Women, children and cancer

Dr Maggie Watson, Head of Psychological Medicine at the Royal Marsden Hospital in the UK, writes about breast cancer and family dynamics

While breast cancer commonly strikes women aged 60 or over, a substantial number of younger women are also affected. In the UK, for example, thanks to screening programmes and early detection, 48% of breast cancers are diagnosed in women aged 40-60. Many will have young families, although the number of dependent children who have a mother with breast cancer is not routinely documented.

At the same time, the current approach to breast cancer treatment in the developed world has brought changes. The increasing use of chemotherapy in women diagnosed with early-stage breast cancer has helped improve survival and given more hope for the future. A consequence of these proactive approaches to care is the need for women often to stay in treatment for longer periods. The frequent hospital visits, physical side effects of treatment (loss of hair, nausea and fatigue), loss of family income through mother’s absence from work, disruption to family routines, and worries about prognosis may all increase family stress.

As part of a project funded by the European Union, a UK study has looked at factors that may increase the vulnerability of families coping with a mother with breast cancer.

The driving force for the study was that there seemed to be little information about how the children might be affected by their parent’s illness. In cancer care, the development of family-focused emotional care seems to be limited; neglect of the needs of children in families where the mother has breast cancer seems commonplace.

Vulnerable families

The UK study set out to identify vulnerability factors in families as a basis for targeting intervention and support programmes at those who have greatest need. This targeting of resources recognises that many families cope well and, indeed, some are strengthened by the experience of dealing with a mother’s breast cancer. But how can those needing more support be recognised?

We studied the families of women aged 55 or under, with children aged 6 to 17, where the mother’s cancer had been diagnosed as early-stage between 3 and 36 months previously. A hundred and seven families agreed to take part and completed the assessments.

We asked if the children had been told of their mother’s diagnosis. For children younger than 11 years, 76% of mothers reported that their children had been told. All adolescents had been told.

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We asked if the children had been told of their mother’s diagnosis. For children younger than 11 years, 76% of mothers reported that their children had been told. All adolescents had been told.
The need for honesty was emphasised by children themselves in a video sponsored by the UK charity Macmillan Cancer Relief. (1) In their tips to parents, the kids asked them not to lie to them and to answer their questions truthfully when they asked.

We reached the following conclusions:

- Children of women with breast cancer have more emotional and behavioural problems than the general population.
- How families function matters. Where parents’ emotional involvement with their children is intrusive, where problem-solving is not shared by families, where families don’t pull together, and where communication is restricted, children are more likely to have emotional problems.
- Fathers seem not to see some of the problems.
- The mothers’ level of depression is a better predictor of emotional problems in children than such medical factors as whether they are in chemotherapy or how long it is since they were diagnosed.

The children’s problems seem more a function of how patient and family are coping.

Some ideas for the future include:

- Cancer services need to pay attention to the dependent children behind the patient, as presently there is evidence of neglect of their needs.
- Families need information about breast cancer that is accessible to both parents and their children.
- Mothers with breast cancer who suffer depression need active psychosocial care programmes to help them cope so that the important processes of childhood are not adversely affected.

While cancer services work to improve survival in women with breast cancer they also have an obligation to ensure that women and families who are not coping are helped. This should be a priority, not only in order to cope so that the important processes of childhood are not adversely affected.

We were honest and open with him from the beginning. We included him in our discussions and he was working and getting good grades. However, by the end of his 8th year he was on the verge of failing. I felt this was my fault, in a way. I was the one who normally kept behind him and helped him with his schoolwork, but in the months following my surgery I needed to focus on myself a bit. My husband was very supportive - with me every step of the way. And my 13-year-old son seemed to be coping just fine.

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While cancer services work to improve survival in women with breast cancer they also have an obligation to ensure that women and families who are not coping are helped. This should be a priority, not only in order to improve the quality of life of the women, but also to safeguard the future of children who are growing up with a mother with breast cancer.
The articles on women, children and cancer in this issue of bloom underline the need for psychosocial support for the families of women with breast cancer - especially their children, who often suffer in silence. The article by Sinéad Jones is a good introduction to global tobacco control. Has your country ratified the Framework Convention on Tobacco Control (www.who.int/tobacco/framework/en/)? If not, can your Reach to Recovery group work with cancer societies and health-care professionals to see that it does?

Upcoming are several events where we shall have the opportunity to meet one another again. RRI will be represented in the Cancer Supportive Care track at the UICC World Cancer Congress in Washington in July 2006 (see p.15). Your group may wish to apply to make an oral or poster presentation. Visit the website and don’t forget to register early.

We are looking forward eagerly to the 3rd Asia-Pacific Reach to Recovery International Breast Cancer Support Conference in Mumbai, India, in November 2006. You may wish to take advantage of early bird registration.

Last but not least, I congratulate Ann Steyn, Tom Hudson and Josephine Skourta on their awards in Athens. We thank you for your contributions to the development of RRI and we are proud of you all. Keep up the good work!

Ranjit Kaur,
President, Reach to Recovery International

Condolences

The International Union Against Cancer (UICC) and its Reach to Recovery International volunteers extend their heartfelt condolences to the Prime Minister of Malaysia, the Honourable Dato’ Seri Abdullah Ahmad Badawi, on the recent demise of his beloved wife, Datin Paduka Seri Endon Mahmood, who put up a brave fight against breast cancer. She played an active role in raising cancer awareness in Malaysia.

After a psychological consultation and testing for learning difficulties, we learned he had a significant attention deficit disorder. He started on medication, his grades improved dramatically and he ended up passing.

Every school year we’ve struggled both with him and with his teachers, and he has succeeded and has even shown gradual improvement. He has tried coming off his medication several times, but to date this hasn’t been successful.

What caused this problem? My husband and I could find no answers. Research I did on the Internet said there could be any number of reasons.

In June 2005, I attended the UICC Reach to Recovery International conference in Athens. Since my breast cancer diagnosis, I have become very active in, and am now president of, an English-speaking cancer association. Athens was an excellent opportunity for me to see how other breast cancer organisations worked and to talk to breast cancer survivors from around the world.

The conference was enlightening, motivating and inspiring, but for me it was also very emotional.

On the first day a UK psychologist, Dr Maggie Watson, talked about the impact of breast cancer on the family. She really hit home. I was absolutely stunned to hear that some children start displaying learning problems, such as attention deficit disorder, as a result of their mother’s diagnosis! I couldn’t believe it. I went through a myriad of emotions listening to Dr Watson.

Had we completely neglected our child? Could we have prevented this from happening? Should we have sought counselling for him? His attention problems had indeed started immediately following my diagnosis.

As soon as I returned home, I spoke with my son about what I had learned. “Could we have done more for you?” At 16, more mature and certainly wiser, he could not tell me. He was indeed upset and very frightened at the time but knew he had to count on us to make sure everything turned out okay. He does not know what would have helped him.

In the end, I decided we did all we could with the resources available to us at the time. It was particularly difficult living in a foreign country and having to cope with such matters in a language that is not our mother tongue. Had we been in the US or the UK, perhaps we could have benefited from family counselling.

Parents living with cancer need to know what to expect from their children and what not to expect. Even though their child seems to be coping just fine, maybe, just maybe, he’s not. This is where family counselling comes into its own. I think what the UK is doing now is wonderful and essential, in reaching out to families and children to help them cope effectively.
Nordkapp 05 expedition

“When we get fed up we will have to remember our commitment and go on riding…”

Their names are Gabriel Gasser and Alan Schindelholz. They were 9 and 12 years old when their mothers died of breast cancer. They were students at the same school in the small town of Le Locle, Switzerland, and that cruel experience of life built a deep friendship between them. They dreamed of cycling through northern Europe, but did not want to do it just for their own pleasure. They thought of meeting that challenge in memory of their mothers and at the same time collecting money for the cancer league. For the 10,000 kilometre journey they paid for their equipment and found “commitment sponsors” for each kilometre ridden. Their goal was to collect money for the Ligue neuchâteloise contre le cancer and to create a special fund for young patients in the region. Cancer leagues and Reach to Recovery groups welcomed and supported the two riders on their journey.

Before their departure they said “When we get fed up we will have to remember our commitment and go on riding…”

Anne Huguenin, Ligue neuchâteloise contre le cancer

Read more: www.lelocle.ch or www.Nordkapp05.ch

When parents are touched by cancer, it is not easy for them to tell their children. Still closely related to the idea of death, the word “cancer” creates fear. Many parents think to protect their children in the “unsaid”, but children need to hear the truth from their parents “in gentle words”.

Marie-France Delaigue-Cosset is a doctor and anaesthetist at the Institut Gustave-Roussy in Villejuif, France. Nicole Landry-Dattée, a psychologist and psychoanalyst at the institute, is responsible for the psychological support of patients and their families. Ten years ago, they set up their first support group for the children of patients affected by cancer, to help them to communicate, ask all their questions, and break the silence.

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16 - 144 pages
Marie-France Delaigue-Cosset
Nicole Landry-Dattée
Collection Espace Éthique
directed by Emmanuel Hirsch
www.vuibert.fr

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Read more: www.espace-ethique.org/fr/documents/enfants_cancer.pdf

Ces enfants qui vivent le cancer d'un parent

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UICC World Cancer Campaign

In June 2005, responding to the urgent need to scale up international awareness of the fight against cancer, UICC launched its World Cancer Campaign, with a first-year focus on childhood cancer.

Each year, more than 160,000 children are diagnosed with cancer and approximately 90,000 die of it.

The types of cancer that occur in children vary greatly from those seen in adults. Leukaemias, brain and other nervous system tumours, lymph node cancers, bone cancers, soft tissue sarcomas, kidney cancers, eye cancers, and adrenal gland cancers are the most common childhood cancers.

Childhood cancer is relatively rare and responds well to prompt and effective treatment, with survival rates of three in four or better in some countries.

At least four out of five children with cancer live in developing countries, however, where they are often diagnosed too late or not diagnosed at all. In partnership with sanofi-aventis, UICC issued a call for projects in 10 of these countries and will select 10 projects for funding at the end of November.

There will be a second focus in the World Cancer Campaign in 2006.

Read more: www.mychildmatters.org

Women and tobacco

Increasingly, the face of the tobacco epidemic is female, says Sinéad Jones, UICC’s Head of Tobacco Control

Half a century after smoking was established as a major cause of lung cancer, new evidence on the health impact of smoking is still emerging. Recent reports bring into focus the impact of smoking on women and their health and highlight a worrying lack of awareness by women about the special hazards we face.

The relationship between smoking and breast cancer has been studied extensively. Reviews of the available evidence by the International Agency for Research on Cancer (IARC) and the US Surgeon General reach the same conclusion: smoking does not seem to increase the overall risk of breast cancer. (1)

But that, for readers of bloom, is the only good news.

Take, for example, cervical cancer. Its primary cause is infection with the human papilloma virus (HPV). However, smoking also has a part to play.

In its authoritative assessment of the evidence, IARC concludes that smoking increases the risk of the more deadly malignant form of cervical cancer two or three times. Put simply, "tumour-promoting" substances present in tobacco smoke travel through the body and speed the progression of early "pre-cancerous" changes in HPV-infected cells towards fully-fledged cancer.

The finding that smoking is a cause of malignant cervical cancer is supported by last year’s US Surgeon General’s Report.

This effect of smoking can be seen right through the detection, treatment and outcome of cervical cancer. Women who smoke are more likely to have abnormal cervical smear (PAP) results and to be diagnosed with malignant cervical cancer. Smoking also appears to reduce the likelihood of successful treatment for cervical cancer.

While many women can identify smoking as a cause of lung cancer, the link between smoking and cervical cancer is not well known. A study of women attending a women’s health clinic in the UK shows that women who smoke are largely unaware of their increased risk of invasive cervical cancer and do not appreciate how important it is for them to have regular smear tests. In fact, women who smoke are less likely to attend for cervical screening than non-smokers are.

The bad news is not all bad, though.

In women who are diagnosed with a cervical pre-cancer, giving up smoking reduces the risk of developing the malignant disease and improves treatment outcomes. So quitting the habit - at any stage - can be beneficial.

While the harmful effect of smoking during pregnancy was identified more than 30 years ago, its impact on other aspects of reproductive health has only recently been appreciated.

A report by the British Medical Association concludes that "smoking has a profound effect on almost every aspect of sexual and reproductive health". In women, the outcomes range from missed and painful periods to increased risk of blood clots in users of the combined contraceptive pill. Women who smoke reach the menopause early - on average, two years earlier than non-smokers - and are liable to suffer more severe menopausal symptoms.

Women who smoke are twice as likely to have difficulties in becoming pregnant. Smoking also damages men’s sexual health, putting them at greater risk of impotence and sperm damage. For couples who are having difficulty in conceiving, the success rate of assisted reproduction is lower when either the man or the woman smokes.

Where both partners smoke, the risk of failure increases almost fivefold.
Again, stopping smoking helps.

Summing up the myriad harmful effects of tobacco, the US Surgeon General says that smoking affects almost every organ system in the human body. Tobacco smoke - a deadly cocktail of over 4,000 toxins and more than 50 known carcinogens - has far-reaching effects on health.

Not least, in fuelling worldwide epidemics of cancer, heart disease and chronic lung disease. Increasingly, the face of the tobacco epidemic is the face of a woman.

Note

News from around the world

Iceland

The Icelandic breast cancer support group Samhjálp kvenna was formed in 1979 by two women diagnosed with breast cancer and two cancer specialists. Today, there are forty women in the support group, equally divided between countryside and the capital, Reykjavik. (Nearly half of Iceland’s 300,000 inhabitants live in Reykjavik.)

Every year, about 170 Icelandic women are diagnosed with breast cancer. The most important part of our work is talking to newly diagnosed women, visiting them in their homes when asked.

In wintertime, Samhjálp kvenna has an open house on the third Tuesday of every month. Doctors, nurses and psychologists speak on topics related to cancer. Sometimes the talk is on a completely unrelated subject, such as gardening. In Iceland there are about 1,800 breast cancer survivors; one-third of them are on our mailing list.

Samhjálp kvenna joined Reach to Recovery International in 1980. From the beginning we have worked with Nordic breast cancer support groups, and in 2003 we joined Europa Donna. In 2001 we became a formal society with a chair, a treasurer, etc. Our group gets great support from hospital staff, the Icelandic Cancer Society and the media.

Gudrun Sigurjonsdottir
Chair, Samhjálp kvenna
samhjalp@krabb.is

Italy

Noi e il Cancro - Volontà di vivere (Cancer and Us - The will to live)

Noi e il Cancro was founded as a registered charity in Padua, Northern Italy, in 1979. Currently there are about 1,500 active members. Most of them have been diagnosed with breast cancer, and many have become volunteers and help in the running of the organisation according to their personal abilities and preferences. There is also a team of paid specialists: psychologists, yoga teachers, physiotherapists and dieticians. In addition to Reach to Recovery, we belong to the National Federation of Women with Breast Cancer (FADOS) and Europa Donna.

Two of our regular activities may be of particular interest:
1) Men’s counselling: Eight evening meetings each year, run by a psychologist. Men are shown how they can support their partners who are living with breast cancer or are helped to cope with mourning the loss of their companions.
2) Education campaigns in schools - the Martina project: We strongly believe that young people must become aware that health is precious and needs to be protected and defended. Martina was only 25 when she detected a small lump in her breast. Her doctor told her not to worry, as the risk of getting breast cancer at that age is very small. Too late, Martina realised the doctor was wrong. She died, but she left us her testament: she stressed the need to teach young people to take care of their health and bodies. This is why every year we talk to 17- and 18-year old students in secondary schools to promote prevention and early detection of cancer. Each student receives the booklet L’informazione aiuta a Vivere (Be informed - Live longer). We are happy to send a copy to anyone who would like to receive it.

Caterina Tanzella
President and founder, Noi e il Cancro
volontadivivere@libero.it
Website: digilander.iol.it/volontadivivere
Poland

"No one here is fighting for a medal, joy of life is sufficient for us"

Polish breast cancer survivors are called "Amazonki", or Amazons. The Polish Federation of Breast Cancer Support Groups - Amazons was set up in 1993 in order to represent women living with breast cancer. It links over 150 Amazons Clubs (support groups), with more than 10,000 members.

The Federation has developed a volunteers programme based on Reach to Recovery principles. In every club there is a group of volunteers ready to provide emotional and practical support to breast cancer patients.

Surgical procedures are changing for breast cancer; hospital stays are shorter than before; therefore we have to find other ways of contacting patients. Advertisements in the newspapers might be a good idea. Other patient groups, friends and the Norwegian Cancer Society help to contact survivors.

We should continue with traditional supportive care but work wherever possible towards having chatrooms and helplines. This would make it possible to reach the large number of women who live in rural areas. RRI and Europa Donna can advocate better health policies for breast cancer survivors. RRI conferences are important for sharing experiences, refreshing the spirit, and encouraging us to do something when we get back home.

Website: www.kreftforeningen.no/dt_front.asp?gid=317

News from around the world

Japan

Takako Watt was awarded the Terese Lasser Award for initiating the development of the Reach to Recovery programme in an exceptional way in Japan. She is the founder member of Akebonokai (Dawn Association).

I was diagnosed with breast cancer in 1977. In those days, there was no psychosocial support. My children were young, 4 and 7. They didn’t know what was happening to their mother except I was in hospital. My husband was very good to bring them to me every evening after his work, so they at least knew where I was.

When they looked at my scar, they thought doctors would give the loss back to me. They certainly became sensitive and nervous. My daughter started blinking her eyes constantly, and my son refused to go inside my friend’s house when he had to be left there without me.

From my own experience of struggling after the cancer shock, I was sure other women must need to share their anxiety and support one another. So in 1978, I founded the Japanese breast cancer patients’ association, Akebonokai (Dawn Association).

Our initial challenges were to make doctors and nurses understand the meaning of this kind of support service and to start going to hospitals.

We now have nearly 4,000 members, in seven groups, and gain two or three members each day. In 1993, Ann Fletcher from Australia gave us proper training. Nearly 1,000 volunteers listened to Ann introducing and demonstrating the Reach to Recovery system.

I sometimes wonder why people still join patient support groups since, unlike the old days, they can obtain plenty of information easily through the internet, TV, or magazines. This indicates that patients need not only information but also psychosocial support to gain confidence to live again. Breast cancer patients are definitely much more open to talking about themselves than before, but psychosocial support is still important.

We would like to know how other countries are developing this unique, meaningful, and historical programme.

Takako Watt, Founder member, Akebonokai
Website: www.akebononet.org/contents/e_main.html

Norway

Lise Hoie, RRI President from 1999 to 2002, spoke to bloom

Reach to Recovery in Norway has 11,500 members, 80% of them breast cancer survivors. There is an increase in the number of volunteers who are eager to give supportive care. Some of the articles in bloom are translated into Norwegian and published in our magazine Athene. Many social gatherings are arranged for survivors and their families.

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News from around the world

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breast cancer treatment. Teams from all over Poland as well as from Ukraine and Germany have taken part. These competitions have become very popular and are spreading as local events. Last year, to celebrate their 10th anniversary, the Lezno Amazons Club held the first Polish Swimming Competition for Amazons.

In 2003, Poznan hosted the World Dragon Boat Championships, moved from China because of the SARS epidemic. Among the contestants were breast cancer survivors from Canada. The Poznan Amazons pulled themselves together and in the space of a few weeks prepared and presented two teams in the breast cancer survivors Dragon Boat races!

In June this year, the Poznan Amazons were invited to the Dragon Boat Festival in Vancouver. Together with the Canadians they made one team, among over sixty teams taking part. They and the Italians were the only Europeans in this contest.

In September this year the first Polish Amazon Archery Championship was held in Poznan.

The driving force of Amazon rehabilitation through sport activities is Krystyna Wechmann, who has been the leader of the Poznan Amazon Group for 15 years, and president of the Federation since 2001. Before she fell ill she was a successful sportswoman, twice the rowing champion of Poland. Even now she is closely connected with sport as a referee. Her enthusiasm has infected many Polish Amazons, bringing them joy and confidence in their ability to overcome the limitations imposed by the disease. Naturally, there can’t be competitions without medals, but the slogan that always appears at our competitions says: “No one here is fighting for a medal, joy of life is sufficient for us” (it rhymes in Polish).

Danuta Dobrska
Vice-president, Polish Federation of Breast Cancer Support Groups - Amazons
Website: www.amazonkifederacja.pl

Singapore

At the 2nd Asia-Pacific RRI Breast Cancer Support Conference in Singapore in 2004, Rosalind Lee won the award for the outstanding RRI volunteer in the region. Lim Choo Hin and Catherine Lee of Reach to Recovery in Singapore interviewed her for bloom.

Rosalind Lee is a survivor of 41 years, now 87 years old. After recuperating from her mastectomy, she began to visit newly diagnosed breast cancer patients in hospital. She had no formal training; she merely visited patients to find out what their concerns were, shared with them her experience, and encouraged them to be positive.

At about the same time, Virginia Frank from Australia started a Reach to Recovery group in Singapore. Dr Tan Khin Koo of the Singapore Cancer Society introduced the two women and urged Rosalind Lee to join the group to ensure the continuity of the programme.

Membership did not grow very rapidly in those early years, as some patients had the misconception that they could contract cancer again if they mingled with other survivors. Many were fearful of disclosing their medical history for fear of being ostracised by the community. Most saw cancer as a "curse" resulting from bad deeds. Out of ignorance and fear, patients avoided talking about it or seeking more information.

Another difficulty was matching volunteers to newly diagnosed patients from different ethnic groups.

Reach to Recovery is a support programme of the Singapore Cancer Society, which has funded several volunteers to attend international conferences and has arranged for training tailored to local volunteer needs.

Psychosocial support is important to breast cancer patients. They have to handle cancer in their body, the effects of cancer treatment, disfigurement, rehabilitation, adjustments in family roles, and communication with family, friends and colleagues.

Breast cancer patients are more open about being survivors than before. There are now also support groups for patients’ spouses and families, unheard of in the past. These caregivers need information and support on the challenges of caring outside the hospital setting.

Website: www.singaporecancersociety.org.sg/
Ukraine

In June 2005, the National Assembly of Ukrainian Invalids (NAUI) organised a round table with high-ranking government officials and officials from the Ministry of Health and Social Protection. Ukraine-Donna was one of four regional organisations represented at the round table. A committee was appointed to compile a report and submit it to a parliament hearing that will take place soon. This is a big step towards improving conditions for patients in Ukraine and we are very proud of this achievement. In Ukraine, 20 October is observed as Breast Cancer Awareness Day.

Larisa Yashchenko
President, Ukraine-Donna
Website: www.kievcentre.kiev.ua/donna/

Slovakia

For almost nine years I have been working to interest the Slovak cancer society in Reach to Recovery. Recently, I have been distributing bloom among breast cancer patients. In the small Southern Slovak town of Nove Zamky, breast cancer women read the newsletter and became their own Terese Lassers. On the initiative of pathologist Maria Istenes MD, local oncologists offered them advice and training in accordance with the UICC Training Manual, and they decided to volunteer for supportive care. Father Gabriel OFM invited them to meet in the Franciscan monastery. I hope these Nove Zamky oncologists and volunteers will serve as an example for doctors and patients in other parts of our country.

Edita Jassingerova, RRI volunteer
editajas@stonline.sk

What is the TNM system?

The appropriate treatment and care of someone with cancer is not possible without knowledge of the extent or “stage” of the cancer. The global standard in cancer staging is the TNM classification of malignant tumours. Doctors throughout the world use the tumour, lymph node, and metastasis (TNM) system for staging most cancers. The TNM system, overseen by the International Union Against Cancer (UICC), serves as a “common language” in cancer care.

The TNM system was developed by Pierre Denoix of France between 1943 and 1952 and adopted by UICC in 1953 as the standard for cancer staging.

The “T” in TNM relates to tumour. It indicates tumour size, extent, or penetration (depth) of the tumour. The “N” stands for node. It indicates the number of lymph nodes with cancer or the location of the cancer-involved lymph nodes. The “M” stands for distant metastasis, or spread of the cancer to other parts of the body. It indicates cancer cells outside the local area of the tumour and its surrounding lymph nodes.

An important part of treating a person with cancer is to first find out how far the cancer has spread. Different tumours may spread to different parts of the body. You may have tests such as computed tomography (CT scans), magnetic resonance imaging (MRI), or positron emission tomography (PET scans). The TNM system is used to classify the extent of cancer and to help you and your doctor decide what treatment is best for you and draw up a treatment plan.

Usually, your doctor stages the cancer at the time of diagnosis and finds out the “clinical stage” of the disease. If you have an operation, a pathologist studies tissue the surgeon removed and assigns it a “pathologic stage.” In general, the pathologic stage is the most important one in making treatment decisions.

What are the most common staged cancers?

The most common cancers that doctors stage using the TNM system are breast, colon and rectal, stomach, oesophagus, pancreas, and lung. Other cancers staged with the TNM system include soft tissue sarcoma and melanoma. Staging systems exist for 52 sites or types of cancer. Some cancers are not staged using the TNM system. Cancers of the blood, bone marrow, brain, and other sites might not use the TNM staging. Gynaecologic cancers use another staging system, which doctors can translate into TNM.
**What does stage grouping mean?**

Once doctors have determined the TNM categories, they can place the cancer into a “stage group”. Stage grouping uses Roman numerals I, II, III, or IV. The larger the number, the more advanced the stage of cancer is. If you will take part in a clinical trial, the stage group of the cancer must be known. It allows you to be placed into the proper treatment group. (A clinical trial is a research study that is conducted with the patient’s permission to see how effective and safe a new treatment is.)

**First all-Africa Reach to Recovery volunteer training**

*Cape Town, South Africa, 13-15 April 2005*

It was with a sense of excitement and a little apprehension that the participants arrived at the venue. Some had travelled many miles to attend and were staying with Reach to Recovery volunteers they knew nothing about. It was the beginning of four wonderful days that left no one involved untouched.

There were 20 participants, of whom 8 came from countries outside South Africa.

"Meeting such a wonderful group of women and being trained with them was a special experience. As a trained volunteer I have the opportunity to provide emotional and practical support to patients who have been diagnosed with breast cancer.

With the important skills that I learned at the training and with the experience I gain, I hope to train other volunteers in the not too distant future."

Jahan-Aara Mohamed (Zimbabwe)

**Call for contributions**

Did you organise a successful local activity that will give other Reach to Recovery groups around the world the chance to develop a similar initiative based on your proven good idea? We would love to hear about it!

Send your contribution to the editorial team at bloom@uicc.org.

Contributions should include:
- Profile of your patient group (75-100 words)
- Summary of your activity (75-100 words)
- Photo, if available (digital 300 dpi or paper)
- Website address, if available
- Your logo, if you have one (eps or tif format)

**Disclaimer**

The content of this newsletter is the sole responsibility of contributors, and does not necessarily reflect the official views of UICC.
"The training in Cape Town really opened my eyes and changed my thinking in many ways. I always thought I was over my cancer, but I realised that this was not the case. Just being with other women who had gone through similar experiences made me stronger and more willing to assist others in a similar position. I now wake every day feeling that I can tackle whatever comes my way."

"Out of the blue I was called and asked if I could visit a lady of 70 in hospital who had had a mastectomy two days before. At first I was nervous, but I recalled what I had learned and very shaky I arrived at the hospital. I presented her with a patient information kit, for which she was very grateful. She asked a lot of questions and I answered with caution but also with enthusiasm. I have since followed up with her and so far all seems well. I must admit that I do feel proud as a first timer. I am also confident that next time will be much better."

Cheryl Ferreira
(Namibia)

"The training was such an eye-opener for me in certain areas, especially visiting patients in hospitals. They willingly share their experiences and openly share their fears. There are also various doctors who have found my support of great help and have been inviting me to see patients who looked disturbed or depressed when diagnosed with breast cancer."

"I studied the way Reach to Recovery is working in South Africa and I was impressed. We do not have a board composed of survivors, neither are there any regional groups. I therefore feel that in Kenya we need another course where we can have training of trainers, who can be used to train others locally in order to expand our services."

Irene Gitau
(Kenya)

Angels in our home

Maretha van Wyk was one of the Reach to Recovery members in South Africa who opened their homes to volunteers from other African countries.

At about midnight on 12 April someone rang the bell at our front gate. The airport bus had brought our special Reach to Recovery guests from Kenya.

That night, Irene Gitau and Mary Onyango did not simply enter our house with their suitcases. Was it because we were joined together by the symbolism of the pink ribbon that we immediately became sisters?

During the following three days, we talked a lot about Reach to Recovery and how services in the two countries differed. They see South Africa from an Africa perspective, as a first world country, with ideal facilities for diagnosing and treating breast cancer. In Kenya it would seem that even general practitioners are unaware of the problem and make incorrect diagnoses. When a woman is eventually referred for proper evaluation, there is usually advanced metastasis. Some of the women also refuse to talk about their treatment. For instance, one woman who lived with her mother did not tell her that she had undergone radiotherapy and chemotherapy. They were surprised to learn we had exactly the same problems!

After the training each day, late afternoons were spent in a mad rush to show Irene and Mary everything: the shops, our beautiful scenery, historical buildings…

We thoroughly enjoyed each other’s company. It didn’t matter that we had to speak English to communicate. At one stage I found myself speaking English to my very Afrikaans cat!

The man who removes our garden rubbish once said to me: “I am part of everyone I have ever met.” It was wonderful to meet Irene and Mary and to become part of them. May they feel the same about us!

Am I not a woman?

Am I not a woman?
My shape has been changed
My form has been revised
My breast has been de-sized
Am I not a woman?
My heart still loves
My arms still hug
My body still craves
Am I not a woman?
My hips still swerve
My lips still entice
My eyes still allure
Am I not a woman?
My fingers still caress
My mouth still soothes
My ears still listen, tenderly
Am I not a woman?

Sylvia Dunnivant
Finding hope through Reach to Recovery

Three years ago, I was diagnosed with breast cancer. I was 38 years old; my children were 5, 7 and 12.

I found a lump in my left breast after doing breast self-examination and I said to myself that it was nothing. I went to the doctor the next morning and was recommended mammography and ultrasound. I brought the results to the doctor, accompanied by my husband, and was shocked when the doctor told me I must have a mastectomy as soon as possible. I was so depressed I thought I was going to die. I didn’t want to make any decision.

Three days later my family persuaded me to follow the doctor’s advice and have a mastectomy and chemotherapy in Mt Elizabeth Hospital, Singapore.

Before I went home after surgery, the nurse gave me a leaflet about Reach to Recovery Singapore, but I had no time to meet any of the volunteers because I was commuting to Singapore only for the chemotherapy.

My husband, my family and my close friends give me constant support and I was able to go back to work as usual, but my mind was still sick and I didn’t want to meet anyone else.

One day a relative gave me a women’s magazine. I read an article about the Indonesian Cancer Foundation and the experience of breast cancer from a doctor who was a survivor for 16 years.

When I contacted the Indonesian Cancer Foundation, I learned there was also a Reach to Recovery programme in Indonesia. I met Dr Rebecca, who is the Reach to Recovery coordinator in the Indonesian Cancer Foundation, and I got to know a group of other survivors. Since then I have been communicating with them frequently.

Now I realise that although there is no certainty of recovery from cancer, there is hope to continue living. Thanks to Reach to Recovery.

Martini Lim
RRI Group, Indonesia

Reach to Recovery conference meets in Athens

"The value of the destination is given by the magic of the journey"
- Nikos Kazantzakis

Over 300 delegates from 40 countries attended the 13th Reach to Recovery International Breast Cancer Support Conference in Athens, Greece, on 1-4 June 2005. The conference was hosted by the Hellenic Association of Women with Breast Cancer and the Society of Volunteers Against Cancer. Leta Chatzi of the Hellenic Association of Women with Breast Cancer chaired the conference organising committee.

It was Leta and her team’s dream to organise a RRI conference in Athens. Their other goal was to deepen awareness of UICC’s Reach to Recovery programme among doctors and to stress the importance of supportive care. Now they receive telephone calls from doctors requesting information on RRI and wanting to help the groups. There are several requests to form groups outside Athens. The next dream is to have a 24-hour hotline for newly diagnosed patients.

Lela Kalogianni, deputy chair of the organising committee, talks to journalist Elena Rizeakou about the project

"The two year journey of preparation was amazing," said Lela.

"It was full of everything - joy and sadness, tension, satisfaction and disappointment, new friendships, new cooperation, and new perspectives."

"We believed the conference would offer women with breast cancer a unique opportunity to share experiences, exchange views, and hear many interesting contributions from international specialists," she said. "The conference focuses on the human, not on the medical, aspect. Its object is the woman living with breast cancer and the problems she may face."

"We thought the conference would bring the Reach to Recovery programme of organised mutual aid to the attention of many Greek women who have been locked in silence after an experience of cancer."

"In our country, sponsors are eager to support serious, necessary and transparent activities. The Society of
Volunteers against Cancer and the Hellenic Association of Women with Breast Cancer meet all of these prerequisites. Our work is important and acknowledged by the state and the broader civic community, and our credibility is ensured by independent audits.

“Likewise, our excellent past and the importance of our work led state bodies to place the conference under their auspices. We cooperate constantly with the medical societies that deal with cancer, and as a result we have their support whenever we ask for it.”

Ranjit Kaur was requested by the RRI Committee and its advisors to continue her presidency for another two-year term (2005-2007). She accepted, and she promised her best efforts to develop the RRI network.

The regional representatives are: Ann Steyn, South Africa (Africa); Ranjit Kaur, Malaysia (Asia); Irina Kozulina, Belarus (Eastern Europe); Maria Cunha Matos, Portugal (Western Europe); Susana Fantino, Argentina (Latin America). The responsibilities of the regional representative are to develop and manage Reach to Recovery programmes in their region.

The advisors to the RRI programme are Dr Jeff Dunn, Chief Executive Officer, Queensland Cancer Fund, Australia, and Isabel Mortara, Executive Director, UICC.

Ann Steyn was the first-ever Reach to Recovery volunteer. In 1953, following her own operation for breast cancer, she initiated the Reach to Recovery programme in the US, dedicating herself to the psychological and physical rehabilitation of others who had undergone a similar experience and enthusiastically training new volunteers.

At the 13th RRI Breast Cancer Support Conference the Terese Lasser award was conferred on Ann Steyn, in recognition of her contribution to the development of the RRI programme in South Africa.

Terese Lasser visited South Africa in 1967. She addressed breast cancer survivors in Johannesburg and as a result Reach to Recovery was started.

“It took off slowly,” Ann recalls, “but when I was diagnosed in August 1990 there was a small group of survivors operating in Cape Town. One of them visited me in hospital - in those days it was a one-off visit. I saw a need for greater support, particularly in all communities. This meant training volunteers from all communities.”

“I was originally trained by our cancer association in 1992 and from 1995 started evolving a training programme relevant to South Africa. It is difficult to give a figure of how many volunteers I have trained - certainly over 200.”

Training is now conducted regionally, and there are currently 34 RRI groups nationwide.

“My emotions when I heard my name announced to receive the Terese Lasser award were mixed!” Ann says.

“First, amazement and disbelief (especially as I have met so many volunteers who would qualify for this award). Then a sense of gratitude to all those volunteers in South Africa, past and present, whose commitment and support to the ideals of RRI made the work I do possible. South Africa is a country of diverse communities, but breast cancer affects us all and has joined together women from these various communities.”

“And finally a realisation of the responsibility I now have to continue to work for the development and growth of RRI in South Africa and in the African region. I hope with the support of UICC and RRI to form a team of trained volunteers throughout the continent that will ensure that women who are diagnosed with breast cancer and their families will have the best care and support,” she says.
Tom Hudson

UICC established the Reach to Recovery International medal for health professionals to recognise outstanding professionals who have encouraged voluntary breast cancer support programmes, aided recognition of volunteers by their communities, and supported their efforts to spread their activities to new communities.

The Reach to Recovery International medal was awarded to Ireland’s Tom Hudson at the 13th RRI Breast Cancer Support Conference in Athens, Greece, in June.

In 1985, while in the process of establishing Reach to Recovery groups in Europe, Francine Timothy of the American Cancer Society visited the Irish Cancer Society and encouraged it to adopt the RRI programme. She had discussions with Tom Hudson, who was the CEO of the Irish Cancer Society, and, in 1990, the 6th RRI conference was organised in Dublin. Tom gave advice and support but, he says modestly, "the women did it all".

He would like to see cancer societies generally being more supportive of supportive care. “We must not forget that the survivor has the unique knowledge and not others," he says.

Tom will continue to give his support to the RRI programme, nationally and internationally.

Josephine Skourta

The Hellenic Association of Women with Breast Cancer and the Society of Volunteers conferred the National Award for the Best Volunteer on Josephine Skourta at the 13th Reach to Recovery International Breast Cancer Support Conference.

Josephine Skourta initiated and developed the RRI programme at the Hellenic Association of Women and trained volunteers to give supportive care. She was one of the people who supported the idea of hosting the conference in Greece.

Josephine Skourta is a social worker. She was Director of Social Services in "METAXA", the Anti-Cancer Hospital of Piraeus, from 1967 to 1991. Today she is the scientific consultant and a member of the scientific committee of the Hellenic Association of Women with Breast Cancer and the Society of Volunteers Against Cancer.

Conference outcomes

Athens conference calls for more support for women with breast cancer

Leaders at the 13th Reach to Recovery International Breast Cancer Support Conference, which met at the beginning of June in Athens, Greece, called for regular reviews of breast cancer treatment guidelines and for peer supportive care to be made available across the globe to those affected by breast cancer. Worldwide, over a million women are diagnosed with breast cancer each year, and more than 400,000 die (IARC, 2002).

“Though we are winning the battle against breast cancer on several fronts, we have to work together to reduce the discrepancies that exist in quality care for women with breast cancer,” said Ranjit Kaur, RRI President. “UICC is working to ensure that quality of life is available globally, which includes psychosocial support offered by women with similar experiences.”

Within the theme "Today’s Reality, Tomorrow Perspectives", the conference included such topics as psychosocial challenges for the family, the importance of volunteerism, advocacy and breast cancer research. Far more than a conference, it was an opportunity to share information and experience, with laughter and hugs heading the agenda.

Recommendations included planning regional breast cancer support programmes in order to meet country needs.
The UICC World Cancer Congress will bring together the world’s foremost leaders and practitioners in the fight to control cancer. It will focus on transforming the latest knowledge into strategies that countries, communities, institutions and individuals can employ to reduce the global cancer burden. By uniting medical, public health, and organisational leaders, it will build capacity to develop effective, data-driven cancer control plans and help transform what is known about cancer into what is routinely done.

Of the congress attendees – an anticipated 5,000 people from 90 countries – half are expected to come from outside the United States.

One of the five congress tracks will highlight the global advances, challenges and barriers in providing supportive care to patients with cancer. In this Cancer Supportive Care track, presenters include Ann Berger, USA; Jimmie Holland, USA; Ranjit Kaur, Malaysia; and Robert Twycross, UK.

The preliminary programme and call for abstracts is now available.

Read more: www.2006conferences.org

The World Conference on Tobacco OR Health will unite thousands of the world’s tobacco control professionals in a comprehensive global effort to reduce tobacco use. Participants will be exposed to successful tobacco control efforts, best practices, and effective intervention techniques used successfully by their colleagues around the world.

“We want to bring together a diverse global community, with differing needs and interests, by including the latest science as well as basic hands-on workshops,” says Yussuf Saloojee, UICC’s Strategic Leader for Tobacco Control, who will co-chair the conference.

Scholarships and fellowships

The organisers recognise the importance of providing support to maximise the number of individuals from low- and middle-income countries who participate in the World Cancer Congress.

A limited number of scholarships will also be awarded to individuals who meet specific criteria to attend both the congress and the World Conference on Tobacco OR Health.

Scholarships will be awarded on a competitive basis. Complete applications, with abstracts, must be received by 21 November 2005.
3rd Asia-Pacific Reach to Recovery International Breast Cancer Support Conference

Jagruti: the awakening
Mumbai, India, 7-10 November 2006

In Indian lore, Jagruti is a flame that is a perpetual source of light and energy. For women with breast cancer, it signifies the ability to regain a meaningful, vibrant life through treatment and psychosocial support. After breast cancer, a woman can still live with dignity and femininity and use the experience to help other women cope with their cancer.

The conference is organised by a coalition of seven Indian NGOs: Cancer Patients Aid Association, Indian Cancer Society, Mastectomy Association (India), Passages, Tata Memorial Hospital, V Care Foundation, and Women's Cancer Initiative (Savaera).

Early bird registration before 30 June 2006
Visit www.jagruti.org.in for details of registration, a call for abstracts and a first announcement of the conference programme.

Mastectomy Association (India), C/7 Bhagya Nagar, Shivaji Park, Mumbai 400 016 India. Tel +91 22 2444 9808 vimalk_9@rediffmail.com

14th Reach to Recovery International Breast Cancer Support Conference

The conference, organised by the Swedish Breast Cancer Association (BRO), will be held in Stockholm, Sweden, on 30 May-2 June 2007.
Website: www.bro.org.se/

Mission Statement
Reach to Recovery International

Reach to Recovery International is a programme of the International Union Against Cancer (UICC). It is built on a simple yet universal principle: that of a woman who has experienced breast cancer herself giving freely of her time and experience to assist and support another woman confronting the same challenge.

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.

About UICC

UICC is the only international non-governmental organisation dedicated exclusively to the global control of cancer. Its vision is of a world where cancer is eliminated as a major life-threatening disease for future generations.

Founded in 1933, UICC is an independent association of more than 270 member organisations in over 80 countries. Members are voluntary cancer leagues and societies, cancer research and treatment centres and, in some countries, ministries of health.

Reach to Recovery International

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If you would like to know more about Reach to Recovery International or would like to order additional copies of bloom, please contact:

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