing treatment at Orchids Clinic, PCCM decided to continue providing emergency support and treatment support to its patients mainly affected with breast cancer. To this

effect, the onco-clinician team at PCCM led by Dr. C. B. Koppiker published a detailed advisory for the safety and well-being of the cancer patients during the lockdown and the fast spread of COVID-19 infection. The advisory described various important topics in detail regarding several aspects of cancer management during the pandemic including consultation for radio-diagnosis, surgery, chemotherapy and radiation therapy. In addition, the advisory also elaborated on the topic of diet/nutrition on cancer patients during COVID-19 crisis as well as use of traditional medicines (Ayurveda and Homeopathy), stress management, exercise and mental health issues.

Services at Orchids Clinic were offered as per the Pune Municipal Corporation guidelines for every phase of the lockdown. With measures to curb the exposure to COVID-19, the number of patients visiting the clinic varied through the lock-down phases. The highest number of consultations were in the month of September 2020 as the regulations were relaxed. We also witnessed a steady rise in the number of biopsies performed at our clinic after resumption of normal services.

After the relaxations in the guidelines, PCCM onco-clinicians as well as paramedical professionals have been providing the best possible services to cancer patients. Telephonic consulting services that served as an important mode of communication during the lockdown have been integrated into our regular practice post COVID. The PCCM pink-ribbon support group of cancer survivors is actively involved in communication with cancer patients and their care givers to check-up on their well-being and other needs. Ration supplies have been provided to needy families as part of the PCCM food bank program.

During the COVID-19 crisis, Dr. Koppiker was inducted as a member of Pune Platform for COVID-19 response (PPRC). PPRC was a group co-ordinated by Maharashtra Chamber of Commerce and Industries (MCCAI) which is helping Pune healthcare organisations from public and private sector with their requirements in the COVID-19 crisis. Through PPRC, Dr. Koppiker was instrumental, with the help of generous donations from philanthropies and Corporate Social Responsibility initiatives of corporate sector entities, in



the procurement of a large-scale supply of Personal Protection Equipment such as N95 masks and ventilators, as well as hospital supplies and consumables.

Considering the current spike in COVID-19 in the country, especially Pune, it is likely that the ongoing COVID-19 crisis may continue for an extended period into the future. In light of this, PCCM remains committed to providing the best possible services and care to its cancer patients as per international advisories and guidelines from the Government of India.

PCCM established a Centre for Translational Cancer Research in 2017 to conduct research on Indian breast cancer. Our research has evolved into national and international collaborations where we have collaborated with scientists from institutes like the Indian Institute of

Science Education and Research, Pune (IISER), National Chemical Laboratory (NCL), Council of Scientific and Industrial Research (CSIR), Council of Science Education and Research, UK, Indiana University and National Institute of Health. Our main focus is research on triple negative breast cancer (TNBC), an aggressive subtype common in Indian women. In this effort, Indian TNBC research has led to better understanding of genetics, molecular pathways, drug therapy outcomes and surgery planning paradigms. CTCR has recently spearheaded the establishment of the Indian Cancer Genome Atlas project to create multiomics profiles of Indian Cancers.

The measures and methods employed at Prashanti Cancer Care Mission are accepted for publication in *South Asian Journal of Cancer Care* and will serve as a

reference to follow optimal standard of care for cancer patients during the pandemic.

Updates and more information are available on the websites below:

www.prashanticancercare.org

www.orchidshealth.in

www.breastoncoplasty.org

www.ctcr.in

www.tcga.ctcr.in

The COVID-19 experience for women living with breast cancer in Palestine

Carol El-Jabari

Palestine



Members of the Sunrise group

As though living with cancer wasn't enough, Covid-19 happened. As we have heard from others, chronic diseases and associated health problems have been neglected or sidelined as health systems struggle to cope with the pandemic. This has been the case in Palestine.

From early March 2020, the government and non-governmental sectors worked to raise awareness about the need for social distancing, hand washing, mask wearing etc. in an effort to protect oneself and others. Unfortunately, many people did not take the calls for self-isolation, and hygiene precautions seriously and numbers of cases (and deaths) rose.

According to worldometer.org, the population of Palestine exceeds 5 million with the mean age at 20.8 years (accessed May 9, 2021). Palestine is one of the most densely populated countries in the world, 8th most according to populationpyramid.net (2019) while being a low-middle income country.

A predominantly young population who express the attitudes "I will not get COVID-19, or I am not at risk" compounded efforts by the authorities to control movement, hygiene precautions, etc. Also compounding the situation are overcrowding, poverty (day labourers need to go to work), and insufficient medical infrastructure. Many of our "Sunrise group" members (women living with cancer) had family members come down with COVID-19 and consequently they also got the virus. Interestingly, while there was advice to take precautions against the virus, this was often ignored or not taken seriously by the

group members or their families. They had simply adopted a fatalistic attitude towards the virus, much as they have done with a cancer diagnosis.

So, with an overwhelmed health service, restrictions on movements and hundreds of infected persons each day, cancer care — whether it be for screening, diagnostics or treatment — has been negatively impacted. Doctor's appointments and follow up became less of a concern. Engaging with patients face to face became impossible and meant all of our efforts to improve their wellness activities came to a halt.

In an effort to continue providing psychosocial support and information for women living with breast cancer, we were available 24/7 via the internet (Facebook, Whatsapp), texting and phone calls. Repeated lockdowns and restrictions meant we could not meet face to face but in an effort to keep contact we conducted video meetings. Not everyone participated, unfortunately, as they did not know how to join or have smartphones or had too many people around them to have a quiet conversation.

This last year has been very challenging on so many levels.

Fast forward more than a year since the first lockdown in 2020: with cancer patients

on the governments priority list to receive vaccines, we are hoping to have turned a corner. We are looking forward to face-to-face meetings, resuming healthy activities and just being available for each other.

“AS WE HAVE HEARD FROM OTHERS, CHRONIC DISEASES AND ASSOCIATED HEALTH PROBLEMS HAVE BEEN NEGLECTED OR SIDELINED AS HEALTH SYSTEMS STRUGGLE TO COPE WITH THE PANDEMIC”

Supportive care for breast cancer in a time of COVID-19: A South African perspective



Stephné Jacobs



Avis Perks

Stephné Jacobs, RRI Regional Representative, Southern Africa Region, and Avis Perks, Reach for Recovery South Africa Alumna

Breast cancer support and care groups in South Africa share their views on how the pandemic has impacted their organisations, and how they have adapted their services. The following summaries are an overview of their work, and were compiled from responses to a questionnaire, focussing on challenges resulting from COVID-19, and how they found ways to continue their services.

AmaBele Belles

bellescommittee@groups.outlook.com

The primary interest of the amaBele Belles is to promote and engage in dragon boat paddling. Their team aims to project an image of the healthy and vigorous lifestyle that can be enjoyed by breast cancer survivors, and to act as a “floating support group” for their members. The team is about 40 strong, and 70% are breast cancer survivors.

The waterfront management and countrywide restrictions during lockdown kept the AmaBele Belles from paddling from the beginning of lockdown in March 2020 to the following October. A second cessation of paddling accompanied the second wave over Christmas 2020. Since the end of January 2021 they have been paddling and fulfilling their “outreach” function as usual. Even now, they are practicing social distancing on the jetties and while climbing on and off the boats. Their main challenge has been keeping up the sense of being part of a team or community, even as they have drawn up strict protocols that allow only 8-10 paddlers on the boat at a time. This has led to frustration when there are too many or too few paddlers, but they have learned to adapt and make the best of a fluid situation.

Breast Health Foundation (BHF)

<https://www.mybreast.org.za/>

The BHF strives to help patients and their families understand what breast cancer is, how to detect breast cancer, what to do with the news of a breast cancer diagnosis, what treatment method is most appropriate,

and how to navigate the public healthcare system during treatment and survivorship.

Initiatives and projects include Community Patient Navigators, Mobile Breast Cancer Education Units, Bosom Buddies (a volunteer-run psychosocial support group that provides emotional and informative support to women and men affected by breast cancer), Meta Buddies (an online support group that provides support to women and men affected with metastatic breast cancer), and a 24-Hour National Care Line that provides psychosocial support and guidance to those in need and is manned by a qualified team, all breast cancer survivors. The BHF publication, Buddies for Life is a boutique magazine for the breast cancer community published bi-monthly in collaboration with Word for Word Media. <https://www.buddiesforlife.co.za>

Due to the pandemic, the mobile education units, which normally visit clinics and health facilities, have ceased to operate. This means BHF has lost the ability to educate face-to-face in the resourced-challenged communities they serve. Patients have had to face their treatments alone, as BHF cannot access the treatment units to provide support. Patients are feeling increased anxiety about treatment, getting to treatment, and fear of COVID-19. Many patients do not have access to smart phones and/or data to use as a communication tool. Although technology has improved internationally and has connected the world, many people in South Africa do not have the income or resources

to use these data driven apps. Even WhatsApp is a challenge.

BHF has elected to do online support meetings for those who do have access to data and devices. It also provides more telephonic support via the care line. However BHF believes that to be fully effective in supporting patients it is imperative to still have the human touch. Patients want someone who shares with them in a compassionate manner. This is very difficult to achieve on a screen.

Cancer Association of South Africa (CANSA)

<https://cansa.org.za/>

CANSA offers a unique, integrated service to the public and to all people affected by cancer.

Its mission is to be the preferred non-profit leader that enables research with regards to lowering cancer risk, educating the public regarding symptoms, screening and risk reduction, and providing care and support to all people affected by cancer. Its Advocacy team performs a watchdog role, striving to ensure that South African policy makers are influenced with regards to important cancer control issues and patients’ rights to healthcare is protected. CANSA is committed to connecting people facing cancer with information, day-to-day help and support. Its aim is to ensure that cancer survivors and their loved ones don’t have to face cancer alone. It offers toll-free professional tele-counselling in 7 languages and online support programmes. The responsibility rests with patients to contact CANSA.

At the onset of the pandemic, CANSA was identified as an emergency service. It had to limit face-to-face interaction with volunteers and patients due to lockdown restrictions. Its public campaigns and fundraising events were also impacted. Major challenges were to continue supporting families face-to-face and utilising volunteers as before, and ensuring a continuous income. It adapted to cope with changed circumstances by realigning its operating structure and service offerings in line with resources available. It also developed more virtual support platforms. Staff can work virtually, which lowers overhead costs and focusses on offices in the bigger centres. They make use of online offerings for training webinars and reach volunteers through online summits

With the onset of COVID-19, CANSA implemented a new staff structure and adapted and combined roles where needed. It had to train all staff in COVID-19 regulations and provide PPE for staff and volunteers working with patients. Patients could continue their treatment but many were scared and some decided to stop treatment. As a result, new tele- and online counselling and support services were started. One positive lesson that CANSA learned from the pandemic experience is that it can be more visible and reachable through various online support offerings like WhatsApp and Facebook.

Look Good...Feel Better South Africa (LGFB) <https://www.lgfb.co.za/>

As part of a global initiative, LGFB South Africa was established by the Cosmetic, Toiletry and Fragrance Association in 2004. It is strongly endorsed by oncologists countrywide as a valued support programme, making a difference in the lives of women in active cancer treatment. It was formed to help women address the visible side-effects of their cancer treatment. The programme is dedicated to improving the wellbeing and self-confidence of people undergoing treatment for any type of cancer. Free two-hour interactive workshops, for patients in active cancer treatment are held in 40 public and private hospitals in seven of South Africa's major cities. Products are donated by the beauty industry each year for the patients' gift bags and are used as tools to address appearance related side effects.

The cosmetic industry was challenged by the COVID-19 pandemic with reduced sales, which impacted on their ability to continue sponsorship. As a result of lockdown restrictions, workshops at hospitals were suspended and the number of patients that could be supported was reduced. In addition, the foundation's fundraising activities were suspended. No fundraising or sponsorship resulted in less income

and, to carry the foundation, staff salaries were cut. The major challenge was how to keep the doors open with no income, while safeguarding the future and continued work of the foundation. These challenges were global, but certainly compounded in the Southern African context, as the cosmetic industry in South Africa is much smaller and unlike the global situation, no support is received from the government. Having an essential service certificate, the foundation managed to host one-on-one workshops as opposed to group workshops, and one group workshop was hosted virtually. The staff adapted well and were diligent and responsible in working from home. Both staff and volunteers embraced new ways of working using digital platforms, and found these opportunities exciting. The foundation's biggest goal now is to continue to instill hope and a will to survive in all patients in need of support.

Reach for Recovery South Africa <https://www.reach4recovery.org.za/>

Reach for Recovery South Africa (RFR) supports more than 6000 breast cancer patients per year at 137 treatment centres across 6 provinces. Its volunteers travel to hospitals and Breast Care units at their own cost to visit patients and provide the vital emotional support they need. Each patient also receives a Care Bag with a booklet and pamphlets dealing with various topics relevant to breast cancer patients, a soft prosthesis, a cushion for under arm comfort and a bag to contain the port-au-vac drain. Between 850 and 1000 state patients are fitted with a subsidized silicone prosthesis annually. RFR has 210 volunteers, more than 190 of whom are breast cancer survivors.

At the onset of the pandemic, meetings with Group Chairpersons were convened immediately to discuss a way forward so that volunteers could still provide support services to breast cancer patients in a safe way. It was clear that breast cancer patients experienced increased anxiety due to delayed diagnosis and treatment caused by strict lockdown regulations at hospitals and clinics. No visits to patients were allowed. RFR's flagship project, the Ditto prosthesis-fitting project, was also a huge challenge. As the fitting process involves very close contact between fitter and recipient, the service had to be suspended. Lockdown regulations further also prohibited any public gatherings where volunteers could do breast health education. The pandemic also impacted fundraising projects.

RFR is still one of the few organisations whose volunteers visit patients in hospitals and clinics. It immediately provided volunteers with tips on how to conduct effective telephone support. Email support

was provided and volunteers engaged with patients via WhatsApp video calls. Volunteers themselves used creative ways to ensure that patients still received their care bags: Some were delivered at hospitals, via treatment centres or handed to family members in a safe space. All public breast health education activities have been suspended. RFR is using its national Facebook page to educate members of the public on the pandemic.

COVID has given the organisation little choice other than to consider other ways of continuing its services. Modern technology makes it possible for volunteers to provide different services from their homes – patient support and breast cancer information via cellphone, WhatsApp video, group meetings and virtual conferencing. RFR has also realized that Zoom conferencing could be a way to continue volunteer training through online sessions.

Wings of Hope Cancer Support <https://wingsofhope.org.za/>

Wings of Hope Cancer support is a non-profit organisation initiated by mainly breast cancer survivors and run by volunteers. It provides emotional support to those affected by cancer, as well as to family and friends, in a warm compassionate environment.

Wings of Hope has found that its major challenge during the pandemic has been a disconnect with patients in hospitals. It moved all face-to-face meetings to an online platform, which it still hosts every 6 weeks. The WhatsApp and social media groups have worked well. Using online platforms provided an opportunity to increase its reach for support group meetings. The ability to provide a national (rather than regionally-based) support mechanism via electronic means has been a positive outcome. Lessons learned are that support work must continue in whatever form possible, and that the organisation needs to remain adaptable.

Conclusion

These stories reflect challenges unique to South Africa, but also show that, as has happened across the world, there have been substantial changes in the roles and responsibilities of breast cancer care and support groups. Due to COVID-19, there has been a shift from face-to-face connection to using telephone, WhatsApp video calls, email, as well as online webinars and social media. A common thread in these responses is the determination of the groups to find ways to continue their services – a powerful testimony to their resilience, dedication, creativity and innovation.

Pink Unity Malaysia: “Giving Hope, Touching Hearts”

Halimah Shaari, Advisor, Pink Unity Committee

The tagline says it all. In the world of cancer where hope is often in short supply, being offered hope is akin to being thrown a lifeline while drowning. A cancer support group, Pink Unity (PU), tries to do just that to ensure that a cancer survivor’s journey need not be a lonely and painful sojourn.

A focus group established in 2008, Pink Unity is a support group of the National Cancer Society of Malaysia for women who have survived cancer. With its tagline “Giving Hope, Touching Hearts”, PU provides a platform to unite women with all types of cancer on their cancer journey.

No matter how sophisticated and cutting edge a country’s cancer treatment and technology is, the road to recovery for a cancer patient is made less stressful and more effective with the involvement and participation of a cancer support group.

PU uses a holistic approach through several initiatives to help cancer survivors. Called the P.I.N.K. Initiatives (Peer Support, Inner Strength, Networking, Knowledge), the activities offered not only create an environment of sharing for cancer survivors, but equally important, empower them through rebuilding their self-confidence which may have been eroded with the physical changes they experienced.

PU is especially proud of its flagship program called “Pink Blossom” which is a sharing session where participants discuss topics/issues pertinent in their recovery. A typical session would include a discussion on a specific topic/issue, games, song and dance. These sessions, conducted every two months, have seen participants “blossom” from being lost, uncertain, sad and angry into survivors who are empowered to take control of their recovery and survivorship.

The world was severely challenged in 2020 in the face of the global COVID-19 pandemic. The first few months of 2021 have been no better; those facing chronic medical conditions are particularly and increasingly tested, with mental health being among the biggest concerns. Realizing this, PU had to step up its programs. And rise to the occasion it did, with various activities that help motivate

members and keep the feeling of isolation and depression at bay.

Since the pandemic curtailed physical interaction, PU had to improvise and conduct many activities through the Zoom platform. This way PU is still able to engage the members in interactive activities and make them feel they are not alone. Activities organised since the first lockdown in March 2020 included virtual DIY classes, games, tea-parties, fitness activities, cultural and religious festivals and talks on mental health, self-empowerment, etc. The various activities try to cater to the interests of as many members as possible. PU also seized the opportunity to make some profits through the cloth mask project. Masks were sold to the public and the proceeds used for PU activities.

Special mention must be made about the PU 2020 Christmas party. Conducting a party via Zoom was not an easy feat. How do you make up for the physical isolation that robbed members of face-to-face interaction? Kudos to the organizing committee, that went to great lengths to ensure members “ate together” during the party the same pre-cooked lasagna which was pre-delivered the day before by Santa and Santrinas. Though physically apart, the celebrations were no less festive with songs, dances, games and competitions.

PU continues to find ways and means to bring a smile to the faces of the members and to inspire them in this unprecedented challenging time. It holds steadfast to its mission to give hope and touch the hearts of members to help them in their cancer treatment and survivorship.



Pink Blossom in session pre COVID-19 lockdown



Members with their ‘masterpieces’ after a decoupage class



PU’s cloth mask project during the pandemic



We will launch the
public exhibition online
in October 2021.
We look forward to
seeing your art!

PATIENT ARTS FOR HEALTH

GLOBAL EXHIBITION

Art making includes a diverse range of human activities involving the creation of visual, auditory, or performing experiences, which communicate the creator's imagination, conceptual ideas, or technical skills, intended to express how we feel and with emotional power.

The Rising Tide Foundation is launching an international Patient Arts for Health - Global Exhibition to collect and curate patient art offering new insights on what quality of life means to you through your art.

The goal is to engage in the creative process that lifts our spirits and feeds our souls. To convey truths about each person's particular situation which is best communicated through the language of the arts. The goal is simple: Invite patients to make art and share this work with others who can both learn and heal from this work.

To participate, please complete the participation form on our website: <https://www.risingtide-foundation.org/patient-arts> and submit your art (in any modality) together with a brief description (text, audio or video) about how this work makes you feel in any of the following electronic formats: JPG, TIF, EPS, mp4.

The participation period starts February 2021 and has no end date. The work must not belong to a public collection, nor have won an award in a competition.



For more information,
please contact
globalexhibition@risingtide.ch

Cedar plank salmon

Global
Kitchen

Summer recipes
from the USA

Ingredients:

1 teaspoon each of dried powder, black pepper, onion powder, and paprika

Zest from ½ orange

2 teaspoons lemon juice

2 lemons, sliced

1 & ½ pound (680 grams) salmon filet with skin removed

Fresh Thyme sprigs

Cedar plank

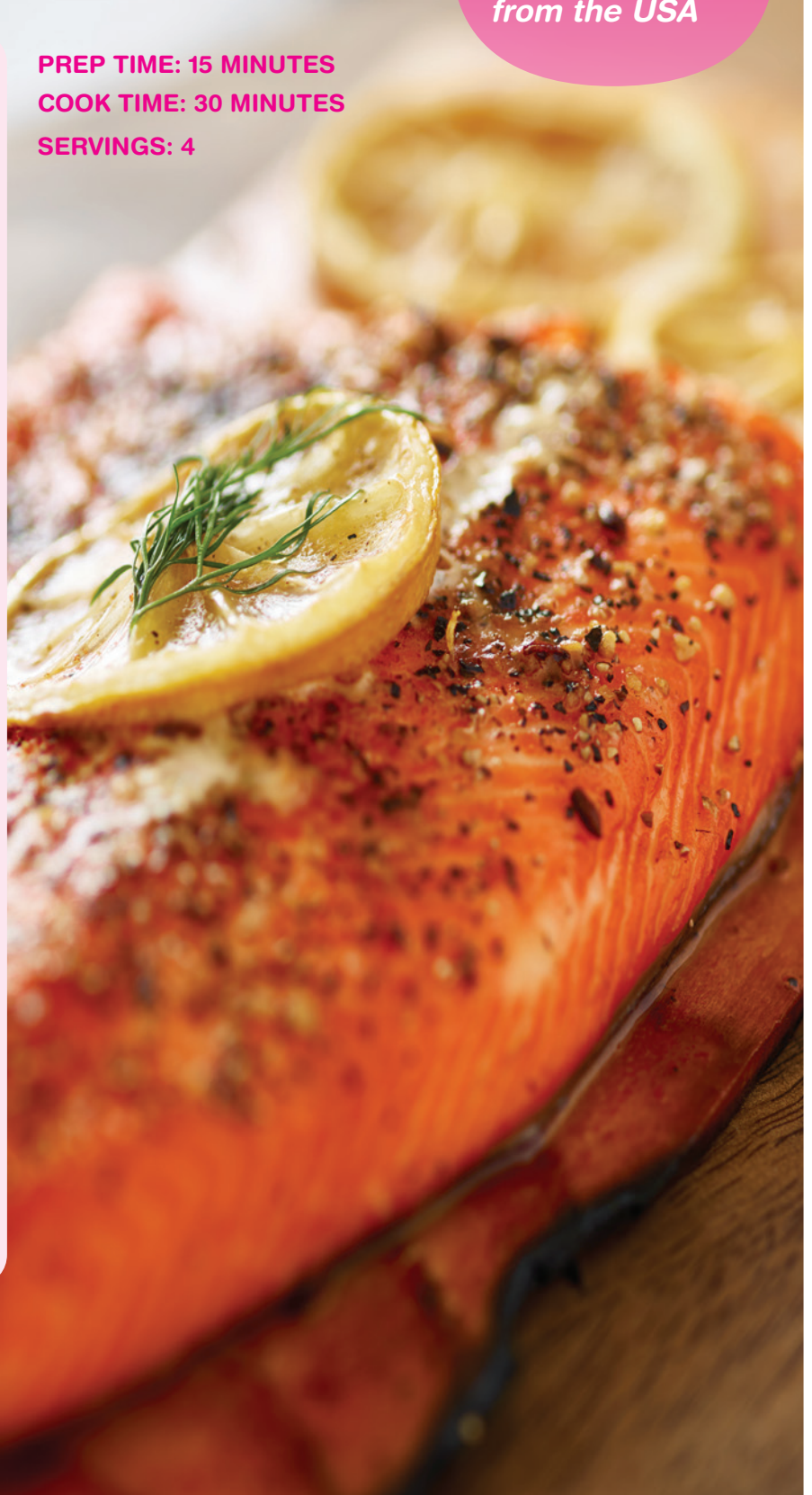
Directions:

1. Preheat oven to 400° F (205 C) or grill to medium-high heat
2. Soak cedar plank in water for at least 15 minutes
3. Line cedar plank with lemon slices
4. Rinse salmon in water and pat dry. Place salmon on top of lemon slides
5. Drizzle lemon juice on top of salmon
6. Combine dried spices, then sprinkle to taste on top of salmon
7. Place Thyme sprigs on salmon
8. Place in oven or on grill until done, about 30 minutes. If using oven, place cedar plank in baking pan before putting in oven

PREP TIME: 15 MINUTES

COOK TIME: 30 MINUTES

SERVINGS: 4



Parmesan roasted zucchini

Global
Kitchen

*Summer recipes
from the USA*



PREP TIME: 10 MINUTES

COOK TIME: 15 MINUTES

SERVINGS: 4

Ingredients:

2 zucchinis, each cut into 4 strips lengthwise
1 tablespoon olive oil
Salt to taste
Garlic powder to taste
Black pepper to taste
½ cup grated parmesan cheese

Directions:

1. Preheat oven to 400 degrees
2. Place zucchini strips cut side up on baking sheet lined with parchment paper
3. Brush olive oil on each strip. Sprinkle with salt, garlic powder, and black pepper to taste
4. Top with parmesan cheese
5. Bake until zucchini is tender and cheese is browned, about 15 minutes