

Lethal Legacy

Will your children inherit breast cancer?

Claire A finally decided to have a bilateral mastectomy on her 40th birthday. “In my family, far from life beginning at 40, the evidence was that being 40 was a death sentence,” she says. Claire’s mother died from breast cancer at the age of 47, and her grandmother and great-grandmother had also died from the disease. What would you have done?

Since the relatively recent discovery of the genes responsible for inherited breast cancer – BRCA1 and BRCA2 – this topic has been widely debated, and genetic testing is welcomed by some and firmly rejected by others. Simply knowing that you carry the faulty genes is no prevention in itself, but being aware that you are at increased risk of breast cancer could make you more vigilant in detecting early changes and having them treated. Some women are against their daughters being tested because they feel that the distress it could lead to would do more harm than good, while others feel they and their relatives would like to know as much as possible. It is not surprising that this has become a highly subjective and emotional issue.

So what is hereditary breast cancer?

The term applies when the cancer runs through a family, affecting successive generations of women. There are several important features of hereditary breast cancer. The first is the early age of onset. While usually more common in older women, with an average age of 62 years among women affected, in ‘breast cancer families’ the average age is 44. Second, there is often more than one tumour in the breast. Finally, the cancer may affect both breasts.

It is important to remember that hereditary breast cancer accounts for only a small proportion of all cases – around five to 10 per cent. If there is a fault in genes BRCA1 or BRCA2 the chances of getting breast cancer may be increased, but this does not mean that it will definitely occur. There may be other breast cancer genes that have not yet been identified. However, it is thought that you have a much greater risk of developing the disease in your lifetime (assessed as up to age 70) than someone who does not have a faulty gene. You will also have a 50:50 chance of passing on the faulty gene to your children.

What are the options?

The options for those at increased risk are include screening, with regular mammograms starting five years before you reach the age at which your relative was diagnosed. Women under 35 are unlikely to be offered screening, as this method is less reliable in younger women whose breast tissue is more dense. A study is currently taking place which is looking at whether a magnetic resonance imaging scan (MRI) would be more helpful than mammography for women who are likely to carry a faulty gene.

For those in a high risk group, it may be possible to have a genetic test to identify whether there is a faulty gene. The test is done on a blood sample at a specialist cancer genetic clinic. Only a few people will be offered this test and, even if it is an option for your family, you may choose not to be tested. Careful genetic counselling will give them information to help them decide.

Before anyone can have a genetic test, a blood sample must be taken from a relative who already has breast or ovarian cancer so that the faulty gene can be found. This search can take many months to complete, as it is technically very difficult. If a faulty gene is not found, it will not be possible for the test to proceed. This does not mean that a fault does not exist, as it could be on a part of a gene that current technology cannot pick up. If a person has been tested and does not carry the faulty gene, their chances of developing breast cancer are the same as that of the general population (i.e. around one in eleven).

Some women who are at high risk of developing breast cancer may consider having both their breasts removed to reduce this risk. This is called a prophylactic bilateral mastectomy, and reconstruction of both breasts is usually offered at the same time. Having this operation may reduce the risk of breast cancer, but since the operation is not very common the precise protection it offers is unknown. It cannot completely eliminate the risk.

To test or not to test?

Although Claire and her sister were unable to have genetic testing, because their mother died before the discovery of the rogue genes, Claire has always been conscious of the need to monitor the health of her breasts, and she became involved in various studies on hereditary breast cancer. She and her family lived in the Netherlands for some years, where it was possible to have regular mammograms despite being quite young. However, on her return to the UK and with her 40th birthday looming, she asked to be referred to an NHS breast consultant. "She asked me about the female relatives on my mother's side who hadn't died of breast cancer, and I said there weren't any! Each generation had suffered from it, and my mother had developed a tumour in her left breast after her earlier mastectomy of the right breast.

"We can't say whether I have got the gene, although the chances are quite high. I told the consultant that, had it been possible to be tested and had the test proved positive, I would have opted for surgery. I understand that removing my breasts didn't guarantee complete immunity – I now have the same chance of developing breast cancer as the male population.

"I was born when my grandma was dying, and I watched my mother dying from the disease. It's always been around my family. I had had enough." After being referred to a psychiatrist, and following more careful consideration, Claire had the bilateral mastectomy. "I thought long and hard about reconstruction, but the consultant said she could only do one side at a time. I felt I would go without for a while, and reconsider it later."

Claire's operation has, she says, given her a new lease of life. "I understand now that people who get a diagnosis live for each day." There was also another factor that Claire had not anticipated. After the operation, the pathology results showed some early cell changes. "This would not have been picked up on a mammogram but the statistics show that it would be quite likely to develop into a malignancy. That made me thank God I did this."

A reader writes...

Having been diagnosed with breast cancer in January 2000, it was discovered in May 2001 that my cancer has a genetic link passing to me through my father. This came as a shock as I'd been led to believe that breast cancer comes through the female line.

In January 2002 I underwent another mastectomy to reduce the risk of a new primary cancer - the risk being 75%. There must be many more women like me out there unaware that the male line, although unlikely to contract the disease, can still be carriers. I now know that my son has a 50% risk of being a carrier.

Spread the word, knowledge is power!

Mrs S

Feeling in control

As the many women we've spoken to will testify, whether they are for or against genetic testing, there is no easy approach to the issue of hereditary breast cancer. If you believe you or your children are at higher risk, the best thing is to discuss your feelings with your GP and, if appropriate, with genetic specialists. At the very least, an increased awareness of your situation will help you to take advantage of any screening offered, while early detection of any problems offers a much greater chance of successful treatment and complete recovery.

Carolyn Warner is glad that she had the tests. "I am someone who needs to know as much as I can about a situation, so that I can feel I am in control of my life." But, she says, "there is no right or wrong about genetic testing. Take your time to weigh up the information and think about what the outcome could mean to you. There shouldn't be any pressure and each individual will do it for their own reasons."

As to the possibility of handing down faulty genes to any children she may have, Carolyn says: "I ask myself would I have wanted my own life? And the answer is a resounding yes! I have travelled the globe, climbed the world's highest mountain. I've had a wonderful life so far and am enjoying every minute of it. I'm sure any future child of mine would look at their life in the same way."

STOP PRESS**Rogue gene is linked to breast cancer**

In April this year, the charity Cancer Research UK announced that scientists have detected a faulty gene which doubles a woman's chance of developing breast cancer. The gene is called CHK2 and it usually repairs damage in the breast. However, when it is faulty it can be very damaging itself. According to Dr Doug Easton at the Cancer Research UK Genetic Epidemiology Unit in Cambridge: "We believe that CHK2 is involved in repairing genetic damage within a woman's breast, which is why her risk of cancer goes up when the gene goes wrong. But in women with abnormal BRCA genes, the system for repairing genes will already be faulty, so a damaged CHK2 gene cannot further increase her risk. This is a very important discovery. By identifying genes that work in combination to raise the risk of breast cancer, we'll gain a much clearer understanding of how the disease develops."

Contacts: For further information regarding hereditary breast cancer, contact the organisations listed below:

CancerBACUP, 3 Bath Place, Rivington Street, London, EC2A 3JR **Tel:** 0808 800 1234 **Website:** www.cancerbacup.org.uk

Provide a wide range of information, including a factsheet on hereditary breast cancer

Breast Cancer Care, Kiln House, 210 New Kings Road, London, SW6 4NZ **Tel:** 0808 800 6000 **Website:** www.breastcancercare.org.uk

Provide a wide range of information, including a factsheet on hereditary breast cancer.

Cancerlink, Macmillan CancerRelief, 89 Albert Embankment, London, SE1 7UQ **Tel:** 0808 808 0000 **Website:** www.cancerlink.org

Provide emotional support and guidance to people affected by cancer and their families and friends. Produces a range of publications on the emotional and practical aspects of living with cancer.

Hereditary Breast Cancer Helpline, St Anne's Cottage, Over Hadden, Derby, DE45 1JE **Tel:** 01629 813000 (24 hour answer phone)

Provide information and advice to women concerned about a family history of breast cancer.

Cancer Research UK, PO Box 123, Lincoln's Inn Fields, London, WC2A 3PX, **Website:** www.cancerresearchuk.org

In the spotlight

Broadcaster and journalist Sally Taylor had a bilateral mastectomy and reconstruction four years ago. She talks Christina Relf about her experience.

Sally Taylor is well-known to viewers in the south of England as the presenter of BBC South's nightly news magazine programme, South Today. When you meet her, she is even slimmer than she appears on screen and, without make-up, looks younger than her 45 years. Relaxed and confident, Sally comes across as someone who can focus on a problem and quickly decide on the best solution, which is what she did in 1999 when she was diagnosed at Winchester Hospital with cancer in her right breast.

Sally had always been vigilant about self-examination, because her mother had died of breast cancer in her thirties, when Sally was just six years old. During a routine check, she found a tiny lump, "the size of a pinhead," and went for a mammogram at Winchester Hospital. The lump itself turned out to be benign, but some cells were identified elsewhere in the breast that were showing signs of pre-cancerous changes.

"My partner, John Paul, and I were completely stunned when the surgeon advised that, because of my mother's history and the possibility that there might have been other relatives who died of breast cancer who we didn't know about, it was best to opt for a full mastectomy. I had thought that because the cancer was in its very early stages, I would simply be put on tamoxifen or, at worst, undergo a lumpectomy," she says.

Sally and John Paul went away to think about things – the surgeon told her she could take a few weeks if she needed to. They sought a second opinion from a London surgeon, who spent a long time talking to them. "I asked him what were the chances of developing cancer in my left breast, and whether he would advise me to have both breasts removed. He replied that he thought it would be sensible under the circumstances, but he stressed that it was entirely my own decision."

Some of Sally's friends were critical about her choice to have a bilateral mastectomy, but Sally's determination in this respect is typical of her decisive and forward-looking character: "We will never know whether I inherited faulty genes from my mother, but given the characteristics of hereditary breast cancer the chances are that if it occurred in one breast it would also occur in the other breast at a later date. I was faced with radical surgery and I did not want to have to go through that twice. I wanted to get the worst over with and get on with my life."

Her decision to have a reconstruction at the same time was, she says, relatively easy to make. "There was never any doubt that I would opt for it," she says. "I was still young, and for me it was important."

Sally's operation was not for the faint-hearted. Known as the 'scarless mastectomy', it took over ten hours, and involved removing the breast tissue and replacing it with muscle from her back, under which were inserted bags full of saline solution. "It was a major operation, and no surgeon would allow you to undergo it if you weren't in tip-top condition. Luckily I've always looked after myself." Sally is a vegetarian who eats

organic food wherever possible, and keeps herself very fit. She spent two weeks in hospital following the operation, and found she needed little in the way of physiotherapy or follow-up treatment. “I was very lucky. I was able to move my arms after two days, and I did not experience any side effects such as swelling or lymphoedema.” Nor did Sally need to take any further drugs to combat the disease.

Four years on, Sally says she rarely thinks about the operation. “I only have a little numbness in the centre of each breast, where there is a very small scar. Otherwise my breasts feel pretty normal.” She has no regrets. “It’s important to remember that a breast cancer diagnosis does not have to mean the worst. I’m thankful that I always checked myself regularly and was able to detect and deal with the problem at such an early stage.”

“The operation was a complete success and I now have a normal life expectancy. I won’t deny that it was a difficult period of my life and equally difficult for my partner. But now I’m out on the other side I can look back and I feel as though I’ve changed. It’s true your priorities do alter. Facing breast cancer is difficult but each one of us has an inner strength, and it’s during these difficult times that we find it.”

In Contact

Do you have a story you'd like to share or some words of encouragement for other readers? Send your letters and photographs for inclusion in AMOENA Life to: Rhoda White, Editor, AMOENA (UK) Ltd, FREEPOST, Eastleigh, Hampshire, SO53 4BJ or e-mail agrwhw@amoena.com

Life couldn't be better!

In February 1999 three days after my 50th birthday, I had a mastectomy followed by chemotherapy and radiotherapy. I have three sons in their twenties, a wonderful husband, family and friends. Thankfully with the care of the medical profession and everyone's love and support I was soon on the road to recovery.

Of course I was devastated about the loss of my breast, what woman wouldn't be, but my main concern was whether I was going to survive. I feared I would not see my sons married, happy and settled.

Three years down the line my two eldest sons are happily married and we now have two fantastic daughters-in-law. In April we were blessed with our first baby grand-daughter Millie. My youngest son, whom I am also very proud of, has just finished his degree.

At the moment life couldn't be better and I thank God everyday that I am still around to see these special events happening and I pray I will be here for many more years to come.

I would like to say to your readers who have been newly diagnosed, that there is light at the end of the tunnel, try to think positively, take one day at a time and finally enjoy life to the full.

Valerie M

Happy we're still here!

The enclosed photo was taken in August 2001 and is of my sister Janet, 52 and myself. From 1975 to 1981 I had six operations for breast cancer and then a course of radiotherapy. In the year 2000 Janet had a lump removed then went in again and had a mastectomy, also her ovaries were removed and she is now on tamoxifen.

Really, it was my worst nightmare, Janet getting breast cancer too, but throughout she's been so optimistic and single minded and coped so well – I'm really proud of her. I'm 68 now, getting fat, but I'm happy and I'm here!

Thank you for the magazine, we both look forward to it arriving.

Mrs Joan F

Back in the swim of things!

I had a lumpectomy in December 2000 aged 53 followed by a mastectomy in January 2001. Trying to stay cheerful for the family over Christmas was hard but I did my best. I had lots of support from my husband and children and I knew they felt as bad as me, so in some ways I was trying to cheer them up as well as vice versa. My husband and I had only been married 1 year 11 months and I felt so worried that this

would change things between us, but now I know that I needn't have worried because his love and support have kept me going. Although I still get a down day now and then, I feel a much stronger person than I did before. My last down day was about five weeks ago when I went shopping with my husband to get a swimsuit for our holiday. I thought if I got a high necked one the prosthesis would be OK, but I went to shop after shop and each time I tried one the prosthesis just looked totally ridiculous. I came home totally worn out and had a good cry, then decided to send for one of your brochures.

I received my swimsuit and Priform two weeks ago and just can't tell you how happy I am with it. Nobody would ever be able to tell the difference. The Priform is light and comfortable and I feel so relieved that I will be able to wear a swimsuit like the rest of our holiday group and not feel different from everyone else.

I was interested to see your article on Deaf Women Against Breast Cancer, as I am deaf and although my hearing aids are OK on a one-to-one basis they are definitely not ideal in a hospital situation. I would like to know how other ladies have coped, as I found trying to hear everyone clearly and asking for statements to be repeated almost as stressful as the operation itself. I attended a support group meeting a couple of weeks after my discharge and found the same thing. There were about 20 people there and everyone was talking at once and I found it impossible to hear what any one person was saying in detail.

I was put on tamoxifen after my mastectomy. As I already had a thickening of the endometrial lining and have had a couple of polyps removed over the last few years I was terrified to take the tablets in case they caused me to get uterine cancer. However my consultant, oncologist and GP all seemed to think I should take it and I have regular checks. I would like to know if any other readers have had this same problem, what decisions they made and what the outcome has been.

Jean B

Comment!

Our reports Feel good food and Living in fear featured in the last issue produced a large mail bag from our readers. We asked authors Professor Jane Plant and **Suzannah Olivier** to comment on some of the issues raised.

Thanks for the kick-start

I just had to write to thank you for your feature on healthy eating. I've been planning on adopting a more healthy approach to my diet for some time and your magazine provided me with the kick-start I needed to give it a go. Having purchased Jane Plant's book, I have to say I was surprised to find just how enjoyable the recipes were – even my husband likes them! I now seem to have much more energy and am convinced this can only be a good thing for my health and future wellbeing.

Lisa K

What should I be thinking about?

I felt dismayed when I realised that if I drink milk I will get breast cancer (Prof. Jane Plant) and if I don't drink milk I will get breast cancer (The Dairy Council).

I had surgery three years ago for breast cancer and, like many others, try to eat a

healthy diet. I am willing to listen to sound advice but somehow having read this article I felt whatever I do it will be my fault if the breast cancer comes back, because of my milk drinking or milk avoidance – well, that just makes me feel really confident! So what is it I should be thinking about before I eat?

Janet W

We reply:

We were sorry to hear that an article featured in our magazine has caused you any distress. We should make it clear, however, that the report you refer to does not state that you will get breast cancer by either drinking or avoiding milk, nor was the focus of the article a ‘for or against milk’ debate. Regrettably the causes of cancer are still unknown and it is therefore impossible for anyone to guarantee a course of action that will prevent either a diagnosis or recurrence of breast cancer.

The aim of this particular feature was to show that there is mounting evidence to suggest that diet may play a part in the development of some cancers. Jane Plant, whom we quote in the article, is an eminent scientist whose cancer was thought to be incurable. However, by making certain lifestyle changes which included giving up all dairy products (not just milk) and eating more plant based foods and soya products, she has been free from cancer for a number of years. Although Jane believes that this has helped to cure her cancer, it was important for us to include a statement from the Dairy Council, although this was not a direct reply to the claims made by Jane Plant.

*We asked Jane Plant for her comments: “As a scientist I have not read any information in the proper, peer-reviewed literature that would persuade me **ever** to eat dairy again. The things in dairy that we are being told are good for us come from the vegetation the cows eat. Fruit and vegetables are a much healthier source of such nutrients. There are many other books beside mine against consuming milk, in particular one by an eminent breast cancer surgeon in the US, Robert M Kradjian, MD, who has also posted a letter to his patients on his website [www.notmilk.com/kradjian.html].”*

We also asked nutritionist Suzannah Olivier for her views: “Certainly the risk of hormones in milk needs to be taken very seriously indeed. But I think that we have to live in the real world. For some people giving up dairy products totally will be difficult and reducing their dairy intake to minimal levels and ensuring that what they do eat is organic, will be sufficient to reduce their exposure to these worrying hormones to a level that is not disruptive for most people.

“I am firmly of the belief that if you are going to drink milk, organic is the better option. If you enjoy dairy then by all means include a moderate amount of it in your diet. Yoghurt, for instance, is important for bowel health, and healthy bowels help to protect against breast cancer because it is through them that we excrete excess oestrogens.”

Is soya good or bad?

Seeing Professor Jane Plant’s book mentioned in the last two editions of INFORM has prompted me to put pen to paper. I was diagnosed with breast cancer in August 2000 and had a mastectomy in September followed by chemotherapy and radiotherapy. A friend lent me Jane Plant’s book which inspired me and I cut dairy

products from my diet. However, my mother mentioned she had seen an article on soya products and that soya might contain oestrogens (mine had been an oestrogen-induced cancer). A friend logged onto the internet and found a wealth of contradictory information.

I am now thoroughly confused and have given up the soya diet and gone back to dairy products (as I also suffer with osteoporosis), because I need the calcium! Could you look into this and see if you can find out whether soya is a plus or minus as far as oestrogen is concerned?

Your article "Living in fear – overcoming the fear of recurrence" was excellent. I am a very positive person and my husband says when I talk about the cancer, that I make it sound as if I just had a cold. But sometimes I am 'struck down' with the thought that it might come back and I might not make it. These negative thoughts just come out of the blue and I really try hard to overcome them. I now carry a copy of your article around in my diary so I can read it when I'm touched with the 'anxiety'.

Thanks for a great publication.

Susan F

We asked Suzannah Olivier for her thoughts: "First I would stress that dairy products are not the best source of calcium. The way to support bone health is to eat a varied whole-food diet which includes plenty of green leafy vegetables, pulses and beans, grains, nuts and seeds. If you prefer to avoid dairy products totally you will do yourself no harm in relation to bone health, and will probably do yourself a lot of good in relation to breast cancer risk.

"Having said this, I do not avoid dairy totally, but have reduced the levels in my diet dramatically. I have eaten a very small amount of dairy – mostly organic, live, plain yoghurt for its beneficial effects on the digestive tract and the immune system, in the twelve years since my brush with breast cancer, and remain happy to do so."

On the subject of the soya debate, Suzannah says:

"Recently there has been some backlash against the premise that adding soy to the diet is of benefit to health in general and breast cancer in particular. It has even been suggested that soy might be harmful. It is, of course, always important to have such debate; however some of the reporting has been particularly one-sided and has served to confuse rather than inform. Some of the criticisms that have been levelled at soy are mentioned below, along with my comments:

Research into soy is largely funded by the huge multinational companies that now reap large profits from its production and sale. This is true, and does mean that we should take a cautious look at the available evidence before taking it at face value. Nevertheless, by far the majority of studies conclude that soy is likely to be of benefit.

The greatest criticism seems to centre on high soy diets, such as that which might be eaten by a very keen vegetarian. The levels suggested (around 225 grams daily) are far higher than the levels I suggest in my book (which are in line with regular consumption in many Eastern countries)

While the critics grudgingly concur that breast and prostate cancers are lower in cultures that eat soy, they also point out that there are other nutritional differences such as oily fish and seaweed (agreed, and these are covered in my book), and that other cancers such as stomach cancer prevail – true, but then nobody is suggesting that we imitate the intake of salt or other factors which are likely to be involved.

“I truly believe that eating a moderate amount of soy, preferably tofu, will do a great deal of good in relation to breast cancer risk, when eaten as part of a mixed diet. If soy does not agree with you, or you prefer not to eat it, then there are a number of other isoflavone rich foods such as pulses and grains (though they are not as potent) which you can enjoy.”

Jane Plant comments: “I have found nothing against the use of soya in the proper, peer-reviewed literature, including the extensive review papers referenced in my book. There is really nothing strange about soya – it is a relative of peas and beans. The oriental people who have used this rather than dairy for about 5000 years have had the lowest rates of breast cancer in the world. I have talked to doctors in China who had hardly seen a case in their careers. Also the idea that plant oestrogens can cause cancer is mischievous. Many plants including berries such as strawberries and wholegrain cereals, peas and beans contain phytoestrogens. Unfortunately the Web contains much un-refereed ‘science’ and most of the attacks on soya that I have read fall into this category.”

Will anyone ever understand?

I eagerly awaited the arrival of your Spring/Summer publication. Would there be some dietary information on how to combat the tamoxifen weight gain? Unfortunately I was disappointed to read only general healthy eating recommendations with advice to take regular exercise.

I was diagnosed with breast cancer in November 2000. Since then I have had a wide excision to my left breast, chemotherapy, radiotherapy and a year on tamoxifen. I have had a healthy eating regime all my adult life. I have also played golf for almost 30 years, playing an average of three times per week. During my treatment, I joined Motorcise, a gentle electrically operated gym for mature ladies, so that I would not vegetate whilst sitting around, and I played golf whenever I felt well enough. I also enjoy swimming, so I have always taken regular exercise.

Since being diagnosed I have gone up from a size 16/18 to a size 20/22. I feel like a beached whale. I feel as if the old me has died and I do mourn her. All her clothes have gone from the wardrobes, but I keep hoping she will come back.

None of my tried and tested diets work now that I am taking tamoxifen. I am a Life Member of Weight Watchers and also employ a lot of the Rosemary Conley theories. What size I will be if I take tamoxifen for five years, or even for life, I dread to think. This is all so sad, because inside this huge balloon I am living in, there is a person eager to enjoy life and be happy.

I tell my oncologist that, had I been attending any other clinic, I would be told that I am obese and should lose weight for the sake of my heart, back, knees and ankles.

He just looks at me and his eyes say “you should be grateful that you are alive”, and then I feel guilty. What is the point of saving a life if the quality of that life is permanently impaired?

So yes, tamoxifen side effects are being ignored. Instead of patting themselves on the back for the good work that tamoxifen undeniably does do for breast cancer patients, why don't the scientists look into refining the drug to prevent the weight gain, or find the key to unlock a diet to combat it? But first they have to acknowledge that this happens and stop making us think that no-one is listening and it is all our own fault.

Linda B

Suzannah Olivier says: “I must congratulate Linda Bacon on her obvious lust for life and the fact that she is actively trying to live healthily. I do sympathise with her efforts to keep her weight down, and I regret that there is no single solution – particularly in the case of those taking tamoxifen.

“My personal opinion is that eating healthily is more important than eating to be thin. If you are under a lot of stress, with a diagnosis of breast cancer or treatment, the last thing you need is the added stress of worrying about excess weight. It may not be the right time for you to go on a weight-loss diet, but if you are increasing your overall consumption of fruits, vegetables and legumes, concentrating on eating healthy fats and reducing harmful fats, and gently increasing exercise, you may surprise yourself and find that you are losing weight slowly at the same time, without consciously dieting to lose weight. It is also possible that you are having chemotherapy or are on tamoxifen, which is having a temporary effect of increasing your body weight. In this case you should try not to become panicked about it as you will probably return to your usual weight when you stop these treatments.

“Finally it is absolutely not a good idea to go on a calorie-restricted crash diet and attempt to lose large amounts of weight in a short time-span if you currently have breast cancer. First of all, you need a highly nutritious diet while dealing with breast cancer, and calorie restricted diets cannot accomplish this. Second, crash-dieting raises oxidation damage to tissues, and one of the key aims of an anti-breast cancer regime is to keep oxidation damage to a minimum in order to avoid overburdening the immune system. So if you do need to lose excess fat, it is a good idea to do it in a relaxed way over time, and not to do it too quickly or let it become a cause of anxiety.”

Helping myself to better health

I would like to say how much I enjoy the magazine. It is absolutely wonderful that ladies who have had cancer operations can write to your magazine and say what they think and feel, not only about their particular experiences but also about the pros and cons of medical support. The issue with exercises for lymphoedema was especially useful to me and I love the fact that the models pictured in your magazine are ladies who have had cancer operations but are still beautiful to look at!

I am absolutely to the letter a follower of Professor Jane Plant's programme. By accident, I got the Daily Mail with an article on Professor Plant and it made a lot of sense to me. I bought her book and rigorously applied her eating plan from day one. I have no difficulty in shopping or cooking and it is easy to adapt ordinary recipes by

substituting dairy with soya products and butter with Pure margarine. We drink decaff or organic tea, adding soya milk when it cools so it does not curdle.

I trust Jane Plant and her unbiased judgement. She went through it herself, she is a scientist and knows what she is talking about.

After my radiotherapy I developed an agonising pain in my right arm (where I had the mastectomy). For four months I could not sleep, waking up four times a night with excruciating pain. I tried every therapy to help myself as no one in the medical profession could help me! Finally, I got an address of a therapist who is professionally trained to do MLD (manual lymphatic drainage). I had 19 sessions with her, and the pain began to move away after the sixth session. By the end I was free of pain, had a fully mobile arm and the swelling around the scar and in the arm was gone. I am still under her supervision, seeing her every six months. It was expensive treatment but worth every penny.

Your magazine has also been a tower of strength to me.

Mrs Sophie O

I feel guilty

I love your magazine and thoroughly enjoyed reading your latest issue, in particular the article 'Living in fear', which really helped me to look more positively towards the future. Your feature 'Feel good food' was also very interesting, although it did leave me feeling a bit guilty as, although I know the importance of eating a healthy diet, I just don't have the will-power to give up "my treats" and really enjoy chocolate, biscuits and the odd cream cake! Although I know I owe it to my family and myself to eat more sensibly, I find it really hard and I know I would never forgive myself if the cancer recurred because I just didn't have the will-power to give up the foods I really enjoy.

Name and address supplied

Suzannah says: "I think it is so important not to get caught in the guilt trap. One chocolate biscuit is not going to give you breast cancer. Have a look at what you are doing. If you are eating three packets of biscuits in one sitting then you know what you have to do. But don't feel guilty because you are having a chocolate biscuit with your cup of tea in the morning – you are being too hard on yourself.

"If you get your diet right 80 per cent of the time, the other 20 per cent is not so important. When I was working as a nutritionist specialising in helping women with breast cancer, one of the key areas we focused on was removing the guilt from their lives."

MAKING GOOD ADVICE WORK FOR YOU

- The reasons why some women develop breast cancer are still unknown and it is therefore impossible for anyone to guarantee a course of action that will prevent either a diagnosis or recurrence of breast cancer.
- Establishing a healthy, well-balanced diet that is rich in vegetables and plant-based foods will be beneficial for your health generally and will help to boost your immune system, regardless of its possible protective effects against cancer.

- Don't get caught in the guilt trap and blame yourself for causing your breast cancer. Although no-one can guarantee whether or not your cancer will recur, eating the chocolate biscuit when you feel like it won't be the reason!
- Look at any information provided with an open mind and apply it to your own life-style and circumstances. If in doubt, seek the advice of your GP or cancer specialist.

FURTHER READING

The Breast Cancer Prevention and Recover Diet: Susannah Olivier, Penguin Books - ISBN 0140283951 £7.99 (paperback) www.healthandnutrition.co.uk

Banish Bloating: Susannah Olivier, Pocket Books - ISBN 0671029533 £6.99 (paperback)

Your Life in Your Hands: Understanding, preventing and overcoming breast cancer: Professor Jane Plant CBE, Virgin Books - ISBN 0753505967 £9.99 (paperback)

The Plant Programme: Recipes for fighting breast cancer: Professor Jane Plant CBE and Gill Tidey, Virgin Books- ISBN 1852279533 £6.99 (paperback)

It's good to talk

The Importance of good communication

During an experience with breast cancer, it is normal to feel the need for comfort, support, validation, and empathy. Women look to family and friends, expecting those people with whom they are most closely connected to come through for them in a crisis situation. However, many women are disappointed and hurt to find that their needs are not being met and it is not unusual to find some basic difficulties in communication at the root of these problems. American psychotherapist and author, Ronnie Kaye, explains why good communication is so important.

When I had my first surgery for breast cancer, I was often angry, disappointed, or deeply hurt by the reactions from people I knew. There were a few who never called. I didn't hear from them for months. Later, I found out that they didn't know what to say and were afraid that they might upset me. Some people who did reach me managed to say exactly the wrong things. One woman burst into my room the day after my operation and exclaimed, "Thank God you didn't have to lose your breast!" I was stunned. "How can she be thinking about my breast," I wondered, "when I have just been told that I have this awful disease that may cost me my life?"

The entire time I was in the hospital, I never felt that there was any respect for my privacy. Two days after surgery, I was still on strong pain medication. I looked dreadful and I felt worse. The last thing I wanted was company. Unfortunately, it happened to be Sunday, a day when people have the leisure to attend to their "obligations". By two o'clock in the afternoon, my room was filled with fifteen well-meaning visitors, most of whom were just acquaintances. I was exhausted, my hair was a mess, my arm was hurting me and I hadn't the strength to put on any makeup. I felt unkempt, exposed, embarrassed and trapped. It never occurred to me to ask them to leave. After all, I had been brought up to be considerate and my manners were beyond reproach. Good manners notwithstanding, I found myself stockpiling a great deal of anger and resentment.

Months later, I began to review my reaction to these events. In retrospect I saw that much of the responsibility had been mine. I had systematically avoided any opportunity to communicate my needs. There were times when I did not have a clear idea of what my needs were. I was often concerned that expressing my needs would seem rude, inappropriate or burdensome and I was unwilling to risk insulting people or making them feel uncomfortable. I realised that there were situations where I was waiting for other people to read my mind, having always believed that if someone really cared about me, he or she would know what I wanted without me having to say anything. I was finally able to admit that depending on others to guess my needs was useless and self-defeating. I came to the conclusion that people don't usually say or do hurtful things deliberately. They might just be feeling awkward or uncomfortable. In difficult and emotion-filled situations, a surprising number of people are completely unaware of how to be supportive or helpful.

During the next three years, I taught myself a great deal about communication. I came to understand communication always involved both a sender and a receiver. In the past, when my needs had not been met, I had blamed the receiver. I was

beginning to appreciate that, as the sender, it was my responsibility to convey my own needs and wants to others in a clear, direct, non-threatening way.

The second time I faced a breast cancer diagnosis, I was determined not make the same mistakes. When I thought of the difficult time that lay ahead, I knew exactly what I would need and I took action immediately. One by one, I called all my relatives, aunts, uncles and cousins, as well as my immediate family. "I'm going through a difficult time," I said "and I need your help. I just found out that I have breast cancer again. I am terribly frightened, and I feel very alone. What I need most of all is a phone call once a week. When you call, I would like you to tell me that my being alive has mattered to you in some way. I need to know that our connection is important to you." Not a day went by without at least one phone call from someone in my family. Each of the calls was unique and very precious, reminding me again and again how very much I was loved. Even though the reality of my medical situation hadn't changed, those phone calls made me feel much more secure. I had learned that the best way to get what I needed was to ask for it. Once my family knew exactly what I wanted they were only too happy to oblige.

If you are finding communication with your friends and family difficult you might find it helpful to consider the following:

The Family Unit

Breast cancer is a family affair. While it presents a real challenge to the woman who is diagnosed, it also has a major impact on the members of her family. Many families discover that this crisis can be an opportunity to grow closer. One of the keys to the strengthening of the family during this time is good communication. Without it, family members tend to distance themselves from each other, and everyone, including the woman with breast cancer, feels isolated, misunderstood and unsupported.

Every family is unique. However, there are certain communication barriers that are fairly common when there is a health crisis. If you are a woman going through a breast cancer experience, you may be reluctant to communicate for one or several different reasons. Here are some reasons that may apply to you:

- Wanting to protect your family, not burden or frighten them.
- Fearing that the people in your family will not understand you, especially when you are expressing your emotions.
- Being unwilling to give up your role or responsibilities in the family, even temporarily.
- Not wanting others to see you as weak, dependent, or needing help.

If any of these reasons seem to explain why the communication in your family is not as open as it might be, you might find it helpful to consider some of these points:

Families do best when they can contribute: The worst thing for a family member, or for anyone who loves you, is the feeling of helplessness that comes from not being able to fix your cancer or make it go away. If you communicate what you want or need, the people in your family will usually be grateful to know that there are things they can do which will make a positive difference in your life.

Accepting help and support: If you find it embarrassing to be needing help and support as you go through breast cancer diagnosis and treatment, remember how

easy it has been for you to help others. You have probably done it many times without giving it very much thought. You are not being lazy or irresponsible if you need to temporarily let go of some of your responsibilities. After all, your main responsibility to yourself and to your family is to get through your treatment so that you can go on with your life. That can be a very big job, and may take up a great deal of your time and energy. If you are clear with your family about your limitations, you may be surprised at how capable they are of filling in the gaps and how co-operative they can be in keeping things running smoothly.

Being kept in the loop is reassuring: Hearing that someone you love has breast cancer can be very frightening. Knowing that something is going on, but being kept in the dark is much worse. People, especially children, will make up terrifying stories in an effort to explain the "vibes" they are picking up. Many times, the stories are much scarier than the reality. If you aren't sure how to talk to your children, send for a copy of Breast Cancer Care's booklet called "Talking With Your Children" or CancerBACUP's booklet "What do I tell the children". Both are filled with wonderful advice on how to keep the lines of communication open and how to best help children understand and deal with the situation.

Knowing when family members need support: If there is no communication in the family, you will not know when the people you love need some help. Support is available for family members; Breast Cancer Care can put your husband or partner in touch with one of their partner volunteers and you can talk to your GP or Breast Care Nurse if you feel your children could benefit from outside support. There is also a wonderful American organisation called Kids Konnected which has a website www.kidskonnected.org offering friendship, understanding, education and support for children who have a parent with cancer. While you are going through treatment, you may not be the right person to offer those you love the support they need. However, if there is good communication in the family, you will know when someone does need help, and you can make sure the right connections are made.

This territory is new for everyone: No matter how accustomed you are to dealing with feelings, breast cancer can bring up emotions that surprise you. If you are unprepared for the feelings that surface, it makes sense that the people in your family would find this territory strange as well. They may not understand how you feel, and they may not know how to respond to you. Instead of shutting down the lines of communication, find a way to educate them. One way to do this is to find a book that explains the emotional aspects of the breast cancer experience. After you have read it, underline the parts that best reflect what seems to be true for you. Then ask your family to read it. Once they have the necessary information, you will be able to have much more fruitful discussions.

Beyond the family

A breast cancer diagnosis also has an impact on your relationships with friends and acquaintances. Some may ignore you completely whilst others will seem embarrassed or unsure of how to react to you. This may be because they really don't understand what you have been through and they are afraid of the issues you have confronted. We live in a death-denying, death phobic society. Your friends may not be afraid of catching cancer from you but the fact that you have gone through cancer diagnosis and treatment reminds them of their own mortality and people just don't know how to deal with that.

In addition, because they can't relate to your experiences, your friends may be afraid of saying the wrong things. In trying to be careful and sensitive, they are seeing a cancer patient instead of the real, familiar you. This is more common than you would think and many women have told me that they have approached a group of friends only to find themselves facing an uncomfortable silence followed by a sudden and awkward change of topic.

Getting back to the easy give and take you had with your friends before you went through your cancer experience just requires some communication. You may do it directly or indirectly. Often a one-on-one approach is probably better. Let the person know how much you have enjoyed the relationship over the years. Then describe what was best about it – the laughter and the irreverence, the confidence that you could share anything with each other. Make it clear that you really miss the old way of relating. You might offer to answer questions about your treatment and recovery to catch the other person up on where you have been and where you are now. Then turn the conversation back into the old familiar direction and give your friend a chance to get back in the groove.

Another way to do this is indirectly. When I was recovering from breast cancer myself, I remember people asking me, "How are you?" in a tone of voice that suggested I was teetering on the edge of my grave. I usually came up with something like, "I'm really upset!" When they would start to get uncomfortable and try to look sympathetic, I would continue, "Of all the times for my kitchen sink to pack up! I'm having 10 people to dinner and I can't get hold of my plumber!" They would quickly get the message that life had returned to normal and so had I."

The Importance of good communication was taken from Ronnie Kaye's book "Spinning Straw into Gold: Your Emotional Recovery from Breast Cancer" and from thebreastcancercaresit.com. Publisher: Simon & Schuster Books, ISBN: 0671701649 (paperback) £7.99. Available from www.amazon.co.uk

Reaching out

For many women, reaching out to others presents a huge challenge, but it can be very reassuring to talk to someone who understands what you are going through. Making contact with other women in a similar situation will also make you feel less isolated and alone, and will give you the opportunity to exchange ideas and information on subjects that are of real importance to you.

Here are just some of the ways you can get in touch.

Become a groupie!

Consider joining a support group so that you can share your own experiences and ask others how they tackled certain situations. There are a variety of groups available, some run by volunteers and others by healthcare professionals. Your breast care nurse will be able to put you in touch with your nearest one, or alternatively contact CancerLink on 0808 808 0000.

Have a chat!

Internet chat groups are also excellent for sharing ideas and concerns, and they have the added advantage that you can retain your anonymity if that's what works best for

you. Try UKBCSupport at <http://groups.yahoo.com/group/UKBCSupport/> This is a very friendly group where you can choose to have e-mails sent to you or read through messages online. Your privacy is important and, while some groups allow you instant access so you never know who is reading the messages, this group requires approval first so you know you can discuss private matters in complete confidence.

Breast Cancer Care also provide a chat forum on their website breastcancercare.org.uk. Their forums offer an opportunity for anyone affected by breast cancer to find support from a large, friendly online community, most of whom have had direct experience of breast cancer themselves. The forums are moderated to ensure that the focus remains on mutual support, but the discussions themselves can be as wide-ranging and frank as the participants desire. The forums are available for any visitor to read and posting a message merely requires a simple registration process that can be completed in a matter of seconds. The atmosphere is always welcoming to new participants and requires no technical expertise or experience of other online communities. If you require a specific answer to a particular question, breast cancer cares “ask the nurse” service guarantees a personal reply by e-mail.

Get connected!

Breast Cancer Care run unique telephone support groups for women who feel particularly isolated by their diagnosis. This service is especially of help to those who don't feel they are able to meet others in a similar situation, or who don't have access to a local support group where they can share their thoughts and feelings.

Linked together from their own homes, participants can express their feelings and discuss the practical and emotional impact of living with breast cancer. The groups “meet” once a week for eight weeks, professionally facilitated by a counsellor and breast care nurse.

Some of the telephone support groups that have run in the past include:

- women in their 20s and 30s with breast cancer;
- women with secondary breast cancer;
- lesbian and bisexual women with breast cancer.
- urdu language group

For further information contact the Breast Cancer Care helpline on 0808 800 6000.

Further Reading:

Who Can Ever Understand – Talking about your Cancer

What do I tell the Children –A guide for a parent with Cancer

Both available from CancerBACUP (see address details below)

Contacts:

CancerLink, 89 Albert Embankment, London, SE1 7UQ, Tel: 020 7840 7840

Website: www.cancerlink.org

Provide information including a booklet on talking to children. CancerLink can also provide details of your nearest support group.

Cancer Counselling Trust, 1 Noel Road, London, N1 8HQ. Tel: 020 7704 1137

Website: www.cctrust.org.uk

Offer counselling to individuals or families affected by cancer. Appointments are held at the London office and telephone counselling is available for those outside the London area.

Breast Cancer Care, Kiln House, 210 New Kings Road, London, SW6 4NZ Tel: 0808 800 6000 Website: www.breastcancercare.org.uk

Provide a wide range of information, including factsheets on talking with children. Breast Cancer Care also provide a helpline of women and for their partners.

CancerBACUP, 3 Bath Place, Rivington Street, London, EC2A 3JR. Tel: 0808 800 1234 Website: www.cancerbacup.org.uk

Provide a wide range of support services and information, including booklets on Talking about Cancer (see above).

Top form!

Most women are amazed when they hold a breast form for the first time. The silicone is so soft and the construction so intricate that they feel and act just like a natural breast. But prostheses weren't always this realistic and manufacturers are still striving to develop even better designs to help women feel comfortable, attractive and secure after breast surgery.

Christina Relf traces the history of the breast prosthesis and looks at how they compare with the modern-day equivalent.

The early days

When mastectomies were first performed at the beginning of the last century, breast forms did not exist. Women either went without a prosthesis or made their own out of whatever materials were to hand. "My mastectomy was over 50 years ago," says Kathleen J. "In those days there was little aftercare, no counselling, special bras or breast forms. We were advised to use cotton wool or make a bag and fill it with bird seed!"

In fact, proprietary breast forms did not come into existence until the 1940s, with the invention of the surgical bra for conditions such as chronic mastitis. As this condition often led to the loss of one or both breasts, 'mastitis pads' – little bags filled with kapok, similar to the temporary breast forms of today - were included in the cups of these bras to replace the missing breast.

These were replaced in the late 1940s by an inflatable prosthesis which was placed in the bra and then blown up through a straw until it looked about the right size. The straw was then tied and tucked in. Although they adjusted for size very well, they had an unfortunate habit of deflating – sometimes noisily – at any time. This was a particular problem for travellers, as the change in atmospheric pressure in an aircraft cabin could cause the air inside the prosthesis to expand – sometimes with explosive results!

Although many women recall the breast form affectionately known as the 'bird seed', these little bags were actually filled with tiny glass beads. They got their name not only because that's what the contents felt like, but also because ladies who gained weight would often undo the seam and fill them up with bird seed to make them larger.

Mrs Phylis S, who underwent her surgery in 1957, remembers these early prostheses were rather primitive: "I had one that was so hard and unyielding that it felt like a cricket ball. From this I graduated to a bag of bird seed, a bag of nylon scraps made from discarded stockings and an inflatable breast which often deflated at inconvenient moments! As I was a teacher, my frequent trips behind the blackboard to reflate the thing gave my class of 11-year-olds considerable puzzlement!"

The next generation

The late 1960s saw a complete revolution with the introduction of a oil-filled breast form. These not only looked like a real breast but moved naturally as well. They became the standard breast form of choice, until a young Bavarian bioengineering

student, Cornelius Rechenberg, started working in a prosthesis factory during his summer holiday. He believed that with the use of different materials and modern technology, something far better could be produced.

Convinced his theory would work, Cornelius started experimenting using wallpaper paste and polythene bags, and once he had found the right formula he used his mother's food processor to mix silicone which he then baked in her pressure cooker. Cornelius was so enthusiastic about his product that, undeterred by lack of interest from manufacturing companies, he set about supplying them from his mother's home, until 1975 when he founded his own company and the Amoena silicone breast form was born. It was to become the benchmark for the breast forms that are manufactured today.

The great advantage of using silicone was that it could be made to look, feel and behave like a natural breast. It was to have an immediate and dramatic effect on thousands of women: "As soon as I started wearing an Amoena silicone form my life changed," says Mrs Jean H. "It was fantastic to wear something that felt so realistic, I no longer worried about people bumping into me or about giving friends a hug".

With the introduction of silicone, manufacturers started looking at ways to refine and develop breast forms to help improve the quality of women's lives. This led to the evolution of many new concepts, including Amoena's patented two-layer and lighter-weight breast forms. But the development process never stands still.

Staying power - Tomorrow's technology – today

Although breast forms were starting to look and feel like a real breast to the touch, they still did not compare fully in terms of weight distribution and movement.

Most women had a story to tell of 'the time they lost their breast form'. "I remember losing my breast form in one of the deep freezers in Sainsbury's, when I bent too far over trying to retrieve a bag of peas," recalls Norma W. "The look on the young lad's face who was filling the freezers was hilarious. My husband said it was a good job we noticed, or someone might have thought it was a chicken fillet!" Norma can laugh at the situation now, but for many women the thought of losing their breast form can cause considerable consternation, and this led to the idea of a self-adhesive breast form.

Adhering the breast form to the body was not a new idea. Many manufacturers realised that this was a way to stop movement and offer greater security, and several methods had been tried with varying degrees of success: double-sided tape, adhesive sets and the modern-day skin support/velcro system.

Says Pam W, "I remember when the Amoena adhesive kit first became available. I thought it was the best thing since sliced bread. It was supplied with bottles and a brush, not unlike a large bottle of nail varnish, and you had to paint the adhesive onto the back of the breast form. It took quite a lot of time and was rather fiddly, but it was great to feel secure. The only down side was the adhesive remover, which had quite a potent smell to say the least. It was worth it, though, because it meant you could do things like run for a bus without having to grab hold of your bosom, just in case!"

Pam was also one of the first women to try a new type of breast form that was called

'self supporting'. It was held in place by special skin supports which allowed the form to be removed and replaced as required, something which hadn't been possible with the adhesive tapes and sets. "Oh, it was much better," admits Pam. "I had two – a Discrene and a Tria Plus – and I remember thinking 'they've done it again, it really can't get better than this'."

But a new design was already in the pipeline, a prototype called simply Contact, that had a tacky silicone gel on the back to allow the breast form to be attached directly to the body. The idea came from the adhesive silicone band which is used to keep strapless bras and hold-up stockings in place. Amoena's specialist team looked at the process and improved it until it could be applied for the first time to hold the weight of a breast form. Once the development team were sure that the product was 'road worthy', a group of German women were invited to try the product for themselves and were asked to report back with their comments.

Until then these women had worn their breast forms in a cover or pocketed bra and, when trials began, they were sceptical about using an adhesive version which would have to be worn directly on their bare skin. However, the verdict at the end of the trials was unanimously favourable. All the women found the Contact pleasant to wear and similar to their natural breast.

"It was hard to come to terms with my new appearance after the operation and I never looked in the mirror," says Christine, who was 39 at the time of her surgery. "But this new breast form helped me to accept my body." Ulrike, a prosthesis wearer since 1983, also tried the Contact and was very enthusiastic. "You can't help being inhibited in a dress or jumper with a low neckline when you wear a standard breast form," she says, "but now I feel I can wear almost anything without fear of embarrassment."

All-round improvement

A long-term study has recently confirmed that the Contact breast form greatly improves women's self-confidence. It increases acceptance of their own body, makes them more confident in their interactions with others and gives them the courage to wear revealing clothes.

"I think attitudes today are totally different, women are more confident and more demanding about wanting to look good after surgery". Says Judith S. "I remember my aunt having a mastectomy when I was a teenager and she went from being quite fashionable to wearing awful baggy clothes and trying to hide her figure. When I was diagnosed in 1998 I was still only 35 and I knew I didn't want to hide myself away as my aunt had. I'm still deciding whether to have a reconstruction, but in the meantime, my Contact breast form is the next best thing."

Beryl W agrees, "Women today have so many options, breast reconstruction, realistic breast forms and pretty lingerie. I only wish all this had been available when I had my radical mastectomy in 1972. The onus then was very much on getting rid of the disease rather than on the cosmetic results. If you complained you were made to feel as if you were being vain and ungrateful it was very much a 'we've saved your life what more do you want' attitude. In those days, women were just expected to put up with it. But I'm still here 30 years later and that's the main thing!"

More recent studies have shown that self adhesive breast forms are not only beneficial for cosmetic reasons but can also have some medical advantages. Adhering the breast form to the body helps to distribute weight more evenly, relieving pressure on the shoulders and improving lymph flow.

“Nothing can compensate for the loss of a natural breast,” concludes Jean M, a prosthetic fitter who herself has undergone a mastectomy. “But there is no doubt that a life-like breast form that fits comfortably, behaves naturally and is completely undetectable to the onlooker makes a massive difference to a woman’s self-confidence and helps her to overcome the trauma of breast surgery and get on with her life.”