

bloom

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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 Cathy Hirsch

President of Reach to Recovery International

We spend a great deal of effort trying to determine how best to support the breast cancer patient and even the patient's spouse or caregiver. But who else is affected by a breast cancer diagnosis – in some cases as profoundly as the patient herself? In this edition of *Bloom*, we focus on the affects breast cancer has on the children of the patient, whether the child is so young that he or she relies on the parent for almost everything in life, or is grown but still turns to the parent for guidance and emotional support.

In the article *Telling Your Child About Breast Cancer: 5 Things You Need to Know*, the American Cancer Society offers tips for talking about breast cancer with a child, no matter the age, in order to ensure that the message they take away is the intended one. The Society discusses a book it has published, *And Still They Bloom*, which is geared for children ages 8 to 12 and explores the loss of a parent, grief, and healing from a child's perspective.

Also recognizing that it can be easier for parents to explain a complicated subject such as cancer to children with the help of an appropriate storybook, Breast Cancer Care UK has made a narrated e-book version of the award-winning book *Mummy's Lump* available via its website. Breast Cancer UK's Julie Bell reviews *Mummy's Lump*, a book written by a Consultant Child Psychiatrist and Senior Research Fellow at Oxford University who was diagnosed with breast cancer when her children were just 5- and 7-years old.

Emma Marquez, LBSW, and Anne Marie Norman, both of LIVESTRONG, offer tips on talking to children about a parent's cancer diagnosis. They also introduce LIVESTRONG at School, a program designed to help children cope while they are away from home.

Several breast cancer survivors offer their own perspectives. Heidi Rummel of the United States describes the stress her family endured when she was diagnosed with breast cancer, and the relief they experienced when they learned of Camp Kesem, a network of 54 camps operated at colleges throughout

the U.S. that provides fun and emotional support, free of charge, to children of cancer patients. Kara Brandenburg, a Reach to Recovery volunteer also from the U.S., explains how a project she and her children undertook while she was undergoing treatment helped all of them feel a sense of control and learn compassion at the same time. Teresa Cuda of Australia explains that being fully open and honest with her children, as well as assuring them of her unconditional love, helped her family get through the experience. Noela Moran, also of Australia, recalls how concerns about helping her young children cope with her diagnosis led her to pen the book *What is Happening to Mummy?*, which was later published by Cancer Council Queensland. Fellow Australian Page Massey relates that, thanks to her father and sister who pitched in to help, she was able to ensure that all of the needs of her young children were met while she underwent treatment.

Page's now grown daughter, Katherine Massey, writes that her mother's willingness to answer her questions,

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Email your bloom submissions! Email your bloom submissions! The theme of the next edition will be *Pregnancy, fertility and cancer*. Submissions close 20 January 2014. Please send submissions in Microsoft Word format with any photos to info@reachtorecoveryinternational.org

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For more information about RRI, go to www.reachtorecoveryinternational.org



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

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



Message from Cathy Hirsch

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The theme for this issue is Patient's children - the hidden costs of cancer.

as well as the efforts made to ensure that her routine was only minimally disrupted, helped her and her brother to stay positive. From Uganda, Elizabeth Mugalu describes the pain her entire family endured when her grown son's soon-to-be fiancée, left him after learning that Elizabeth had been diagnosed with cancer. Ms. Mugalu goes on to describe the steps the family took to return to happiness.

Also in this edition of *Bloom*, RRI Board of Management provides a

progress report on the International Psycho-Oncology Society's efforts to integrate psychological care into all clinical practice. RRI Immediate Past President Ann Steyn reports on the Breast Health Global Initiative (BHGI), which works to establish guidelines for effective breast cancer care for all nations. The BHGI takes into account the availability of resources in particular countries in order to develop guideless that are evidence based, economically feasible, and culturally appropriate.

We hear from several individual member and member organizations that are making news. Sonia Silver of the Portuguese Cancer League's Reach to Recovery group reports on the success of that group's 4th annual walk to raise awareness about breast cancer screening and the importance of early detection. The walk is called "Pequenos Passos, Grandes Gestos," or "Small Steps, Big Gestures." Huong Phung Thi of Vietnam relates her breast cancer story and describes the work she and her family are doing with the Breast Cancer Club in Hanoi.

Email info@reachtorecoveryinternational.org



Cathy Hirsch

From our global kitchen, our friends the Redcliffe Pink Snapdragons from Queensland, Australia share a recipe for a delicious – and best of all healthy – snack.

We look forward to sharing with you, in the very near future, the site of the 18th Reach to Recovery International Breast Cancer Support Conference, to be held in 2015. Please continue to check the Reach to Recovery International website for updates.



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Telling your child you have breast cancer: 5 things you need to know*

Hearing the words, “You have breast cancer,” is an overwhelming experience. Telling your children about your diagnosis? That can feel just as overwhelming. That’s why having an idea of what to say – and how to say it – can be extremely helpful when it comes to discussing your breast cancer diagnosis with your kids.

There is no one “right way” to tell your kids you have cancer, but there are some things you can say to help relieve their fears and communicate what this diagnosis means for everyone. Keep the following points in mind as you talk with your children, no matter their age:

- 1. Give them the facts.** Some people may not want to “burden” their children with the details of their diagnosis, but it’s important for kids of all ages to get good information about what’s happening. Kids are often very aware that something has changed, and what they imagine to be true can often be much more frightening than reality. Give your kids honest and age-appropriate descriptions of what cancer is, how the disease or treatment might affect you physically, and how you may feel emotionally. Allow them to ask questions, and give them an opportunity to talk about their fears and feelings, too.
- 2. Let them know it’s not their fault.** Children are the centers of their own world, and when something
- 3. Explain that cancer is not contagious.** Children, especially pre-schoolers, may think that cancer is like a cold, and that touching, hugging, or sharing space with a person with cancer might mean they will get cancer, too. Take the time to explain that cancer works differently from many other diseases, and that nobody can “catch” cancer from you.
- 4. Reassure them that the family will work together to handle the future.** One of the most important things you can do is to explain to kids that even though changes will happen because of your diagnosis, you will work together to make sure everyone’s needs are handled. This is especially important because many children fear they may be forgotten

like a cancer diagnosis happens, they may feel as if they caused it to happen or that it is somehow their fault. It’s important to reassure them, again and again, that your having cancer isn’t anyone’s fault, and that nothing they said or did made your cancer happen.

while the focus is on your health. Remind them that their needs will always be taken care of, and talk as a family about the specific ways you will make sure that responsibilities, both new and old, will be met.

- 5. Remind them that they are loved.** During a stressful time or when a conversation isn’t going the way you hoped, the most powerful words you can say to your child may simply be “I love you.” Make a point to let them know they are loved and reassure them that those feelings won’t change, no matter what.

If you need more information on how to talk to your kids about your cancer diagnosis, the American Cancer Society can help.



Learn more on cancer.org in the section Helping Children When a Family Member Has Cancer, or find books on cancer for kids in our online bookstore.



Resources:

[Learn more about breast cancer](#)

[Signs and symptoms of breast cancer](#)

[Screening reminder tool](#)

[Breast cancer Stories of Hope](#)

[More news about breast cancer](#)

[How ACS is involved in breast cancer research](#)

[Making Strides Against Breast Cancer](#)

A mother and daughter share their experience

Page Massey's Story

The first hurdle we had to face when I diagnosed with breast cancer was how to tell my daughter Katherine, who was eight, and my son Luke, who was five. For my son I kept it very simple and said I wasn't well, I had a lump in my breast and they would have to cut it out to make me well. In some ways it was easier to tell him because he didn't really know or understand the word 'cancer'. My daughter on the other hand was quite savvy for her age and I had to go into more depth with her. I assured both of them that it was a good thing I was having my operation so that my lump wouldn't make me sick.

The next hurdle was to make sure they were well looked after while I spent five days in hospital recovering from my mastectomy. My family were wonderful and my father and sister both took up the slack while I was in hospital and then later during my chemotherapy and radiation. I came up with the idea of buying them each a special teddy bear that would take care of them while I was away. My son is now 16 and he mentioned that just the other day at school they were talking about possessions they treasured and he mentioned that bear. So I can say that that definitely helped. My father, who was retired at the time, brought the children up to see me every day, so that they knew I was okay. I think it was very important for them to see me.

After six weeks recovery from my operation I started my chemotherapy. This was one treatment every three weeks, for a total of four treatments. Once again my father and sister were wonderful. I was more or less out of action for the week I had my chemo. The children were taken to school by dad and they were still able to do their soccer and swimming and dancing. I think this is so important, for their own routine to be as stable as possible with all the activities they love to do. I made sure I prepared them for the weeks I wouldn't take them to things but assured them it would be back to normal the next two weeks. They seemed to accept this. When

prepared, I think children will surprise you with their flexibility and resilience. Also when I was feeling well between treatments I would try and do something special like a movie or trip to the park to make up for missing other outings.

I think it's important as well to tell their teachers and parents of their close friends about your diagnosis, so that any behaviour they display out of the ordinary can be accounted for and understood. Lots of friends and parents at the children's school offered to help and I would say don't be embarrassed or too proud to accept it, whether it's cooking a meal, taking children to and from school or having your child for a play date while you're not well. I believe what goes around comes around and once you're back on your feet and feeling better you can repay the favour.

The main thing with the children was to answer their questions and yes, cancer is a serious illness, but to point out to them that lots of mummies and daddies get better and that life will be back to normal when the treatment is finished. They take their cues from you and if you can stay calm with them and give them lots of opportunities to talk to you if they're struggling with you being unwell, they can surprise you with what little troopers they are. It's important, while staying calm with them, for you to have someone with whom you can share how you feel. Cancer Council Queensland has some great services and people you can speak to about your feelings, when you're struggling emotionally.

Katherine Massey's Story

Individuals differ in their need for information. Whilst some find the bare minimum of information keeps them satisfied, others prefer to seek out every available resource to increase the breadth of their comprehension. I identify with the latter type. I find that the more I know, the more comfortable I feel within a particular situation. This has been the case since I was little. I was eight years old when



my mum was diagnosed with breast cancer. Mum was worried about how to explain what was wrong to me and my younger brother, who was five at the time. She thought it was important that we talk about what it might be so that we wouldn't be shocked by whatever the doctors had to say. Now we joke about how it was actually her who was surprised when she got home from the doctors with her diagnosis and I said, "You have cancer, don't you?"

I have always been grateful that we had such an open environment at home to ask anything we wanted, not only when mum was going through treatment but also throughout our entire lives. I read through all the pamphlets and books mum received from her doctors, and persistently asked questions regarding her mastectomy and subsequent chemotherapy and radiation. I wanted to know what was going on and I wanted to understand why. I must stress that although all my questions were taken seriously and answered fully, the information was always tailored to a level that I could comprehend. Whilst I believe it important (especially in situations like this) to make sure children feel they can be taken seriously, they differ in their maturity levels and thus responses need to be adapted to what the parent feels the child can handle. My family provided a supportive environment not only for mum, but for all of us, so that we could get through it together.

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Katherine Massey's Story

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My grandfather took me and my brother up to visit mum each day she was in hospital. We had to take two buses, one into the city and then another one to the Holy Spirit Hospital. These trips were never considered gloomy or treated negatively. As a reward for behaving on the buses, we would get a 30-cent cone from McDonald's in the Myer Centre on our way home. I believe these visits were crucial to my feeling secure and to knowing that the doctors were really taking care of my mum. Every day she looked just that bit better, until she finally got to come home. Things were different when she got home though, and I think that that is what can be most difficult for children to understand. I had a general understanding that mum's recovery would take longer than just a trip to the hospital, but I don't think I was

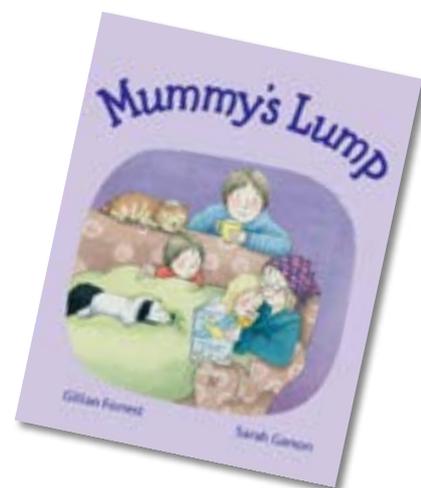
prepared for all the things she would have to miss out on. It was difficult not having her there at school concerts and swim club nights, but my grandfather and aunty were always ready to step in. I really appreciate the wonderful lengths that mum, grandpa and my aunt went to, to ensure our regular routine was only minimally disrupted.

Mum and my aunt were determined to keep us all involved during mum's treatment. We got to help shave mum's head when her hair started to fall out due to chemo, and we three went to try on wigs and hair pieces together. It was hilarious seeing mum in various different coloured and styled wigs. Then they started on me and my aunt. I tried on long pony tail extensions, short ones, curly ones and straight ones! In the end we

all got a little something. I think the fact that we were involved in this side of her treatment really helped us to stay positive.

Although going through this experience is not one that I would wish upon anyone else, I believe I have learnt a lot from it. It has made me more aware of the prevalence of breast cancer, as well as cancer in general and that regular self-checks can help to recognise cancer in its early stages for the best possible prognosis. Mum always checked herself regularly, and upon feeling something not quite right, she went straight to her GP. I am deeply grateful for the dedication of the doctors and the love and support my family provided for each other! Ten years on mum is still going strong!

Mummy's Lump – Support for parents talking to children about breast cancer



Breast Cancer Care (UK) provides specialist support and tailored information for anyone affected by breast cancer. We have a range of more than 100 free evidence-based publications, most of which can be downloaded from our website.

And we've taken the principle of free digital resources a step further with an e-book edition of the award-winning **Mummy's Lump**, narrated by British actress and Harry Potter star Zoë Wanamaker. This iPad, iPhone and iPod Touch version can be downloaded from our website or from the iTunes store (search for 'Breast Cancer Care').

Mummy's Lump is for any family needing to talk to children aged seven and under about the difficult subject of cancer. It follows Elly and Jack as they learn of their mother's diagnosis and treatment for breast cancer. Written by Gillian Forrest with illustrations by Sarah Garson, it has the look and feel of a classic children's story book.

Gillian, diagnosed with breast cancer when her children were five and seven, is a Consultant Child Psychiatrist and Senior Research Fellow at Oxford University. Her research* with over 30 mothers with early breast cancer and their children showed that the youngest children had a much greater awareness of cancer than parents realized.

She said: 'Despite being an experienced child psychiatrist, when I got my own breast cancer diagnosis I was anxious and unsure about what to tell my children.'

'It can be easier for parents to broach something as sensitive as a cancer diagnosis through a story rather than a conversation so I wrote **Mummy's Lump** just like a normal story book.'

'Now, as a narrated e-book there should be even fewer barriers to being open with children about a breast cancer diagnosis.'

Other Breast Cancer Care e-books titles, which can be downloaded from our website on to any e-reader, include:

- Living with lymphoedema
- Menopausal symptoms and breast cancer
- Radiotherapy for primary (early) breast cancer
- Diet and breast cancer
- Your operation and recovery
- Breast pain
- Docetaxel (Taxotere)
- Paclitaxel (Taxol)
- Gynaecomastia

Breast Cancer Care
www.breastcancercare.org.uk

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* Breast cancer in the family – children's perceptions of their mother's cancer and its initial treatment: qualitative study, Gillian Forrest et al., BMJ 2006;332:998. To read the full study, go to www.bmj.com/cgi/content/abstract/332/7548/998

Hats of Hope Made by Kids who Care

Kara Brandenburg, Baltimore, Maryland (USA) area Reach to Recovery volunteer

When I was diagnosed with breast cancer my son, Luke, was eight years old and my daughter, Savannah, was twelve. My first worry was how to tell them about my diagnosis, but that was quickly replaced with worries about how to help them cope. Luke was particularly concerned with the fact that I was going to lose my hair, while Savannah was quiet and scared.

The lack of control over what was happening was frightening to us all as a family and confusing to my children. I let Luke give me a Mohawk when my hair started falling out, and with that we learned through waves of laughter how to take some control when it appeared there was none to be found. After that, my mom bought some plain white baseball hats and some art supplies from our local craft store. We gathered all the kids in my extended family together and they started decorating hats for me. My daughter and my niece came up with the idea of writing funny messages – like “Bad Hair Day” and “I am usually gorgeous – it’s my day off” – on the backs of the hats above what, for anyone else, would have been the “pony tail” holes. Roars of laughter replaced the

fear in my house, as the kids continued to decorate more hats. By then I was completely bald, but the kids did not always see the outward signs that I was sick. Instead, they saw their works of art, and often they would jump up smiling when I walked into a room, looking to see which hat I was wearing that day!

When I told the kids about all of the compliments I received about the hats from my fellow patients at the chemotherapy unit, they sprang into action again. We started decorating more hats for the chemo unit. We called our project “Hats of Hope Made By Kids Who Care.” We made a box with a message of hope on it, and we filled the box with decorated hats. Together, we delivered the box to the chemo unit so that anyone who wanted a hat could choose one. The kids were so proud when they actually saw people in their chemo chairs wearing the hats they had decorated! We also made hat-decorating kits for moms who had young kids of their own so those kids, too, could make hats and feel a measure of control.

The “Hats of Hope” project was transformative for all of us. We learned compassion, and how to walk through fear and take control. I have often said that one of the hardest parts of going through cancer treatment is the

physical changes it causes, like hair loss. There is no denying, to yourself or anyone who sees you, that you are a cancer patient. I explained to my kids that the physical changes were from a treatment that was going to make me well, but that was hard, even for me sometimes, to understand. I understood how difficult it was for the kids, and what a miracle those hats had worked.

As a parent with cancer, you cannot prevent your children from feeling fear and confusion any more than you can prevent what you yourself must go through. I was scared when I was diagnosed at 36, and then again at 38, but I was also empowered to teach my children something about life! I wanted them to know that, no matter what happened, we could cry, we could laugh, we could be angry and then we could take a little control and do something for ourselves and others. We could still experience true joy!

My children are now 15 and 20. I would never wish what my family went through on any other family. At the same time, I’m grateful that the experience gave them a sense of compassion and an understanding of the important things in life. They know how to take control of what they can, and how to accept the rest with grace.



What is happening to my Mummy?

Noela Moran, Australia

I can still remember that night in hospital. During the hours of darkness I worked my way through all of the possible outcomes of a diagnosis of breast cancer. I am of that personality type which must envisage all of the possibilities, emotionally engage with these and then move on to coping with the day to day realities. It was on this night after imagining my own death and my family without me that I picked up a pen and wrote the words that would become the book *What is happening to my Mummy?*

At the time of my diagnosis, my younger son James was eight and younger daughter Kate was six, and my greatest concern was helping them cope with the cancer journey that was just beginning for us all. Those words scribbled during the night were turned into a one-off children's book by a dear friend Teresa Jordan who later illustrated the published version.

She created drawings which gave life to my words so that my children then had a beautiful and simple explanation of what was happening to their mother. Years later, when Cancer Council Queensland published this little book, I asked that it be produced in black and white so that children reading it could colour it in and make it personal and cheerful, just as Kate had done with the original copy.

While it seems strange, everyone who has journeyed with cancer will know that this disease also brings great gifts and the most precious of these is a deep appreciation of every moment of life. I am not sure that without cancer I would have celebrated each milestone such as birthdays, graduations, Christmas celebrations and holidays with quite the same vigour and enthusiasm. I look at photos of the six of us at a local beach all wearing huge sunhats in solidarity with hairless me and I can actually feel the joy of that carefree day. I insisted that we get a puppy because I felt that if I were to lose the battle with cancer James and Kate would need an extra creature to love and to be loved by. So Pepper the black cocker spaniel joined our family and through her life brought only joy to



us all. I suspect we would have remained dogless had I not had cancer, and what a loss that would have been. And then there was our campervan holiday in New Zealand. To this day any mention of New Zealand will cause them to recall whale watching, swimming with seals, caving, exploring Milford Sound, visiting the Maori village and sitting on our campervan bed at night listening to Bill Bryson on the radio. Journeying with cancer makes you create lots of precious memories and that is what childhood is all about.

My two younger children are now grown up, both solicitors and beautiful young adults. When I had a subsequent (and less serious) breast cancer five years ago, I had no deep concerns about them. I looked at them and felt that they had the emotional resilience to cope with the future. Twelve months after that surgery Kate and I had a wonderful month's holiday in Germany over Christmas. We shared a magical time together, making memories which will sustain us forever. A year after that trip Kate presented

me with a book filled with photos and special memories. In this book she writes that "without you I couldn't have grown into the person I am. They say that every girl grows into her mother. I hope this is true. If one day I am even half the person you are, I would consider myself lucky." That is indeed a great gift.



Click to download
"What is happening to my mummy?"

A parent's story: Camp Kesem



Heidi Rummel, USA

On July 27, 2010, I dropped my three kids at day camp, spent a few hours in the office, had lunch with my students, and found out that I had breast cancer. As the radiologist biopsied my left breast, I asked him what he thought. What he thought was already written on his face, but I still wanted to believe that this thing wasn't happening to me. "It's cancer – we can't be a hundred percent until we do a biopsy, but it's cancer," he said.

I drove home feeling very small and alone in the world. Over the next hours, days, weeks, I found the courage to say the words out loud. First to my husband. I have cancer. And then to my best friend. Next, to my father and brothers. I have been diagnosed with breast cancer. The more I said it out loud, the easier it was to believe it was happening to me. I have Stage IIB invasive breast cancer. I have to do chemo. I'm going to lose my hair. And then I'm going to lose my breasts.

And then came the hardest day — when I had to say it out loud to my children. My ten-year old son cried. My eight-year old daughter took notes. And my four-year old daughter asked, "What's cancer?"

I managed to be strong in the face of the baldness and needles and poison and surgeries and complications from surgeries and pain and exhaustion and day after day of radiation treatments. And I was fortunate to be surrounded by more love and support than I could have imagined – friends, family, and strangers who lifted me up and cared for me.

But the pain of watching my children suffer was almost too much to bear. In a moment, their world was turned upside down. And I was not able to be the mother they needed and wanted me to be. I could not fix their sadness or anger or fear, because I was sad and angry and afraid. I did not know how to make the world right again.

Until I learned about Camp Kesem. Kesem means magic – and Camp Kesem is a magical place. It is a place where kids can forget and have fun and where they can remember and relate and be understood. In so many ways, Camp Kesem has been the "mother" that I was not. Camp Kesem parents many children who have lost a parent to cancer. Today I am a survivor. But I live with the prospect of recurrence or metastasis. And the reality that too many women are no longer survivors. It reassures me to know that my kids will always have Kesem. Kesem is family.

About Camp Kesem:

Camp Kesem recognizes and embraces the often-overlooked population of children affected by a parent's cancer. Camp Kesem provides a safe and supportive peer-based support network, where children befriend peers who can relate to their unique situation, and gain the strategies and confidence needed to cope with their parent's illness or death. This network is rooted in our signature program – a network of free, college-student run summer camps. While children find support, college students develop critical leadership skills as they create, manage, fundraise and run every aspect of their local Camp Kesem chapter.

Camp Kesem was founded at Stanford University in 2000, and has since expanded to 54 college chapters in 27 states. In 2013, over 1400 college student volunteers around the country delivered the Camp Kesem "magic" – completely free of charge – to nearly 3000 children. Camp Kesem plans to continue this expansion, until the organization is serving all of the 3+ million children affected by a parent's cancer.

For more information about Camp Kesem and its programs, please visit www.campkesem.org



Breast Health Global Initiative



*Ann Steyn, South Africa
Immediate past president Reach
to Recovery International*

The Reach to Recovery programme was originally conceived by Therese Lasser in 1953. It was established as a programme offering emotional and practical support to improve the quality of life for newly diagnosed breast cancer patients. Over the years improving the quality of life for women has included educating communities about breast cancer and advocating for suitable breast health policies. These programmes are especially important in low and middle resourced countries where significantly more deaths from breast cancer occur than in developed countries.

Many Reach to Recovery volunteers are involved in influencing the formation of breast health policies in their countries. Any volunteers undertaking this task are strongly encouraged to access and read the guidelines provided by the Breast Health Global Initiative (BHGI), as these guidelines are an excellent tool to assist with breast health care policy decisions.

BHGI was established in 2002 by Dr Ben Anderson with the aim of developing breast cancer guidelines that were evidence based, economically feasible and culturally appropriate. Fred Hutchinson Cancer Research Center and Susan G Komen for the Cure, both based in the United States, are co-sponsors of the programme.

Global Summits have been held in 2002 (Seattle, USA), 2005 (Bethesda, USA), 2007 (Budapest, Hungary), 2010 (Chicago, USA) and 2012 (Vienna, Austria)

At each of these summits a range of international breast cancer experts was assembled, including scientists, clinicians, policy makers and – most importantly – breast cancer advocates and survivors.

From the start, it was obvious that guidelines defining optimal breast care and services as suggested by the World Health Organization (WHO) would not be practical in resource constrained countries. To address this issue, the BHGI developed a four-tier resource allocation system:

Basic: Fundamental services absolutely necessary for any breast health care system to function. Typically a single clinical interaction

Limited: Services that are intended to produce an improvement in outcome and can be achieved with limited finances and infrastructure.

Enhanced: Services that are optional but important and further improve the outcome and increase the number and quality of options and patient choices

Maximal: Offering high level services. These should be considered lower priority than those services listed in the basic, limited or enhanced level due to their high cost. To be useful they depend on the existence of all the lower level resources.

Over the past decade, the BHGI Global Summits have discussed and widely researched all aspects of breast cancer including health systems, early detection, diagnosis, the various treatments available, management of metastatic breast cancer, and palliative care. Focus groups were used to address and research specific issues and when consensus was achieved recommendations were placed in the four tier stratified table.

The guidelines were completed at the final summit held in Vienna in 2012. This summit looked at supportive care and quality of life issues and how to integrate them into existing medical infrastructures.

Breast Health Global Initiative

continued from p 10

The need for survivorship guidelines was highlighted by a 2012 World Cancer Congress report that found there was no uniform standard for supportive and survivorship care. This is an issue close to the heart of Reach to Recovery International. It was agreed that breast cancer programmes can no longer focus on just curing cancer, important as that is. Programmes need to treat the patient as a whole, not just the disease, and evidence clearly demonstrates attending to the psychosocial needs of the patient will improve their quality of life.

The Vienna summit had three expert consensus panels – supportive care during treatment for breast cancer, survivorship care, and supportive and palliative care for metastatic breast cancer. All three panels included in their consensus statements recommendations for the education of health professionals, patients, their families and communities.

I believe there is a role here for trained Reach to Recovery volunteers to educate communities, help to dispel the myths and stigma that surrounds breast cancer and also to offer supportive care.

The recommendations of these groups were placed in their respective four tier resource stratified tables. These make for informative and interesting reading. The tables show how simple supportive care services can be placed at Basic level, and as more resources become available there is an incremental move towards Limited and Enhanced levels.

The supportive care during treatment group agreed that “establishing supportive care during treatment will help ensure that breast cancer patients receive comprehensive care that can help 1) improve adherence to treatment recommendations, 2) manage treatment related toxicities and other treatment related symptoms, and 3) address the psychosocial and spiritual aspects of breast cancer and breast cancer treatments.”

Over the past decade BHGI has become recognized internationally for its resource stratified guidelines for breast health and cancer control in low and middle resourced countries. The guidelines have now been published and can be found on their website: www.bhgi.info. By using the best standard of care that is practical in a given setting, they provide an excellent

framework for the establishment of breast health care guidelines world-wide.

BHGI brought together culturally diverse groups of breast cancer experts who defined the minimum needs for providing breast cancer care in any health setting. Low and middle resourced countries will find standards against which they are able to measure improvement in quality care for breast cancer patients.

Using these guidelines, health care systems will be able to ensure that they respond appropriately to the needs of breast cancer patients. The voice of RRI, which speaks for many women, was heard throughout the development of the guidelines with Ranjit Kaur, the late Mary Onyango and myself attending various summits.

I believe we owe a great debt to the BHGI under the leadership of Dr Ben Anderson for formulating such a comprehensive set of workable guidelines for breast health policies. I encourage everyone to work towards their implementation, and by doing so improve the quality of life for all women.

Therese Lasser would most certainly endorse them!

Small steps, big gestures

The Portuguese League Against Cancer Movimento Vencer e Viver

The Portuguese League Against Cancer's Reach to Recovery peer support group, Movimento Vencer e Viver, recently organized the fourth Pequenos Passos, Grandes Gestos (Small Steps, Big Gestures) walks to raise awareness of breast cancer and the early detection program led by the Portuguese League Against Cancer, and to raise funds to support women diagnosed with breast cancer.

The Small Steps, Big Gestures walks took place during Breast Cancer Awareness Month (October) simultaneously in seven Portuguese cities – Aveiro, Castelo Branco, Coimbra, Covilhã, Guarda, Leiria and Viseu.

More than 6000 people participated, including patients, survivors, families and organizations, all with a common goal: to raise awareness of breast cancer and funds to support women diagnosed with the disease. Since 2010, more than 20,000 people have become involved

in these communities. The Portuguese League Against Cancer attributes the development and success of the Small Steps, Big Gestures walks to the dedication of its volunteers, to whom it is very grateful.

Breast cancer is the most common type of cancer among women in Portugal and the second leading cause of death in women. In Portugal, 4500 new breast cancer cases are diagnosed every year and 1500 women die every year from this disease.

The Movimento Vencer e Viver was founded in 1996 by the Portuguese League Against Cancer. It is a group of volunteers who have survived breast cancer and provide emotional support to other women diagnosed with



the disease. The group also provides women diagnosed with breast cancer with practical support, including breast prostheses, bras, swimwear and wigs at substantially lower prices.

The hidden costs of cancer

Emma Marquez, LBSW
Anne Marie Norman

LIVESTRONG

FOUNDATION

The LIVESTRONG Foundation's Navigation Center receives hundreds of calls from cancer survivors daily. Navigators are trained to respond to the specific needs of each client: emotional, financial, or fertility to name a few. From parents exploring ways to help their children to cope, to those wanting to preserve their fertility, there are a number of emotional barriers that cancer creates. Below we explore one of these real life challenges – the emotional distress of children who have a parent with cancer – as well as resources that outline the importance of educating individuals and families affected by cancer.

Family communication: Emotional support for children*

Standing nervously at the front of the room, Jane bravely shared her story of how she told her son, Joe, that she had cancer, and how at first it seemed like no big deal. She mentioned how she was unaware of the effects the word "cancer" would have on her family in the coming days and months to come. Jane knew she had to seek support that would help Joe cope with the uncertainty and fear of losing his mother.

All too often, patients and families find they have a difficult time explaining their cancer diagnosis to their children, and what this means for them as a family.

The Centers for Disease Control and Prevention (CDC) estimates that each year 12.7 million people worldwide learn they have cancer (CDC, 2013). As a result, millions of parents often face a lack of support for their child's emotional support needs. Despite the numbers of families affected, there is little information available about their needs and outcomes.

Cancer affects the entire family. Data shows children whose parents are diagnosed with cancer are more likely to experience an increase in distress and anxiety as the child's needs are often overlooked (Coscarelli, 2011). Parents and families can address their children's needs with some simple strategies:

- Communicate honestly with children. Doing so can minimize the distress of misconceptions they develop or as children interact with peers. In addition, set expectations by clarifying what treatment will be involved, which can help reduce the child's distress and anxiety (Kornreich et al., 2008).
- Let the child know that it is okay to cry and be afraid. Children often feel as if they need to stay strong, and may try to keep their feelings to themselves for fear of burdening their parents. Encourage expression of emotion through drawing, writing a letter or a poem, or keeping a journal, as this can provide a foundation of support.

- Try to create a routine for the child's schedule. Allowing children to spend time with friends and be involved in their usual activities, as this can help them feel safe and regulate their emotions.

As Jane reflected back on her and her son's experience, she focused on the importance of support for children who have a parent diagnosed with cancer, since patients' children are at an "increased risk for problems in emotional, social, cognitive, behavioral, and physical functioning domains" (Weaver et al., 2010). There are resources to help parents cope with the stress cancer brings to a family. The LIVESTRONG Foundation, for example, provides emotional support and short-term counseling services to meet the needs of patients and their affected family members. Referrals to appropriate professionals such as social workers, school counselors, or psychiatrists are imperative.

continued on p. 13

continued from p. 12

Whether through their own diagnosis or that of a grandparents, parent, family member, friend or teacher, children in classrooms are dealing with cancer right now. Often the problem is not that kids are unaware of cancer, but that their experience goes unacknowledged. However, data shows that school is a place of stability for children during a time of crisis at home (Fasciano et al., 2006).

For parents like Jane, the **LIVESTRONG** at School program can support children and families dealing with a cancer diagnosis. The curriculum offers online lessons for grades K-12 that teach children and adolescents about cancer in a way that is age-appropriate, inspiring and empowering. **LIVESTRONG** at School addresses the range of reactions children can have to a cancer experience and models how adults and children can come together to support one another. It provides materials like informative health and

language art lessons that help students cope as well as get involved in the fight against cancer in their communities.

For both survivors who are looking to preserve their fertility in hopes of a family in the future, or for those who find themselves asking “How do I help my child cope with cancer?” challenging barriers exist. Resources like **LIVESTRONG** Fertility, Emotional Support Navigators, and **LIVESTRONG** at School provide survivors and their loved ones a way to move forward, informed and empowered.

Click for more information on:

[LIVESTRONG Emotional Support Navigators](#)

[LIVESTRONG at School](#)

References

- Centers for Disease Control and Prevention (CDC). (2013, June 25). World Cancer Day. Retrieved September 13, 2013, from <http://www.cdc.gov/cancer/dccp/resources/features/WorldCancerDay/>
- Coscarelli, A. (2011). When a Parent Has Cancer: Taking Care of the Children. *Simms/Mann UCLA Center for Integrative Oncology News*, 41, 1-3. Retrieved from <http://www.simmsmanncenter.ucla.edu/pdf/information/news-spring-2011.pdf>
- Fasciano, K. M., Berman, H., Moore, C., DeFrino, B., Jameson, R., Kennedy, V., & Golant, M. (2006). When a parent has cancer: a community based program for school personnel. *Psycho-Oncology*, 16, 158-167. doi: 10.1002/pon.1148
- Kornreich, D., Mannheim, H., & Acelrod, D. (2008). How Children Live with Parental Cancer. *Primary Psychiatry*, 15(10), 64-70. Retrieved from http://mbldownloads.com/1008PP_Kornreich.pdf
- Rauch, P. K., Muriel, A. C., & Cassem, N. H. (2002). Parents With Cancer: Who's Looking After the Children?. *Journal of Clinical Oncology*, 20(21), 4399-4402. Retrieved from <http://jco.ascopubs.org/content/20/21/4399.full.pdf+html>
- Weaver, K. E., Rowland, J. H., Alfano, C. M., & McNeel, T. S. (2010). Parental cancer and the family: A population-based estimate of the number of US cancer survivors residing with their minor children. *Cancer*, 116(18), 4395-4401. doi:10.1002/cncr.25368.

* Names have been changed to observe confidentiality





Progress update

Towards global implementation of the IPOS International Standard

As you know, in July 2010, the International Psycho-Oncology Society (IPOS) Board of Directors formally codified the IPOS International Standard of Quality Cancer Care, calling for global endorsement of distress as the 6th Vital Sign in cancer care.

Since then, 74 international organisations, including the UICC, have endorsed Distress as the 6th Vital Sign, with many requesting collaboration and partnership on supportive care initiatives.

In a further demonstration of the UICC's commitment to supportive care for cancer patients, the UICC Board of Directors unanimously resolved at their most recent meeting to refresh the wording of the World Cancer Declaration, acknowledging the recommendation of IPOS to include distress as a key target.

Details of the IPOS submission are featured below.

Our recommendations were guided by the understanding that the IPOS International Quality Standard is essential to quality of life and therefore merits appropriate acknowledgement in a renewed Declaration.

The refreshed Declaration and Priority Actions will be launched at this year's World Cancer Leaders' Summit.

IPOS has extended its expertise and assistance to the UICC with all efforts towards attainment of the refreshed Declaration in accord with the IPOS International Standard.

The outcomes of the current process will underpin our ongoing collaborations with the UICC and further strengthen the influence of IPOS within international networks.

.....
 Professor Jeff Dunn
 November, 2013

Did you know?
 The IPOS International Standard has been endorsed by more than 74 organisations worldwide.

UICC World Cancer Declaration refresh IPOS recommendations IN FOCUS:

The UICC consultation on refresh of the World Cancer Declaration has occurred in two stages. In the first stage, the IPOS recommendation to include distress management within the revised wording of the WCD Targets was successful, under a revised Target 8:

Effective pain control measures, and distress management, will be available to all cancer patients in all countries.

In responding to the second stage of consultation, IPOS applauded the inclusion of distress management in Target 8 of the draft refreshed World Cancer Declaration, as well as changes to the Priority Actions adopting IPOS amendments in relation to people-centred care, multi-disciplinary treatment, patient self-determination and preventive action.

At the same time, IPOS urged that the WCD Targets be further strengthened by standardizing screening for pain and distress. Evidence has proven that the application of a structured and standardized screening instrument is more reliable than relying on patient reports and reactive clinical care. A structured screening method, via questionnaire, provides greater consistency in diagnosis and treatment.

The IPOS Board of Directors therefore recommended the following new Target be included in the WCD:

All patients will be screened for distress as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain, with psychosocial care integrated into routine clinical practice.

COLLABORATIONS with the NCD Alliance and World Health Organisation

IPOS informing global action and policy

Over the past 12 months, IPOS has strengthened collaborations with international affiliates, supporting the work of agencies such as the World Health Organisation and NCD Alliance.

In particular, IPOS has taken a key focus on informing the work of the WHO to drive forward the Global Action Plan on addressing noncommunicable diseases (NCDs).

The IPOS Board of Directors are currently preparing a submission to the WHO's discussion paper on the recently released *Terms of Reference for the United Nations Interagency Task Force on the Prevention and Control of Noncommunicable Diseases*.

In the draft submission, IPOS has supported the broad objectives identified by the WHO and recommended the inclusion of two additional objectives:

1. *To ensure the psychosocial dimensions of NCDs are addressed through advocacy to promote screening for distress as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain, with psychosocial care integrated into routine clinical practice.*

2. *To promote and support national capacity for high quality behavioural and psychosocial research for the prevention, management, and control of NCDs, and to work with affiliate agencies to facilitate translation of research into practice at the country level.*

The draft additionally recommends that Task Force responsibilities specifically include the establishment of a framework for progress reporting that measures and evaluates the achievement of Task Force objectives. And further, that the Task Force consults with affiliate organisations, such as IPOS, to develop and finalise the framework.

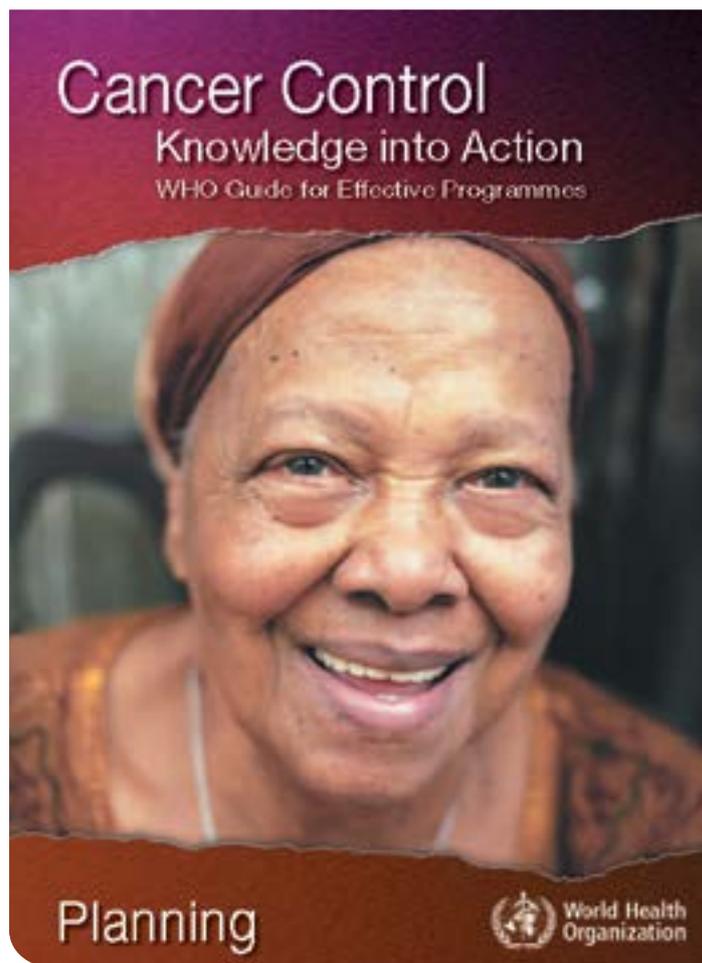
The proposed Terms of Reference for the Task Force included suggested areas of work, seeking comment on these. IPOS broadly agrees with the suggested areas of work but has recommended in its draft submission the inclusion of an additional task in Objective 4, which has the intended purpose to strengthen and orient health systems to address the prevention and control of NCDs and the underlying social determinants through people-centred primary health care and universal health coverage.

The draft wording of the additional task recommended by IPOS is:

To promote screening for distress as the 6th Vital Sign after temperature, blood pressure, pulse, respiratory rate and pain, and the integration of psychosocial care into routine clinical practice, from point of diagnosis and at all phases in treatment, including palliative care.

As the world's leading multi-disciplinary international association responsible for psychological, social and behavioural issues in cancer care, IPOS is well positioned to support the Task Force in its mission to improve outcomes for people living with NCDs.

Appropriately codifying NCD-related distress prevention, control, and management within the Terms of Reference for the Task Force will raise awareness to improve psychosocial support and behavioural risk management for people at risk of and living with NCDs. It will also drive ongoing research to better understand NCD-related distress and how it can be effectively prevented and managed.



NEXT STEPS

The next steps are to build on these gains to promote the Quality Standard, with a view to achieving the following objectives:

1. Codification of the Quality Standard key Cancer Control reference documents and by key organisations.
2. Normalisation of the IPOS Quality Standard as routine practice in cancer management.

There are three key areas of focus in support of these objectives.

First: Representation and Profile

Continue to build the IPOS presence at major international and professional meetings and gatherings and in leading journals and periodicals. Confirm the standing of IPOS as one of the lead organisations in the cancer control community.

Second: Advocacy

Initiate Advocacy activity with leading organisations to codify or at least reference the Quality Standard within their guidelines, manuals and training resources. Particular organisations might include CDC, ASCO, medical colleges and professional bodies.

Third: Programmatic

Pursue a program of activity aimed at translating the Quality Standard into routine practice. Such activity might include: Development of a sample package for inclusion in National Cancer Control Plans; Development of a coalition of organisations to serve as a resource/mentor group; Establishment of demonstration projects translating the Standard into practice; Encouraging collaborative applied research activity demonstrating the efficacy of the Standard in routine care; Development of educational initiatives, such as Fellowships and roundtable meetings, to support translation of the Standard into routine care. •

For more information, please email jeffdunn@cancerqld.org.au

Finding happiness after breast cancer

Huong Phung Thi, Breast cancer survivor
Breast Cancer Club (BCC),
Hanoi, Vietnam

I have found happiness after five years of fighting breast cancer and participating in many activities for the cancer community.

Following my breast cancer diagnosis in 2007, I had my right breast removed and received chemotherapy and radiotherapy treatments. During this time, my husband was very supportive. He changed my bandages, drove me to appointments and travelled to Singapore with me for treatment 14 times. Although we have had to use most of our savings for my treatment, my husband has never complained.

After I was diagnosed with breast cancer, I joined the Breast Cancer Club (BCC) in Hanoi, Vietnam as a volunteer. Meetings are held on the last Saturday of each month. Throughout the month, we collect and translate breast cancer information

and research, which we share with breast cancer patients and their families at the meetings. Topics focus on diet, exercise, treatment plans and sexual issues, and answer questions from patients and their families. My husband and two sons sometimes join in BCC activities.

After just three years, the BCC now has more than 3500 members. We receive a lot of support from individuals and organizations. We use donations to provide practical support such as milk, cloth caps, bras, and cancer information. We encourage BCC members to share their knowledge with people affected by breast cancer in their local community. Becoming a member of the BCC has helped me and many others feel more optimistic about the future.

In 2011, I was nominated as an ambassador by the American Cancer Society and attended the World Conference in New York City. Then, in 2012, my husband and I were invited to share our story at the World Cancer

Congress in Canada. I learned a great deal at this conference, from both health professionals and other cancer survivors.

Because of the support I have received from my family, friends and colleagues and my involvement with the BCC, I have found happiness despite my breast cancer diagnosis.



ACS book for children addresses grief*

Ten-year-old Emily and 7-year-old Ben have just lost their mother to cancer. They are characters in a book for children, "And Still They Bloom: A Family's Journey of Loss and Healing" written by Amy Rovere and published by the American Cancer Society. Though Emily and Ben are fictional, the emotions they express are very realistic. The author, who serves on the editorial staff of the American Cancer Society's Books Division, was motivated by her own experiences after her mother died of lung cancer when she was 9.

Rovere said, "This story comes from a very personal place. It's not autobiographical and doesn't represent what happened in my family. But because of my experience, I can relate to the feelings and questions children have when they lose a parent."

Emily's and Ben's struggles with grief and their steps toward healing are expressed through conversations with their father. He helps them find acceptance through memories and keepsakes, activities such as writing and drawing, and caring for their mother's garden.

Rovere said, "I wanted to create in the best possible circumstances how children can be helped. The father in the book is coping amazingly well, which is not usually what happens in real life. It's meant to be an idealistic model for parents about how to help children when they experience loss."

More than half a million children in the U.S. have a mother or father who has been diagnosed with cancer. *And Still They Bloom* explores loss of a parent, grief, and healing from a child's perspective. It's written for kids ages 8 to 12, but Rovere said adults can also benefit, by learning what children may be feeling but are unable or unwilling to express. She said grief is complicated, and children sometimes have trouble understanding and talking about their emotions.

And Still They Bloom is one of several books published by the American Cancer Society to teach children about cancer and help them cope with their own cancer diagnosis and treatment, or with that of a parent or other family member. Other titles include *The Long and the Short of It*, which tells the story of two girls, one a cancer survivor, and one who donates her hair.

And Still They Bloom, *The Long and the Short of It*, and other books published by the American Cancer Society for and about children and cancer are available for purchase through the American Cancer Society [online bookstore](#). For orders outside the United States contact Eurospan Customer Services: Tel: +44 (0)1767 604800 Fax: +44 (0)1767 601640. Email: eurospan@turpin-distribution.com



[Watch the author discuss And Still They Bloom](#)

[Read about how to help a child who has lost a parent to cancer](#)

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Patients' children: the hidden cost of cancer

Teresa Cuda, Australia

- talking
- maintaining routine
- negotiating tasks
- telling children it is not their fault
- encouraging children to participate in sport and normal activities
- giving information in stages
- letting children talk even about difficult things
- letting the school know
- letting them see that you are upset sometimes.

Being told that I had breast cancer was a devastating experience. But nothing compares with the time my husband and I had to sit down and explain to our children what was going to happen with me, my health, and our future as a family. We did not want our children to become the collateral damage in this phase of our lives. We wanted them to know that family love is totally unconditional, that the love between us and towards them was not going to be shaken by the immense tornado about to hit our precious family.

We needed to consider their ages: Our eldest daughter had just finished secondary school and was about to start university; our second daughter was a senior in secondary school; and our son was just six and about to start primary school. We established an open dialogue routine where no subject was “out of bounds”.

The Breast Cancer Network Australia (BCNA) ‘My Journey Kit’ provided me with useful information about communicating with the children about my breast cancer diagnosis.

Another thing that helped us was the presence of the local breast care nurse and a social worker from the hospital who facilitated a morning chat with my two daughters. This was an “all women” meeting and very fruitful since I had two professionals spelling a few truths where my knowledge of the days ahead was not quite clear, especially how to deal with the big changes and the enormous grief for the loss of our daily lives. We had to sit down and tell our younger son the big changes in our near future. I used dialogue and a few books such as “My Mum Has Breast Cancer” by Lisa



and Harrison Seawards and also “Safina and the Hat Tree” by Cynthia Hartman. Often we related to the stages described in both book with what was going on in our lives and he became a well-adjusted fine young boy, very knowledgeable in big words such as “chemotherapy,” “radiation,” and “physiotherapy.”

I know that we had many “raised eyebrows” among our family and friends about being so open with our children and our way of involving them in the emotional roller coaster that is being diagnosed with cancer. We provided them with the right information, found suitable support for all of us and by doing so we improved the impact of breast cancer diagnosis in our family and how it has affected us emotionally, physically, and financially. I have no doubt that it was (and sometimes is) a very tough time, with feelings of shock, disbelief, loss and anger, but they knew and they know that they are infinitely loved beyond any health status.

It is a curse: A Ugandan perspective

Elizabeth Mugalu, Kampala, Uganda

When I was diagnosed with breast cancer in January 2010, I knew my life would never be the same. What I did not anticipate was that my predicament would affect my children. After all, my children were all adults.

My third child, Andy was finishing his university education. He was pursuing a degree in civil engineering at Makerere University, a renowned college in my country, Uganda. His good performance had earned him a government scholarship for the four years of his university education, and he was doing very well. Everyone in the family was certain Andy would graduate with a good degree. Indeed, the future was bright.

While at Makerere, Andy met a girl and befriended her. Their relationship had been steady for the past three and a half years. Phina was a very beautiful girl. Not only that, she was also very intelligent. These two young people were so close that each time Andy visited us without Phina everyone at home would ask if she was all right. Andy had confided in me that as soon as he got a job he would propose to Phina.

“Mummy I will waste no time,” he had told me. I encouraged him to go for what his heart told him; after all Phina was in a good job, she was kind and we all loved her. She also loved us back, or at least she seemed to.

I was admitted for mastectomy on January 12th 2010. The operation took over eight hours. When I came to, the first people I saw in my room were Andy and Phina. She had brought me flowers and a get well card. She sat on my bed and said, “Mummy you are going to get well.” I smiled to reassure her and, more so, for my son.

After the pleasantries, Phina sat on the visitors’ chair. She looked at my file which hung at the end of my bed. Suddenly she sprang up and in an agitated voice said my son’s name.

“What is wrong?” Andy responded.

“You mean your mother has cancer?”

After a few minutes, she excused herself and Andy escorted her out. What happened outside, away from prying eyes, knocked my son out. Phina announced that she did not want anything to do with Andy. She told him she did not want to get

involved with a family that “has cancer.” Her reason was that it was a curse.

Andy did not take this lightly. He had planned to settle down with the love of his life. As he put it, life lost meaning when she dumped him. He took to drinking. He jumped from one pub to the next, looking for solace.

I was at a loss. I didn’t know how to help my son out of his depression. Thankfully, a friend of mine who has since passed on, Alice Nuwagira, introduced me to Uganda Women’s Cancer Support Organization (UWOCASO), where I met a counselor. When I explained my problem to the counselor, she advised me to bring Andy in for help. This was not easy because he resisted at first. It took a whole lot of convincing to get him to accept. When he finally agreed, he went for several counseling sessions. Slowly, Andy was helped to stop blaming himself for the breakup. Soon, he realized that his life had to continue without Phina.

I am glad that I can now see positive changes in Andy’s lifestyle. He is steady in his job and looks forward to the future.

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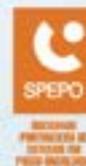
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Global Kitchen

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

If you have a recipe to share, please email info@reachtorecoveryinternational.org



Recipe from the recently launched *Dragons in the Kitchen* cookbook by the Redcliffe Pink Snap Dragons breast cancer survivors and supporters dragon boat team.

This recipe is brought to you from Queensland, Australia.



Fruit and Seed Slice

Gluten free
Makes 12-16 slices

Ingredients

- 1 ¼ cups quinoa flakes
- ½ cup desiccated coconut
- ¾ cup diced dried fruit (of your choice)
- ¼ cup LSA meal
- 2 tsp chia seeds (black or white)
- 2 tbsp sunflower seeds
- 2 tbsp sesame seeds
- 1 tsp freshly grated orange rind
- 1 tsp cinnamon
- 100g butter, chopped
- ½ cup honey

Method

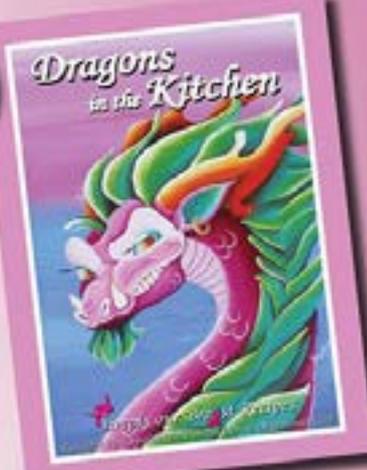
- Heat oven to 180 C
- Grease and line the base of a slice tray
- Combine all dry ingredients
- Combine butter and honey in a small saucepan and melt over a low heat. Increase heat and simmer for two minutes
- Stir through dry ingredients until well combined, press into a tray.
- Bake for 15 minutes until golden
- Allow to cool before slicing into squares

A tasty slice to share with family and friends



<http://pinksnapdragons.com/>
www.facebook.com/RedcliffePinkSnapdragons

ONLY \$20!



Our fabulous new Fundraising Cookbook is here!

Over 100 yummy home-style recipes from the kitchens of our Breast Cancer Survivors and Supporters.

With inspirational photos of our members promoting awareness both on and off the water it makes a beautiful gift for your loved ones, or treat yourself!

email us at info@pinksnapdragons.com to order or purchase from the following outlets -
Goodyear Auto Care - 214 Anzac Ave, Kippa Ring
Sugarland Cafe Toppers - 4/1020 Anzac Ave, North Lakes

All proceeds from cookbook sales will go towards sending a team to compete at the International Breast Cancer Participatory Festival in Toronto, Florida USA in October 2014.

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Orlando, Florida, USA

**C4YW – Annual Conference for Young
Women Affected by Breast Cancer**
21 – 23 February 2014
www.c4yw.org

Glasgow, Scotland

9th European Breast Cancer Conference (EBCC 9)
19 – 21 March 2014
www.ecco-org.eu

Lisbon, Portugal

16th World Congress of Psycho Oncology
20 – 24 October 2014
www.ipos-society.org/ipos2014

Melbourne, Australia

2014 World Cancer Congress
3 – 6 December 2014
www.worldcancercongress.org

Our mission

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

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

To contact RRI please email 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.

